

GERONTOLOGICAL SOCIAL WORKERS AND END-OF-LIFE CARE IN SOUTH KOREA:  
AN EXPLORATORY STUDY

by

Sung Ae Kwon

(Under the Direction of Stacey Kolomer)

ABSTRACT

This dissertation has examined the attitudes and tendencies of geriatric/gerontological social workers regarding end-of-life care issues and their willingness or intention to provide end-of-life care in a large metropolitan area of South Korea. The findings of this study indicate that geriatric/gerontological social workers have little or no education or training on end-of-life care issues, especially about advance directives. The social workers tend to agree on the need for end-of-life care in geriatric/gerontological institutions and show a moderate willingness to address end-of-life care issues for older adults. However, they feel they are not ready or prepared to provide psychological, psychosocial, or emotional support within the area of death and dying. Participants in this study tend to have a positive attitude toward hospice care and advance directive planning and prefer not to use sustaining treatment during the last stage of life. Moreover, the study found that people emphasize self-determination in end-of-life care decision-making and value the principle that one's wish is regarded as the most important factor when there are conflicts between oneself and a family member. By contrast, half the respondents in this study still prefer a family decision-making process, and some even want to exclude the patient from the process to protect him or her from feelings of fear or abandonment. In addition, because

of the cultural influence related to death and dying, social workers generally feel uncomfortable talking about death with elders and worry that such a discussion might cause distress or upset to older adults. This study refocuses and readdresses the issue of end-of-life care decision-making (individualism versus collectivism) and disclosure of diagnosis of a terminal illness. It also raises a concern about the discrepancy between the social workers' professional values, the ethical principle of self-determination and the traditions of Korean culture. The findings of this study suggests the need for an educational and informational program for social workers to achieve competency in end-of-life care, as well as education for the general public, in order to bring the topic of death and dying into the public arena and promote familiarity with the concept and practice of end-of-life care.

**INDEX WORDS:** Death and dying, End-of-life care, Gerontology social worker in South Korea, Hospice with Asian culture

GERONTOLOGICAL SOCIAL WORKERS AND END-OF-LIFE CARE IN SOUTH KOREA:  
AN EXPLORATORY STUDY

by

Sung Ae Kwon

B.S.W, Seoul Theological University, South Korea, 2005

M.S.W., New York University, 2008

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial  
Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2012

© 2012

Sung Ae Kwon

All Rights Reserved

GERONTOLOGICAL SOCIAL WORKERS AND END-OF-LIFE CARE IN SOUTH KOREA:  
AN EXPLORATORY STUDY

by

Sung Ae Kwon

Major Professor: Edwin Risler

Committee: Stacey Kolomer  
Anne Glass  
Nancy Rothenberg

Electronic Version Approved:

Maureen Grasso  
Dean of the Graduate School  
The University of Georgia  
December 2012

## ACKNOWLEDGEMENTS

There are so many people who have supported and guided me throughout my doctoral program. I am the person who is living due to the warmth and support of my family, friends, professors and God. Without their help and encouragement, I would not be standing where I am today. I would like to thank my professors: my dissertation chair Dr. Stacey Kolomer, Dr. Edwin Risler, Dr. Anne Glass, Dr. Nancy Rothenberg, and Dr. Park, and my colleagues in the doctoral program at the University of Georgia.

Most importantly, this dissertation could not have been completed without the assistance of my loving family members. My father and my mother have been the greatest inspiration in my life. Their unconditional love and trust have kept me strong and kept me believing in myself. I would also like to express my gratitude to my brother, sister, brother-in-law and niece, EunHa, and my lovely friends.

## TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS.....	iv
LIST OF TABLES .....	viii
LIST OF FIGURES.....	x
CHAPTER	
I INTRODUCTION .....	1
Overview and Statement of the Problem.....	1
Rationales of the Study .....	9
Objectives of the Study .....	13
Significance of the Study .....	14
II LITERATURE REVIEW .....	17
Nature of End-of-Life Care .....	17
Ways of Achieving a Good Death.....	18
Global Hospice and Palliative Care .....	20
End-of-Life Issues in the Social Work Profession.....	21
Hospice Care in America.....	26
Barriers to the Accessibility of Hospice Care.....	29
The Asian Culture and End-of-Life Care Issues.....	35
Disclosure of Terminal Illness: Truth Telling .....	37
The Decision Making Process .....	39

Advance Directive Preference .....	41
Religiosity and End-of-Life Care .....	45
End-of-Life Care in Korean Culture .....	50
End-of-Life Care Education in Korea.....	54
Attitude Study on End-of-Life Care in Korean Culture.....	56
Conceptual Framework .....	62
Learning Theory.....	62
Intercultural Competence Model .....	63
Intercultural Competence and End-of-Life Care .....	66
III RESEARCH METHODOLOGY .....	70
Research Questions .....	70
Hypotheses .....	71
Research Design and Sampling Methods.....	72
Data Collection and Procedures.....	74
Sample Size and Power Calculation .....	74
Human Subjects .....	75
Instrument Translation .....	75
Measurement .....	75
Dependent Variable .....	76
Independent Variables .....	76
Data Analysis and Statistical Analyses .....	81
IV RESULTS.....	83
Descriptive Analysis .....	83



Univariate Analysis .....	101
Correlational Analysis .....	107
Regression Analysis .....	109
V IMPLICATIONS AND DISCUSSION.....	113
Hypotheses Testing .....	113
Summary of Results .....	115
Summary of Findings.....	125
Implications for Social Work Education and Policy.....	128
Limitations of Study.....	134
Strengths of Study.....	136
Directions for Future Studies.....	137
Conclusion.....	139
REFERENCES .....	141
APPENDICES .....	174
A QUESTIONNAIRE (ENGLISH) .....	175
B INTRODUCTION LETTER OF STUDY (KOREAN).....	186
C INFORMED CONSENT STATEMENT .....	187
D QUESTIONNAIRE (KOREAN).....	188

## LIST OF TABLES

	Page
Table 1: Characteristics of the Sample (N=246).....	84
Table 2: Experience with End-of-Life Care .....	87
Table 3: Descriptive Statistics for the Knowledge Scale on Hospice Care (N=246).....	89
Table 4: Descriptive Statistics for Attitude Scale Part I on Hospice Philosophy (N=246) .....	92
Table 5: Descriptive Statistics for Attitude Scale II: Cultural Prejudice (N=246).....	93
Table 6: Descriptive Statistics for Comfort Level with Death Discussion (N=246) .....	94
Table 7: Descriptive Statistics for Social Worker’s Role and the Need and Willingness to Provide End-of-Life Care (N=246) .....	95
Table 8: Descriptive Statistics for Who Should be Involved in the Decision-Making Process (N=246).....	97
Table 9: Descriptive Statistics for Truthful Disclosure (N=246).....	98
Table 10: Descriptive Statistics for Awareness of Advance Directive Planning (N=246) .....	99
Table 11: Descriptive Statistics for Attitude Regarding Advance Directive Planning (N=246) .	100
Table 12: Effects of Social Workers’ Characteristics on Willingness to Provide End-of-Life Care (N=246) .....	102
Table 13: Effect of Social Workers’ Experiences on Willingness to Provide End-of-Life Care (N=246).....	106
Table 14: Correlation of Independent Variables on Willingness for Providing End-of-Life Care (N=246).....	108

Table 15: Correlation of Attitude on Advance Directive and Willingness for Providing AD .....	108
Table 16: Factor Analysis with Predictor Variables .....	110
Table 17: Coefficients of Predictor Variables in Regression Analysis (N=246).....	112

## LIST OF FIGURES

	Page
Figure 1: Barrier factors to access end-of-life care among minority groups.....	30
Figure 2: Conceptual framework .....	67
Figure 3: Research sites in South Korea .....	73

## CHAPTER I

### INTRODUCTION

Considering the demographic shift toward a graying Korean society and a widespread unfamiliarity with end-of-life care due to the cultural influence on death and dying in the Korean domestic setting, this dissertation discusses the nature of end-of-life care in light of Korean culture and explores the attitudes and tendencies of geriatric/gerontological social workers regarding end-of-life care issues and their willingness or intention to provide end-of-life care.

#### **Overview and Statement of the Problem**

The United Nations (UN) has described the growth of the older adult population as “unprecedented, pervasive, and enduring” (2009). In the 21st century, we will witness an even greater increase in the number of older adults than in the past century. Researchers have estimated that older individuals will account for 22% of the world’s population by 2050 (Lutz, 2008; McDermott, 2010; UN, 2009; World Population Aging, 2002). The World Population Aging (2002) report indicates that over a fifth of the population is currently aged 60 years or over in more developed regions, and nearly a third of the population in developed countries is forecasted to be in that age group by 2050. In the case of less developed regions, “older persons account today for just eight percent of the population, but by 2050 they are expected to account for a fifth of the population” (p. ix). In particular, the aging population in developing or less developed countries is increasing at a faster pace than in industrialized countries, meaning that developing or less advanced countries have less time to adjust to the consequences of an aging population (UN, 2009). Although aged population rates vary across nations, this ongoing global

phenomenon is associated with another critical worldwide issue—providing proper care for the increasing number of aging persons (Longman, 2010).

Modern medical advancements have enabled early detection of diseases and cutting-edge treatments, allowing for healthier living conditions than in decades past (Holloway, 2009). Accordingly, longer life expectancy is anticipated; the average life expectancy worldwide is projected to be 75 years by 2025, and by 2050 life expectancy will range from 75.3 to 87.5 years, and no countries will have life expectancies of less than 50 years (UN, 2005; World Health Organization [WHO], 2004; Seale, 2000). While advanced medical technologies have allowed persons to live longer despite increased disabilities and multiple illnesses, there is also increased attention around issues regarding quality of life for these older adults.

The demographic shift toward a graying population brings attention to the issues of death and dying. Hence, critical questions about enhancing the quality of life of dying individuals and their families have been raised, with the ultimate goal of maximizing their chances of experiencing comfortable deaths and making their remaining time meaningful (Kulys & Davis, 1986). Though death is inevitable and undeniably a universal part of life, it is viewed as a distressing, sensitive, and complex process intertwined with a person's unique upbringing, personal experiences, and individual beliefs and values about dying (Emanuel & Emanuel, 1998). In other words, the ways of understanding and acceptance of death and dying tend to be significantly influenced by an individual's historical and cultural environment.

Despite death's inevitability, or perhaps because of it, not much attention has been paid to the issue of death and dying. Rather, our societies view the matter of dying from a distance and as an uncomfortable issue to address in public. Furthermore, some countries, particularly Asian countries, view death and dying as a taboo topic due to a death denial culture (Kwak &

Salmon, 2007; Oh, 2011). Therefore, to enhance the quality of life of dying individuals from those particular cultures, it might be best to explore one's culture, customs, beliefs, attitudes, and perceptions regarding death, dying, and end-of-life care by questioning what people think about and how they understand these issues in terms of their historical and cultural environments.

### **End-of-Life Care in Korea: Demographic Trends in Korea**

South Korea is experiencing a rapid rate of growth in its old population, which is presupposed to surpass that of other countries. In 2009, the older adult population accounted for 11% (5,176,242) of the entire population and is expected to reach 20.8% in 2028 and 38.2% in 2050 (Choi, 2009). This rate is much higher than the average rate (22% by 2050) of the aging population in the rest of the world, and it is forecasted that Korea will have one of the largest old populations in the world.

Korea has experienced not only a great rate of growth in its older population but also an increased rate of incidences of cancer, the leading cause of death in the country, in recent years. The expectation regarding incidences of cancer is that they will increase as South Korean society ages (Yoo, 2010). A statistic report on cancer by the Ministry of Health, Welfare, and Family Affairs (2010) estimated that if people meet their predicted life expectancy (77 years for a man and 83 years for a woman) then, on average, one in three (34% of the population) will likely be diagnosed at some point with cancer.

### **Death and Dying in Korea**

Korea's demographic trends lead to the logical assumption that providing care for those dying individuals will become a crucial issue throughout the nation. However, in the context of Korea culture, the lack of understanding regarding death and denial of death historically has been deep-rooted, and hence Korea society tends to have an immature death culture (Oh, 2011).

According to an evaluation survey of the quality of the end-of-life care across 40 countries, Korea ranked 34th in terms of the quality of death of older adults. The survey revealed that Korea lacked training, accreditation, and an end-of-life care program, which, together with the inherent cultural factors, affects the availability of and willingness to provide hospice and palliative care. These services effectively address the multifaceted needs of dying individuals and their families and for maximizing patient dignity and quality of life (Economist Intelligence Unit, 2010; WHO, 2011). Therefore, families in Korea are less likely to benefit from these services. More detail regarding hospice and palliative care will be discussed in the next chapter.

### **Formal Services for End-of-Life Care in Korea**

As a formal service providing care for dying individuals, hospice care commenced in Korea in 1965, two years earlier than in the United States. Compared with the United States, where currently more than 5,000 hospice programs and associations operate, in Korea only 120 hospice and palliative care programs existed in 2007 despite the longer history of hospice programs. The categorized total, 120 hospice and palliative programs, includes all hospice and palliative care programs, medical-affiliated independent facilities, and home visit care programs existing throughout the nation. The number of hospice programs has been expanding since 2000, and most hospice and palliative services are supported by religions and charity organizations (Glass, Chen, Hwang, Ono, & Nahapetyan, 2010; Yun et al., 2002). Government support programs and health insurance to cover hospice care for cancer patients do not exist yet (Glass et al., 2010), but there is currently an ongoing process occurring to try to make insurance benefits available for hospice care (Bum, 2010). Along with the absence of official hospice benefits, the number of care facilities in Korea is insufficient to take care of all terminally ill patients and their families needing assistance. These issues have not been addressed properly and and quality of



life for dying individuals has not been made a priority (Park, 2006). Currently, only 6.3% of terminally ill patients receive end-of-life services in Korea (Lee, 2009).

### **Cultural Context of the General Korean Attitude toward End-of-Life Care**

Although Korean society has a long history of hospice care and end-of-life care services, also known as formal services, the development of these services has been slow, and not enough attention has been paid to them due to the cultural context of the issues surrounding death and dying. First, historically in Korean culture, a notable tradition of respect for older adults, which is rooted in the Confucian teachings of filial piety, has been emphasized (Choi, 2001; Lew, 1995; Sung, 2001). Respect for elders has been accepted as a customary and normative duty of the young, and the way of respecting elders by providing family support for older parents has been maintained (Sung, 1998; Seok, 2010). In other words, taking care of aged parents is considered a moral responsibility for an adult child. In addition, the cycle of reciprocity is core to family harmony between generations, and it is regarded in Korean culture as a moral principle, which should be maintained at all times. Consequently, because of the effect of this cultural value on elder care, families are given the responsibility of caring for elder parents, making them less likely to seek assistance outside of the family, and this responsibility is an underlying factor in avoiding formal end-of-life care services (Blackhall et al., 1999; Kim & Rhee, 1999).

Relevant previous studies found that from a traditional cultural point of view, people tend to see death as uncomfortable and unpleasant, and discussing death is considered disrespectful and insensitive (Kwak & Salmon, 2007). In studies, Korean Americans were more likely to have negative attitudes and a lack of knowledge or misconceptions about end-of-life or hospice care, and Korean Americans preferred life-sustaining treatment rather than palliative care (Jang, Chiriboga, Allen, Kwak, & Haley, 2010; Kwak & Salmon, 2007; Moon, Lubben, & Villa, 1998;

Smith, Earle, & McCarthy, 2009). Also, family-based decision-making patterns have been maintained as the family's responsibility including end-of-life decision-making. Studies of Koreans in Korea confirmed that not only health professionals, but also the public lack awareness of hospice services have led to an unfavorable attitude regarding hospice and palliative care (Jung et al., 2010; Kim, 2002; Kim, 2011; Moon et al., 2006; Shin et al., 2010; Yoon et al., 2004). Furthermore, some scholars have noted that Koreans do not believe hospice care is needed for older adults (Yoo, 2008).

### **End-of-Life Decisions with Self-Determination**

Self-determination has been regarded as a core tenet of end-of-life care such as hospice and palliative care (WHO, 2011). In western culture, self-determination is a core value of the end-of-life care process, and facilitating an autonomous decision is considered an important factor for ensuring the quality of one's remaining time (Cagel & Kovacs, 2009; Mezey, Mitty, Rappaport, & Ramsey, 1997). However, throughout Asian culture, autonomy in making a decision about end-of-life care in terms of hospice and palliative care is seldom perceived as empowering. The notion of self-determination or autonomous decision, which is emphasized in western culture and end-of-life care philosophy, cannot equally apply to all cultures.

In the case of Asian cultures, disclosure of a cancer diagnosis may be less likely in terminal cases when a bad outcome is expected. Asian Americans prefer not to talk about death, especially when a family member is dying (Blackhall, Frank, Murphy, & Michel, 2001). Family members may attempt to keep knowledge of death from a loved one to avoid emotional distress and preserve the ability of the soul to obtain liberation (Tewari & Alvarez, 2009, p. 510). Due to cultural attitudes, making such a decision is instead seen as burdensome and may give rise to a loss of hope (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Kwak & Salmon, 2007).

Moreover, not only end-of-life care decisions but also any other medical decisions frequently require the involvement of family members; the physician tends to explain the patient's terminal illness and death to family members and accepts the family's decision without sufficiently considering whether it coincides with the patient's wishes or preferences (Kim, 2011). Korean law states that the person who has been given responsibility to give consent for treatment on behalf of a patient who is incapable of making a medical decision must consider the patient's actual wishes (Civil Act, 933, 2009 as cited in Kim, 2011, p. 508). Despite the legal regulation, a strong traditional cultural expectation still remains and is maintained, so the family tends to make a surrogate decision about end-of-life care treatment even when the patient is capable of making his or her own decision. Especially in end-of-life care decisions, people prefer not to talk about death until the last minute of a family member's life (Kwak & Salmon, 2007). Many dying individuals in Asian culture are unlikely to be officially told that they are dying (Shin et al., 2010). Consequently, unlike western culture, the right to have a choice and to make one's own decision in Asian culture is not necessarily respected nor is the individual necessarily empowered with the information.

### **End-of-Life Care in the Context of the Social Work Profession**

Social workers are key players in developing community care services for older adults, with the aim of enhancing quality of life (Howe & Daratsos, 2006; Berkman, Gardner, Zodikoff, & Harootyan, 2006). In addition, social workers work with people who are dying and bereaved in various settings as front-line workers; additionally, social workers have been considered integral team members of hospice teams (National Association of Social Workers [NASW], 2004; The National Hospice and Palliative Care Organization [NHPCO], 2011). Specifically, social workers have been assigned to improve the quality of end-of life care in academic and

clinical settings by examining the psychosocial needs of the dying person and his or her family (Benzoff, 2003, 2008; Cagle & Kovacs, 2009, 2011).

Despite the importance of the social worker's role in end-of-life care settings, education and training of hospice or palliative social workers have received little attention in Korea compared with the affiliated health care professionals in end-of-life care settings, such as physicians and nurses (Kang, Kim, Shin, Kim, & Lee, 2010 a). Recently, a standard 60-hour training program, that is, a basic training program for general health care providers based on WHO (2007) guidelines for hospice and palliative care, was launched for physicians, nurses, social workers, volunteers, and other individuals involved in hospice and palliative care (Kang et al., 2010 b). Compared to other professions that have their own professional training for end-of-life care staff, specialized programs for social workers who have the potential to be experts in care for the dying do not exist for the social worker profession.

### **Barriers to Providing End-of-Life Care**

Researchers call attention to the fact that medical or hospice social workers who are currently working in hospital settings with terminally ill patients tend to lack specialized hospice and palliative care experience, knowledge, and skills and are constrained by inferior practice environments (Lee, 1998; Lee, 2008; Lee & Lee, 2005; Kang et al., 2009; Kang et al., 2010 a). Moreover, lack of professionalism is a prevailing issue among medical social workers, who have multiple responsibilities for all of their patients, who range from general patients to terminally ill patients. Lee (1998) pointed out that the identified issues related to hospice social workers include the absence of an obvious team approach, which results in a lack of definition for the work performed by social workers. Moreover, the responsibilities of social workers with terminally ill patients are based on team composition and institutional purpose. Each team or

institution requires the social workers to perform a different task, and there is a tendency to neglect or pay insufficient attention to the segment of the social work profession aimed at end-of-life care.

In addition, social workers in the current hospice settings tend to just attend hospice administration/committee meetings or provide limited services as consultants as a matter of form rather than providing holistic care, which includes psychological and emotional support for dying people and their families (Lee, 1998). Accordingly, the role of the social worker in end-of-life settings has not been performed in terms of enhancing the quality of end-of-life care, with absence of focusing on the psychosocial needs of dying patients and their families.

### **Rationales of the Study**

The service programs in Korea for improving the quality of life for dying individuals and their families are insufficient and underdeveloped. Government policies and involvement at a distance based on unfavorable cultural beliefs and values toward death and dying are some of the limiting factors.

Currently, Korean society is undergoing changes; these changes are gradually occurring due to the increasing westernization of Korea and the growing individualization of citizens. The role of the family in providing sole support and protection to family members has weakened; many older adults tend to live alone or with their spouses, not with their adult children, who according to tradition are supposed to be the primary caregivers (Kim et al., 2000). Compared to the past, Korean values have gradually shifted from those that emphasize harmonious human relatedness to values that favor individualistic self-determination. There has been a shift from life-sustaining end-of-life treatment toward advance directives and palliative end-of-life care; people show a positive attitude toward comfortable deaths while avoiding unnecessary pain due

to curative treatment and advance directives to represent their own wishes regarding the process of dying (Kim, 2011). Compared to past decades, perceptions of death are more open, and preparing for death has become more active, in pursuit of the concept of “dying well” (Kang et al., 2011).

It is a global mission to prepare upcoming aging societies to meet the needs of older adults and to ensure the quality of end-of-life care, and to educate social workers on current death and dying practices (NASW, 2004). Of course, social workers who work in health care institutions are now available to a significant portion of older people, who are the ones more likely to require help with these issues (Damron-Rodriguez, Villa, Tseng, & Lubben, 1997). Due to the increasing aging population and the high rate of chronic illness, caring for dying individuals and their families must not be limited to the health care setting; rather, it should extend to health and mental health agencies, hospitals, hospices, home care, nursing homes, and day care and senior centers (NASW, 2004).

In the United States, a national social work competencies survey and report (2000) stated that the required knowledge for those working in geriatric services and/or with older populations should include a section on death and dying. This was identified as one of the five basic competencies for practice by geriatric social workers (Council on Social Work Education [CSWE], 2000, 2001). In addition, the NASW (2004) recommended that training gerontology workers on the subject of death and dying regardless of their practice settings should be required. That is, all social workers should be knowledgeable and skillful in giving assistance in cases involving the stages of the dying process, illness-related issues, the manifestations of pain, advance directives, and the range of settings that provide care at the end of life (NASW, 2004).

However, this recommendation is not addressed by the Council on Social Work Education (CSWE), the accrediting body of social work programs.

In Korea, overall care for older adults is developing with the establishment of long-term care insurance, a universal coverage program for individuals aged 65 and above who are very frail and sick; eligibility is limited to significantly severe cases. Long-term care is determined on a 3 grade severity scale: 1 very severe, 2 severe, and 3 moderate. It is based on a standardized evaluation of senile functional disorders such as dementia, cerebrovascular disease, and Parkinson's disease. The severity of each patient is determined by a standardized assessment. This assessment is conducted by a visiting NHIC team (the insurer), and it follows 52 items based on standards in five areas of physical functions (activities of daily living): cognition, behavioral changes/problems, demands for nursing, demands for rehabilitation, and judgment standards made in consideration of service hours deemed necessary. After gathering this information, the committee selects those who are eligible.

In total, 2,114 long-term care facilities for significantly severe cases provide residential care benefits, with the capacity to serve 77,919 people; this can cover 1.5% of Koreans over 65 years and 29% of the population admitted to care. Furthermore, 14,639 institutions offer home care benefits, and 6,404 institutions offer home help for older adults who can perform most of their daily activities but need assistance with some (National Health Insurance Corporation, 2009; Ministry for Health, Welfare, and Family Affairs, 2009). These developments mean that a large percentage of older adults will spend their later years while receiving those benefits, with which gerontological social workers will hopefully be involved. Therefore, appropriate end-of-life care or education for enhancing the quality of the later years of older adults should be addressed.

Gutheil and Souza (2006) pointed out that an important step for social workers to initiate providing end-of-life care is to know one's own beliefs, perceptions, and attitudes through a process of self-reflection. Through deeper awareness of the meaning of death for them, and their beliefs, and their values to ensure, they can help that they do not have undesirable influences on dying person and his or her family. One identified barrier to discussing end-of-life care with dying patients and their families among health professionals is professionals' discomfort or unfamiliarity with the particular topic of death and dying, which may stem from a lack of confidence through a lack of knowledge, a fearful attitude, and misunderstanding in providing hospice and palliative care (Pfeifer et al., 1994). Potentially, the fear of death can have an impact on the response to situations requiring interaction with dying patients and their families.

Due to discomfort with death and dying and unfamiliarity with end-of-life care as a formal care in Korean culture, death is not approached holistically; rather, the discussion and understanding of death only consider medical and legal aspects, and denial of death is pervasively common (Oh, 2011). It is quite possible that this attitude negatively affects the quality of end-of-life care, and has consciously or unconsciously affected health care professionals in Korea. Professionals' own cultural and religious beliefs, death anxiety, denial of death, and medical treatment preference have been identified as crucial variables that influence client outcomes in end-of-life care (Reese, 1995; Reese, 2000; Reese & Sontag, 2001; Reese, Ahern, Nair, O'Fair, & Warrne, 1999). Scholars have emphasized the importance of understanding health professionals' perspectives, especially in death and dying, to provide professional recommendations that include all available options (Christ & Sormanti, 1999; Kramer, 1998; Reese et al., 2005). Also, as Moller (1996) noted, hesitation to address death comfortably could affect the scope of a social worker's engagement in end-of-life care.



Accordingly, self-reflection among Korean gerontology social workers is necessary for effective practice at the end of life. Further research is essential to understand the relationship between Korean social workers views and feelings toward death and end-of-life care.

### **Objectives of the Study**

This study targeted geriatric social workers in Korea and was designed to explore the knowledge and attitudes of social workers in geriatric institutions regarding end-of-life care treatment options, hospice care, and advance directive planning, particularly in Korean culture. This study also aimed to explain how these workers perceive their role in the practice of end-of-life care along with how comfortable social workers are with discussing death, dying, and end-of-life care.

Focusing on end-of-life care decision making processes, a patient's right to participate in decisions about his or her health is a core principle for allied professionals in providing end-of-life care (WHO, 2011). The NASW (2004) standards for social work practice in palliative and end-of-life care emphasize the importance of supporting patient self-determination and decision-making. Accordingly, the guidelines enhance patients' autonomy by discussing and promoting understanding as one of the responsibilities of a social worker. Similar to the professional codes of ethics in other countries, the social workers' code of ethics in Korea identifies patient autonomy and self-determination as part of the profession's core values (Korea Association of Social Workers; Code of Ethics, 2011).

In addition to exploring the self-determination principle, which focuses on an individual's rights, another purpose of this study is to explore how social workers understand the concepts of clients' autonomy and self-determination, and how important these concepts are in social work, and how these principles have been understood or modified in practice in Korean culture

(individualism versus collectivism). Also, by exploring who makes the decisions regarding end-of-life care, this study considers whether Western culture's emphasis on an individual's autonomy can be applied directly to Korean culture in end-of-life care decision-making. Finally, this study will investigate how the identified factors—knowledge; attitudes regarding end-of-life care and advance directive planning; comfort level in discussing about death; self-determination and awareness of the role of social work including socio-demographic information such as age, gender, house arrangement with elders, religious affiliations—influence the willingness of social workers to discuss death and dying practices in Korea.

### **Significance of the Study**

This study, exploring the knowledge of service providers in Korea, presents significant implications regarding the extension of the delivery of end-of-life care to older clients in geriatric institutions. In keeping up with global trends, Korean society has been gradually paying more attention to the quality of end-of-life services for dying individuals and their families. Accordingly, standardized guidelines and education programs for social workers are urgently needed. Undoubtedly, the professions should define the required competencies related to the quality of life of dying individuals. In other words, the social work profession needs to determine the necessary knowledge and skill set required of social workers dealing with death and dying issues.

It is also important to identify how social workers view and understand the subject of death and dying and end-of-life care based on their culture. Generally, the results of competency studies are employed to prepare either students or practitioners in a specialized area of practice. The core tenets for the care of older persons, developed by a committee of the American Geriatrics Society, provide a curricular framework for multicultural geriatric care in

schools of medicine and other allied health professions and provide teaching strategies and resources for faculty (Xakellis et al., 2004). This study partly aims to assess social workers' competencies in death and dying issues and to provide data to professional, medical, and government agencies for enhancing the quality of end-of-life care services.

Studies on death, dying and end-of life care in different cultures are lacking despite the need for comprehensive research (Kwak & Haley, 2005). Since the present study is being conducted in a particular culture, this study will yield a better understanding of end-of-life care in Korea from the standpoint of service providers. To the best of our knowledge, no previous studies have been conducted in Korea with a particular focus on the attitude and perception of geriatric social workers regarding end-of-life care. Therefore, the results of this study can be compared and contrasted with findings from other cultures, with attention given to how service providers (American, European, or those from the same culture, such as Korean American hospice social workers) differ in their understanding of death and dying and how cultures and attitudes affect geriatric practices.

Moreover, this study will enhance the knowledge and skills of social workers when dealing with Korean, at home and elsewhere in the world. Although many Koreans live in many foreign countries, in case of the United States Korean Americans tend to continue to follow Korean ways of life, maintaining their Korean culture, beliefs, customs, and kinship-oriented lifestyles (Kauh, 1997). The results of this study will benefit social workers by clarifying issues pertaining to providing hospice care to Korean Americans, in addition to shedding light on their culture, preferences, and decision-making processes.

This chapter contains an overall review of the increasing attention being paid to the topic of death and dying and providing end-of-life services for enhancing the quality of life of dying

individuals and their families. Based on a cultural and historical understanding of death and dying in Korean culture, this chapter addressed why the present study is rationally and practically needed. The following chapter discusses relevant studies of end-of-life care in the context of cultural diversity and uniqueness among ethnic groups, with a particular focus on the Korean population.

## **CHAPTER II**

### **LITERATURE REVIEW**

This chapter first discusses the nature of end-of-life care and then looks at how social workers provide end-of-life care in a variety of settings. Along with the reception of end-of-life care within minority populations in the United States, this chapter presents the factors that influence ethnic groups, such as barriers to access, cultural preference, attitudes, decision-making processes, advance directives, and religious affiliations. Last, focusing on the Korean population, this chapter presents the prevalence of end-of-life studies.

#### **Nature of End-of-Life Care**

Although there is no single definition of a good death, from the standpoint of the hospice movement initiated in the United Kingdom, a good death has been defined as dying at home in dignity, tranquility, and comfort, and surrounded by loved ones (Asch-Goodkin, 2000). Furthermore, a good death is closely related to the dying person's preferences for treatment and circumstances surrounding death (Patrick, Engelberg, & Curties, 2001). Specifically, the important factors regarding end-of-life care arising from not only the long-term care setting but also end-of-life care settings have been identified as managing pain and symptoms, treatment of a person as a whole, alleviating the burden of loved ones, providing social relationships and support, and avoidance of prolonging the dying process (Goodridge, Bond, Cameron, & McKean, 2005; Munn & Zimmerman, 2006; Patrick et al., 2001; Touhy, Brown, & Smith, 2005; Singer, Martin, & Kelner, 1999; Steinhäuser et al., 2000). In addition, making peace with God and tending to unresolved psychosocial matters are also important factors in achieving a good

death (Byrce et al., 2004; Hart, Kohlwes, Deyo, Rhodes, & Bowen, 2003). In contrast, a poor death has been characterized as having a high level of patient pain and distress along with caregiver burden (Steinhauser et al., 2000). In summary, the crucial factors to achieve a good quality of death are not only connected to health-related domains but also include emotional, social, and spiritual spheres (Steinhauser et al., 2000). In other words, a good or comfortable death is more likely to be achieved by satisfying physical, psychosocial, and spiritual needs.

### **Ways of Achieving a Good Death**

#### **Definition of End-of-Life Care**

The terms *palliative care* and *hospice care* are considered different terms in the United States, but the care programs share the goals of offering symptom relief and pain management (Hill, 2007; Twycross, 1995, 2002). To be specific, both hospice and palliative care have been designed to address the multifaceted needs of dying individuals and their families and share the goal of relieving symptoms or suffering, maximizing patient dignity and quality of life, and facilitating a good death (Orloff, Quance, Perszyk, Flowers, & Veale, 2004). The four basic principles of the concept of hospices are the following: 1) the patient and their family are regarded as the unit of care; 2) an interdisciplinary team serves to address the physical, psychosocial, and spiritual needs, as well as family bereavement counseling, and coordinated care, pain medications, homemaker services, and respite care; 3) Management of pain and symptoms are delivered to provide comfort, not for any curative effort; 4) Bereavement follow-up is provided to the family members after the patient's death to address their emotional suffering. To be eligible for hospice care, Medicare and most other insurers require that a physician certify that the patient is anticipated to die within 6 months if their illness follows its anticipated course, and the patient has to agree to forgo curative treatment (NHPCO, 2011; U.S.

General Accounting Office (GAO), 1979). Care can be provided in any home setting, such as a private residence, nursing home, assisted living community, or group home (Hospice and Palliative Care of Greensboro [HPCG], 2007).

Similarly, the goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for both patients and their families. However, palliative care can be given regardless of the stage of the disease or the need for other therapies (National Cancer Institute [NCI], 2010; Palliative Care and End-of-Life Care, 2011; WHO, 2011). It means that palliative care expands traditional disease-model medical treatments to include the goals of enhancing the quality of life for patient and family, who can concurrently receive management care with curative treatment. Palliative care is mostly delivered in area hospitals, assisted living (AL) and skilled nursing facilities (SNF) (HPCG, 2007; NCI, 2010).

In regard to palliative services, the following issues have been: (a) Physical: to aggressively treat and expertly manage all pain and physical symptoms associated with dying by medicine, nutrition and physical therapy, chemotherapy or radiation therapy etc. (b) Emotional and Coping: to support individuals and families in the process of coping with dying and to provide bereavement support for family members after the death of their loved one by providing counseling, support groups, family meetings or referral to mental health professionals, etc. (c) Practical: to address financial and legal worries, insurance questions, employment concerns, and concerns about completing advance directives to promote the individual's and family members' senses of autonomy, individuality, self-worth, and security. (d) Spiritual: to help people explore their beliefs and values so as to find a sense of peace or reach a point of acceptance in the given situation (National Cancer Institute [NCI], 2010).

End-of-life care that emphasizes an individual's multifaceted needs and interdisciplinary assistance that facilitates quality of life can be categorized, respectively, as formal and informal support systems, and while they are distinct, the two care systems do interact with one another. According to the Hospice Association of America [HAA] (2009), formal support can be viewed as any organization-based service, such as in-patient and resident hospices, homecare, disease-related support groups, or faith communities. Hospice services can be provided by the patient's usual health-care providers in hospital units or with the assistance of experts in palliative care. This care can be provided in nursing homes and other health-care facilities, in the patient's home, or in a freestanding outpatient unit (Rhymes, 1996). Informal support is defined mainly as the assistance provided by family, friends, or significant others (HAA, 2009). Even for patients receiving complex, intensive medical care for life-threatening illnesses, including those who wish to die at home, family caregiving or informal caregiving is typically at the core of what sustains them at the end of life (NHPCO, 2011).

### **Global Hospice and Palliative Care**

The hospice movement originated in the United Kingdom in 1967 when St. Christopher's Hospice opened in London under the direction of Dr. Cicely Saunders. Soon after, the movement spread to South Korea, other countries in Western Europe, and the United States. While this movement originated from a central location, hospice care has been developed differently across the five continents (Clark, 2004, 2007; Twycross, 2002).

A report from the International Observatory on Palliative Care (2006) indicated that even though there are some exceptions, there is little palliative care provision or only localized provision in most resource-poor countries (Clark & Wright, 2007). In contrast, extensive care for the dying is more easily accessible in developed or wealthier countries (Clark, 2007; Wright,



Wood, Lynch, & Clark, 2008). A recent survey from the Economist Intelligence Unit (2010), which evaluated current end-of-life care services across 40 countries, assesses the overall quality of end-of-life care; substantial variation among the 40 countries was identified after scrutiny. Not surprisingly, with such evaluation indicators as public awareness, training availability, access to painkillers, and doctor–patient transparency, the United Kingdom, which initiated the hospice movement and has more developed end-of-life care, ranked number one. Overall, the survey showed that wealthier countries have superior environments for end-of-life care; Australia ranked second, and both Canada and the United States equally ranked ninth. With respect to Asia, Taiwan ranked 16th, Singapore 18th, Japan 23rd, Hong Kong 24th, and South Korea 32nd. In addition, not surprisingly, most developing nations, such as China, Mexico, Brazil, India, and Uganda, ranked at the bottom of the list, although these nations have high mortality rates for cancer-related deaths, and especially in the case of Africa, AIDS-related deaths (Clark, 2007; Economist Intelligence Unit, 2010). However, wealth was not always correlated with a high-quality of end of life care. Denmark, Italy, and Finland, which are wealthy, developed nations, ranked poorly compared to other developed nations at 22<sup>nd</sup>, 24<sup>th</sup>, and 28<sup>th</sup>, respectively (Ling, 2010). Thus, initiating and developing end-of-life care to ensure a good quality death for the dying and their family is a global issue and should be accorded increasing attention as an extension of the well-being of older adults.

### **End-of-Life Issues in the Social Work Profession**

In 2004, the National Consensus Project for Quality Palliative Care (NCP) developed Clinical Practice Guidelines for Quality Palliative Care after examining the national and international standards currently employed in the palliative care field. The guidelines delineated eight domains essential to providing palliative care:

(a) structure and processes of care; (b) physical aspects of care; (c) psychological and psychiatric aspects of care; (d) social aspects of care; (e) spiritual, religious, and existential aspects of care; (f) cultural aspects of care; (g) care of patients whose deaths are imminent; and (h) ethical and legal aspects of care. (Palliative Care and End-of-Life Care, 2011, p. 5)

Social work professionals in general help people achieve an effective level of psychosocial functioning, and effect societal changes to enhance the well-being of all people (Barker, 1991). Regarding end-of-life care, the primary role of the social worker is to provide psychosocial and support services based on a holistic approach (Beresford, Adshead, & Croft, 2007). Specifically, the social worker provides care to patients, families, and caregivers by addressing the emotional, psychological, social, spiritual, cultural, financial, and environmental aspects of care. Social workers have also been identified as critical members of various interdisciplinary health-care teams for dying patients and frequently serve as members of palliative care teams (Altilio, Otis-Green, & Dahlin 2008; Foley & Gelband, 2001; Holland, 1998; Raymer, 2011).

Traditionally, hospice and palliative care, including care for the families of dying patients, has been provided to terminally ill patients in health-care facilities by clinical/medical or palliative care social workers. However, with rapid increases in aging populations and higher cancer rates, social workers are more likely to be involved in the issue of death and dying regardless of the settings or population they are working with (Kramer, 1998, 2002). For instance, social work practitioners are more likely to encounter adults and their families who are experiencing life threatening illness and face death or death of a family member and subsequent bereavement in a variety of health and social service settings including acute and long-term care facilities, and institutional and community-based facilities (Christ & Blacker, 2005). A study by

the NASW indicated that 73 percent of all clinical social workers provide services to adults who are aged 55 years and over regardless of the practice setting or focus (Whitaker, Weismiller, & Clark, 2006). Therefore, the need to address end-of-life care issues throughout the social work field has been raised, and the role of the social worker has been extended and modified across many practice areas (Kramer, Pacourek, & Hovland-Scafe, 2003), such as health care, hospice services, crisis services, school settings, child welfare, trauma, disaster relief services, as well as agencies that serve the poor and older adults, such as home care settings and nursing homes, where social workers are more likely to encounter end-of-life situations (NASW, 2004).

Based on the National Association of Social Workers' Standards for Social Work Practice in Palliative and End-of-Life Care (NASW, 2004), the role and contribution of social workers in many hospitals and intensive care units include practical services, such as referrals to community resources, discharge planning, and liaising with other professionals. The interventions that social workers are more likely to employ or apply to practice in palliative and end-of-life care have been identified as the following:

(a) individual counseling and psychotherapy, (b) family counseling and family team conferencing, (c) crisis counseling, (d) information and education, (e) multidimensional intervention regarding symptom management, (f) support groups and bereavement groups, (g) case management and discharge planning, (h) decision-making support and client advocacy, and (i) assistance with navigating systems and resource counseling. (NASW, 2004, p. 21)

Also, one study identified the role of a social worker in end-of-life care as that of broker, teacher, mediator, enabler, and advocator (Compton & Galaway, 1999). Social workers have also been assigned to the domain of life-sustaining treatment decision (Werner & Carmel, 2001b) and various other issues related to family dynamics, community resources, and education on the

process of dying (Bern-Klug, Gessert, & Forbes, 2001). In addition, the social worker can play a key role in empowering churches to become supportive communities that take care of people during all seasons of life, including the end of life (Curtis, 2010).

For example, Bern-Klug, Gessert, and Forbes (2001) found that social workers tend to help a family consider how and where they would like the death to occur and help clients prepare for their meetings with physicians and other health-care professionals to facilitate discussions on what should or should not be done medically. Furthermore, social workers help other members of the health-care team understand the patient's hopes, desires, and fears regarding his or her death. A survey of 77 social workers in health-care settings indicated that specific social work activities with the dying include promoting self-determination, acting as liaisons with family and health-care professionals, identifying end-of-life options, discussing the patient's wishes for care, and making referrals to other professionals (Csikai & Bass, 2000).

To examine social workers' activities in palliative care in intensive care units, McCormick, Curtis, Stowell-Weiss, Toms, and Engelberg (2010) conducted surveys with 590 patients, 275 families, and 35 social workers. The researchers found that talking with family members about their feelings and providing support for the decisions made by the family were the activities in which social workers most frequently engaged. Furthermore, the study indicated that the greatest barrier to providing palliative care services to families was a heavy patient caseload. Increasing social workers' years of experience and having a lighter caseload are independently associated with better family experiences with social workers' services. For effective social work services in end-of-life care, prior experience, which is more likely to accompany a high level of proficiency, and strong listening and communication skills are very important. In addition, particularly in an emergency room, the social worker's activities in

relation to palliative care have been identified as assessing the situation, providing information to families, acting as a liaison with other professionals, encouraging the expression of emotion, and offering support for dealing with grief (Holland & Rogich, 1980).

The NASW (2010) emphasized those responsibilities of nursing home social workers that are related to psychosocial services. “Psychosocial concerns include mental health disorders such as depression, anxiety, dementia, and delirium, as well as a range of issues with more obvious social dimensions, including loss of relationships, loss of personal control and identity, and adjustment to the facility” (Social Work Policy Institute, 2010, Para. 3). In nursing care settings, the roles of social workers typically include facilitating the admissions and discharge processes, participating in developing an individualized care plan, addressing the social and psychosocial well-being of residents and family members, and involving the entire nursing home in meeting residents’ psychosocial needs. Nursing home social workers are often the first staff members to meet family members and residents upon admission, to encourage the discussion of end-of-life care planning, and to introduce a form of advance directives (Happ et al., 2002; Lacey, 2002, 2005, 2006; Mezey et al., 1997).

Bern-Klug (2010) examined psychosocial concerns and needs in the context of geriatric palliative care in nursing home settings. Since nursing home residents are potential candidates for palliative care, psychosocial care is an important part of palliative care in nursing homes. This study indicated that many older adults living in institutions suffer from depression, suicide, loss, and grief. Therefore, social workers that address psychosocial well-being as a key component of palliative care can be a resource for patients and family members as well as other professionals seeking to enhance psychosocial well-being. Specifically, nursing home social workers and other staff need to work with family members to anticipate residents’ functional and

cognitive decline and to help families deal with their anticipatory grief, as well as death and dying issues. Social workers also need to proactively plan palliative care interventions with family members to minimize potential conflicts, especially in crisis decision-making (Bern-Klug et al., 2001). The U.S. government approved the Patient-Self Determination Act (PSDA) in 1990, mandating that the staff of Medicare-certified hospitals and nursing homes educate patients about their advance directive rights for future treatment in end-of-life care by engaging in informal conversations to establish health-care preferences (Kahana, Dan, Kahana, & Kercher, 2004). Social workers are often given the role of discussing advance directives with nursing home residents and their family members (Lacey, 2005, 2006).

In summary, social workers in diverse practice settings play essential roles not only in assisting patients and their families with psychosocial and environmental needs, but also in acting as liaisons with other professionals related to issues of end-of-life care. In addition to working with patients, advocating for patients' rights to make their own decisions regarding future care has been identified as an important aspect of the social worker's job in the long-term care setting. The Social Work Policy Institute (2010) identified that one barrier to adequate and continuous mental health and psychosocial care in nursing homes is a lack of professionally qualified social workers employed in these facilities. Accordingly, to be effective in end-of-life care, social workers must possess the necessary psychosocial skills to assist family members and dying individuals as they prepare for death and the grieving process.

### **Hospice Care in America**

In 2010, over 5000 hospice programs were operating in the United States (U.S.). These hospice programs are classified into four types of facilities: independent or freestanding agencies (58.0%), part of a hospital system (21.3%), part of a home health agency (19.2%), and part of a

nursing home (1.4%) (NHPCO, 2011). Hospice care cost is generally covered under Medicare, Medicaid, and private insurance plans, and patients receive hospice care regardless of ability to pay in the United States (NHPCO, 2011). Since Medicare hospice benefits were originally legislated in 1982; the majority of hospice and palliative care programs has been supported by Medicare (Centers for Medicare & Medicaid Services, 2011). For instance, in 2010, the percentages of patients by payer were as follows: Medicare hospice benefits (83.8%), managed care or private insurance (7.9%), Medicaid hospice benefits (4.9%), uncompensated or charity care (1.5%), self-pay (1.1%), and other payment sources (0.8%) (NHPCO, 2011).

The National Hospice and Palliative Care Organization (2011) reported that approximately 41.9% of all decedents (1,029,000 hospice deaths out of 2,452,000 deaths in the U.S.) received hospice care in 2010. The percent of U.S deaths served by hospice is calculated by dividing the number of death in hospice by the total number of death in the U.S. (NHPCO, 2011, p.4). In 2007, 30.1% of Medicare recipients accessed three or more days of hospice service, and 43.4% of Medicare recipients with a cancer diagnosis accessed three or more days of hospice care. Despite greater use of hospice, the majority of hospice care patients have short stays.

In 2010, the median length of receiving the service was 19.7 days, meaning half of hospice patients received care for less than three weeks, and specifically, approximately 35.3% of hospice patients die or were discharged within seven days of admission (NHPCO, 2011). This means that the majority of Americans still do not receive sufficient hospice care.

In 2010, 82.7% of hospice patients were age 65 or older; more than one-third (38.9%) of all hospice patients were age 85 or older. In terms of types of illnesses being treated in hospice care in the United States, while cancer patients were the majority of hospice patients in the past

decades, currently cancer patients (35.6%) account for less than half of all hospice admissions, and the total includes other terminal diseases (e.g., heart disease, dementia, and lung disease) (NHPCO, 2011). This illustrates that hospice care is not only for terminally ill cancer patients but also for all chronically ill patients.

Most Americans facing a terminal illness show a preference for dying at home (Gatrell et al., 2003; Gott, Seymour, Bellamy, Clark & Ahmedzai, 2004; Grunier et al., 2007; Tang, 2003), as do most people from non-Western cultures. The National Center for Health Statistics (2010) reported that most Americans suffering from cancer and other chronic conditions still die in institutional settings. More specifically, in 2007 one-quarter died at home and more people died in nursing homes or long-term care settings. Mitchell, Teno, Miller, & Mor (2005) found that hospital was the most common place of death for all conditions which were not related to dementia (52.2%), and 66.9% of deaths related to dementia occurred in nursing homes. Regarding where Americans die, age is identified as a significant factor to influence the place of death (Flory et al., 2004). In 2007, decedents under age 65 were more likely to die at home (30%) than those aged 65 and over (24%). Compared to those under age 65, older decedents were five times more likely to die in nursing homes (National Center for Health Statistics, 2010, p. 43-44). Nursing home deaths are particularly common among the oldest-old age groups: one-third of older adults aged 75 and older faced death in a nursing home (Mitchell et al., 2005), and this rate is anticipated to be nearly 40% by 2020 (Brock & Foley, 1998).

The NHPCO (2011) reported that minority, non-White patients (multiracial, African American, Asian American, Hawaiian, other Pacific Islander, American Indian, or Alaskan Native) accounted for only 19.5% of hospice patients, while 80.5% of the patients were Caucasian. A study confirmed that Asian and African Americans, as well as Latinos, underuse



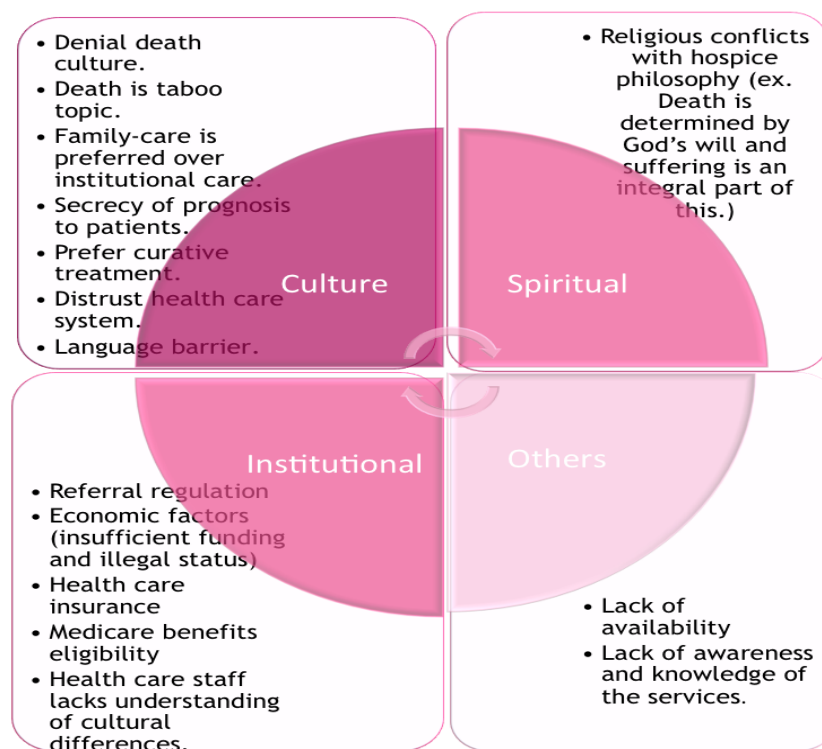
hospice care compared to non-Hispanic Whites (Haas et al., 2007). Furthermore, Smith and colleagues (2009) conducted a secondary data analysis with 4,960 participants and found that Asian and African American patients with advanced cancer were more likely to be hospitalized frequently and for prolonged periods than Caucasians; moreover, Asian and African American patients tended to die in the hospital with low rates of hospice utilization. Ngo-Metzger and colleagues (2003) examined hospice use among Asian American patients compared to Caucasian patients ( $N = 184,081$ ) and reported that older Asian Americans dying of cancer were less likely to use hospice care than Caucasian patients, especially those who were born abroad.

### **Barriers to the Accessibility of Hospice Care**

Numerous factors which influence the accessibility of hospice care have been identified: policy, health care insurance coverage, economic factors, the attitudes and practice of health care providers, and health care consumers' preferences (Jennings, Ryndes, D'Onofrio, & Baily, 2003). Specifically, the identified factors can be categorized as the following: (1) the structure or institutional barriers such as laws, policies, and regulations affecting the organization, financing, and delivery of care, and (2) barriers from the standpoint of service providers such as the attitudes and practices of health care providers, including referring physicians and hospice professionals themselves, who are the gatekeepers of the system (Jennings, Ryndes, D'Onofrio, & Baily, 2003). For instance, to be admitted to a hospice program with Medicare hospice benefits, a person must have been given a prognosis by their physician as having six months or less to live (Centers For Medicare & Medicaid Services, 2012). But it may be difficult for a physician to make such a clear-cut diagnosis when estimating the life expectancy of a patient, so there is a referral barrier. In addition, (3) service consumer misunderstanding, misinformation, and stigma against hospices may create barriers to the accessibility of hospice programs (Jennings, Ryndes,

D’Onofrio, & Baily, 2003). A study of how hospital patients view palliative care in the hospital setting found that the meaning of palliative care is primarily perceived as limiting life-sustaining treatments or allowing death in acute care hospitals. Specifically, the prevailing perception of palliative care is that it provides death services rather than pain and symptom management and consultation services and that receiving these services is a signal that physicians have given up on the patient (Rodriguez, Barnato, & Arnold, 2007).

Focusing on minority ethnic groups, *Figure 1* visually presents possible barriers by scholarly review of previous published research (Cort, 2004; Krakauer, Crenner, & Fox, 2002; Reese et al., 1999; Moon, Lubben, & Villa, 1998; Rodriguez, Barnato, & Arnold, 2007; Michaelsen, Krasnik, Nielsen, Norredam, & Torres, 2004; Karim, Bailey, & Tunna, 2000).



*Figure 1.* Barrier factors to access end-of-life care among minority groups (Kwon, 2012)

For instance, Reese et al. (1999) specified that a lack of knowledge of services, economic factors, lack of trust among African Americans of the health-care system, and a lack of diversity in health staff are institutional barriers to hospice use. Similarly, Krakauer, Crenner, and Fox (2002) categorized the barriers to utilization of end-of-life care for minority patients as institutional, cultural, and individual. Institutional barriers include economic barriers such as inadequate health insurance, social barriers such as unequal access unrelated to insurance, and underrepresentation of minorities in medicine. The cultural differences between patients or families and health-care providers and the insensitivity of providers to such differences lead to cultural barriers. Lastly, individual barriers include racially discriminatory practices by individual physicians, psychological barriers caused by mistrust or discrimination at the individual and institutional level, and by cultural insensitivity. Other barriers in the African American community include the prohibitive cost of health care along with mistrust of the health system, while Latinos reported that language barriers prevent them from accessing end-of-life care (Born et al., 2004). In addition, in a study with a Korean American population, Moon, Lubben, and Villa (1998) measured the awareness and use of community long-term care services and found that only 1.3% of Korean Americans had ever heard of hospice care, while 48.3% of Caucasians were aware of hospice care.

As discussed briefly above, culture is one of the barriers to optimum hospice care, since culture and ethnicity are the primary factors influencing one's attitude toward hospice care (Kwak & Haley, 2005; Volker, 2005). The NHPCO (2010) emphasizes that each person involved in the end-of-life setting might have a unique understanding or perception of end-of-life care based on ethical, religious, and cultural differences, and emotional and legal policies, along with allocations of individual, family, and societal resources related to health care and decision-

making. In other words, each cultural/ethnic group, even within subcultures, has its own view of palliative and end-of-life care that influences the group's perceptions of illness and death, personal autonomy, and control. Furthermore, these differing perceptions and beliefs may affect how "a good death" is defined, the desire for information about the illness and the prognosis, and the wish to plan end-of-life care (Mitty, 2001).

Relevant end-of-life care studies associated with cultural differences have been conducted to investigate perceptions and attitudes toward end-of-life issues and knowledge of hospice care with predominately Caucasian and African American populations (Rosenfeld et al., 2007). First of all, African Americans are more likely to prefer to die outside the home (Crawley, 2002; Field & Cassell, 2010; National Hospice Organization, 1998), which is inconsistent with the beliefs of Americans in general. That is, African Americans prefer staying in an intensive care unit, hospice, or nursing home during the stage of end-of-life compared to other minority ethnic groups (Duffy, Jackson, Schim, Ronis, & Fowler, 2006). African Americans prefer to die in the hospital, even though death in the hospital setting has been associated with a lower level of care and unmet emotional, informational, and symptom needs. A study found that 62% of African Americans would prefer to die in a hospital (Neubauer & Hamilton, 1990).

With regard to hospice care, a study by Ludke and Smucker (2007) confirmed that African Americans not only underuse hospice services but also may have a lower level of interest in hospice care. Some studies have also indicated that African Americans are less interested in and knowledgeable about hospice care than Caucasian Americans (Burrs, 1995; Crawley, 2002; Harper, 1995; Reese et al., 1999). Recent statistical data have shown that African Americans represent only 8% of patients who use hospice care, whereas the White population represents 83% of those in hospices (NHPCO, 2011). In addition, a research found that African Americans

are more likely to choose lifesaving procedures and less likely to complete advance directives (O'Brien et al., 1995). A study by Johnson, Kuchibhatla, and Tulsky (2008) explored African Americans' and Caucasians' attitudes toward hospice care by administering a survey employing the following five scales: Hospice Beliefs and Attitudes, Preferences for Care, Spirituality, Health Care Distrust, and Beliefs about Dying and Advance Care Planning. The study confirmed that African Americans are more likely to feel uncomfortable discussing death and dying, want more aggressive care at the end of life, have spiritual beliefs that conflict with the goal of palliative care, and distrust the health-care system. Furthermore, the African Americans in this study were significantly less likely to consider hospice use if the patients were suffering from a terminal illness and were near the end of their lives, even if their doctor strongly recommended hospice use (Johnson et al., 2008). A study by Rhodes, Teno, and Welch (2006) using a mortality follow-back survey of 1,578 people examined how informed people were about the option of hospices; 111 respondents were identified as African American. The survey found that more than half of the African American patients had not been informed about hospice services and that 8.9% had been informed but would not use hospice services.

Reese and colleagues (2005) noted that barriers that exist in professionals' own unexamined cultural and religious beliefs, and treatment preferences may prevent them from considering all end-of-life care options when making professional recommendations to clients. Lack of personal preparation in terms of adequate knowledge and skills to cope with grieving or dying clients may lead to professional recommendations that do not include all available options (Christ & Sormanti, 1999; Kramer, 1998; Reese et al., 2005). For instance, among health professionals, Rosenfeld and colleagues (2007) found significant neglect with respect to honest communication with patients. This study showed a lack of referrals and a lack of accurate,

spiritually sensitive information regarding end-of-life services. Moreover, Silveira, DiPiero, Gerrity, and Feudtner (2000) noted that misunderstandings about end-of-life choices and hospice care are pervasive and that physicians do not inform patients of their options.

Michaelsen, Krasnik, Nielsen, Norredam, and Torres (2004) found that health professionals, including doctors, nurses, and assistant nurses ( $N = 517$ ), showed reluctance to provide end-of-life care to minority patients. Approximately 60% of all three professional groups had experienced minority patients having not understood the professionals' advice and counseling, and 40% felt that they could not fulfill the needs of their minority patients. According to 24% of those surveyed, the minority patients did not generally receive sufficient treatment, care, or advice (Michaelsen et al., 2004).

Karim, Bailey, and Tunna (2000) explored the referral patterns of 15 hospital consultants and 12 general practitioners relating to members of black or minority ethnic communities. This study found that GPs and hospital consultants are less likely to refer members of minority ethnic groups as hospice inpatients or to daycare services compared to white patients. The results of the interviews indicated the following major themes regarding the reason why they less frequently refer minority patients to such care: (a) doctors believed that providing palliative care themselves for ill members is preferred among black or minority ethnic families. Doctors believed that if a family sends its older adult or other family member away to a strange site to die with assistance from people unknown to the patients, it would be considered as a failure on the part of the family and as shameful within the ethnic community based on cultural tradition. (b) The culture of denial of information on the part of the families to the patient is the main conflict in referring patients to hospice care, since the minority ethnic groups tend not to disclose the diagnosis to patients. (c) With regard to the meaning and interpretation of the hospice, most doctors feel that

ethnic minorities are unaware of, or misunderstand, the existence of hospices and the services available; this is a lack of knowledge and information. Additionally, (d) language barriers causing the doctors' inability to communicate directly with patients who are unable to speak or understand English; and (e) agreement among the patient and his or her family members on the usefulness of hospice care, as they are not sure whether the facilities provide culturally sensitive services to minority patients in a culturally familiar environment including religion and language (Karim et al., 2000) (Karim et al., 2000).

Reese and colleagues (2005) explored the differences between three groups -- social work students, community residents, and medical students -- regarding cultural and religious beliefs, death anxiety, denial of terminality and medical treatment preferences. The study found that most social work students, community residents, and medical students were more likely to prefer palliative care as opposed to curative care during terminal illness. They found that community residents were the group that most strongly adhered to religious and cultural beliefs while medical students least strongly adhered to those beliefs. The three groups in this study indicated a moderate amount of death anxiety, but social work students showed the highest level of anxiety. Those who were older and have previous experiences with death through the deaths of parents or spouses showed less or lower death anxiety.

### **The Asian Culture and End-of-Life Care Issues**

Many scholars note that Asians are more likely to have negative attitudes on end-of-life care associated with cultural factors, which significantly influence the behavior and social interaction of Asian groups (Blackhall et al., 2001; Jang, Chiriboga, Allen, Kwak, & Haley, 2010; Jung et al., 2011; Kim, 2002; Kim, 2011; Kwak & Salmon, 2007; Moon, Lubben, & Villa, 1998; Shin et al., 2010; Smith, Earle, & McCarthy, 2009; Yoon et al., 2004).

The major philosophy in Asian culture is Confucianism, which originated as ethical-sociopolitical teaching, which guides and teaches people about the moral behavior they should maintain. The core of Confucianism is humanism; in particular, a filial piety among themes in Confucian thoughts emphasizes the relationship between elders and other family members in regard to elder care (Nuyen, 2004; Sung, 1998). Filial piety is a notion which indicates children's obligation or duty towards their elder parents. That is, it is the moral responsibility and duty, described as respect, loyalty, and devotion to parents, which children must maintain for elder parents (Nuyen, 2004). This notion connotes that children owe their parents, since their parents took care of them until they became adults, so that when parents become frail the adult children are obligated to provide for their parents with financial and emotional support at any cost (Smith & Hung, 2012). In other words, care for aging parents is a sacred obligation in repayment for the care provided by the parents for their children (Sung, 1995).

The cycle of reciprocity is a core value in the culture for familial harmony, and the harmony and unity of the family are concepts keeping the family together as a single unit. In terms of the effect of this value on aged care, families are expected to be responsible for caring for elder parents within the family network and without seeking assistance outside of the family (Kim & Rhee, 1999; Smith & Hung, 2012). This means that people are encouraged to support their elder parents at home or within the family environment away from formal care. Accordingly, if children send their parents to nursing homes or formal care units, it is regarded as shameful and might be seen as shame on the family. People in this culture are often hesitant to talk about death as this is considered bad luck, and the cultural denial of death and reluctance to discuss the prospect of death openly is common in Asian countries (Rhymes, 1996; Oh, 2011). Along with the denial of death culture, the withdrawal of sustaining treatment of any kind could



dishonor the family, since filial piety emphasizes the adult children would do everything possible to extend their parents' lives. Therefore, children who choose to give up curative treatment are perceived as not fulfilling the moral duty as adult children to do everything to prolong life (Kwak & Salmon, 2007). Therefore, members of the Asian culture tend to prefer curative treatment rather than palliative care during end-of-life periods.

Giving high value to filial piety has been stressed on family-centered decision-making when people make an important decision. As expected in the culture, the family is deeply involved in an individual's health care decisions, and sometimes, the family overrides the individual's decisions based on familism (Blackhall et al., 2001). The term of *familism* refers to a devotion or loyalty to family, stresses family harmony, family solidarity, family reciprocity, and filial piety, which includes a value of respecting and caring for elders and obeying one's parents (Smith & Hung, 2012). Autonomy or self-determination is not necessarily respected nor is the individual necessarily empowered; instead, it is regarded as burdensome and causes a loss of hope in situations involving end-of-life decisions in the culture (McLaughlin & Braun, 1998; Glass et al., 2010). In addition, when parents are frail or they are incapacitated, the older child, most often the eldest son, presumes the role of surrogate for the parents, and the other siblings are expected to respect the eldest son's decisions in the customs of Confucian ideal (Fan, 2006; Park & Chesla, 2007).

### **Disclosure of Terminal Illness: Truth Telling**

de Penhney O' Kelly, Urch, and Brown (2011) point out that truth telling is not a globally shared ethical principle. Duffy and colleagues (2006) indicated that White Americans, regarding disclosure of terminal illness, tend to know what to expect physically based on precise information and want the right to make independent decisions regarding their care and illness

(Duffy et al., 2006). However, in Asian cultures, *filial piety* influences people to think that caring for their parents in a situation removed from distress is a moral responsibility. In many social systems, filial duties and obligations form the principal basis of nondisclosure. In such cultures, family members have a strong obligation to protect the patient, which manifests in shielding the patient from distress (Sung, 1998). In other words, nondisclosure of terminal illness has been maintained for the reason of protecting the family member suffering from terminal illness from feeling distress. For example, Blackhall et al. (1995) found that Korean Americans and Mexican Americans are less likely than European Americans and African Americans to endorse informing the patient of his or her prognosis (Blackhall et al., 1995). A case study in an American hospital setting with one Chinese participant and one Georgian participant conducted by Lapine and colleagues (2001) emphasized the lack of truth disclosure in Chinese families. The families desired that the patient not be informed of a cancer diagnosis, despite the physician's insistence. For example, the Chinese family felt a strong obligation based on *filial piety* (Glass, Chen, Hwang, Ono, & Nahapetyan, 2010; McLaughlin & Braun, 1998) to protect the patient from unnecessary stress or worry (Lapine et al., 2001). Seo, Tamura, Morioka and Shijo (2000) conducted a study that explored the attitudes and perceptions regarding truth telling among patients, physicians, and nurses in Japan and found that 46 percent of the population said that it was a family's responsibility to provide a protective role in safeguarding a patient from a painful diagnosis. In Japan, only 13% of physicians inform their cancer patients of their diagnosis, and one third of the patients agree with this practice of nondisclosure. Individuals of Hispanic and Asian backgrounds in United States believe that disclosure removes all hope and may be harmful to the patient. This is not unique to the Asian culture; for instance, in Italy, disclosing a cancer

diagnosis is believed to disrupt the terminally ill patient's serenity (Koenig, & Gates-Williams, 1995; Orona, Koenig, & Davis, 1994).

As a consequence, in many Asian cultures, truth concealment is common in order to protect a loved one who is suffering from a terminal illness, due to the fear that knowing the truth will extinguish his or her hope, leading to despondence, physical suffering, and mental anguish, along with heightened stress and a hastened death. In contrast with the autonomy of patients in Western cultures, illness is more likely to be considered a shared family event, not an individual's disease, and family centered decisions play a dominant role.

### **The Decision Making Process**

Rhymes (1996) pointed out that a core tenet of hospice care in the United Kingdom and the United States is the need to discuss death openly with patients. Western philosophy promotes individual determination as an ideal, and since the enactment of the Patient Self Determination Act in 1990, attention regarding patients' autonomy in making an end-of-life choice has increased (Berger, 1998; Braun, Pietsch, & Blanchette, 2000). However, the premise regarding making one's own decision is rooted in western culture and is not equally accepted by every ethnic group (Kagawa-Singer & Blackhall, 2001; Searight & Gafford, 2005; Kwak & Salmon, 2007), since some cultures do not allow patients to know their advanced cancer diagnoses. If secrecy of terminal illness to patients is common in some cultures in a sense of protecting terminally ill family members, then, how and who should make a decision about end-of-life care for the patients?

Kreling, Selsky, Perret-Gentil, Huerta, and Mandelblatt (2010) conducted qualitative in-depth interviews with Latinos and found that the cultural value of denial, secrecy about prognoses, and a collective, family-centered system influences hospice decisions and the

experiences of this group compared to White non-Latinos. Older Mexican American adults generally prefer having family members make decisions regarding their treatment compared to the Caucasian or African American populations (Blackhall et al., 1999). In addition, older Mexican American adults are more likely to believe that family, specifically adult sons and daughters, should make decisions regarding treatment in the event that a parent becomes incompetent or terminally ill (Blackhall et al., 1999).

Similarly, Blackhall and colleagues (1999) reported that older Korean American adults believe that end-of-life decision-making is the family's responsibility and that filial piety and family centered decision-making patterns in traditional Korean culture were underlying factors for such family involvement. Korean Americans tend to prefer family-decision making, since they think their children would make better decisions for them and specifically prefer their eldest sons to make the decisions on their behalves (Ko & Berkman, 2010). In contrast, African American and Hispanic patients were most likely to have a daughter as the alternate decision-maker, and Caucasian patients were most likely to have a spouse as the alternate decision-maker. Sharing and helping are considered a family's responsibility and duty. Ethnic families want to stay at the hospital with the patient and exclude nonfamily members, bring food, and provide bedside care. It is a way for the family to show love and to protect the family member facing a terminal illness (Lapine et al., 2001; Kangwa-Singer & Blackhall, 2010).

In addition, Kwak and Salmon (2007) pointed out that the Korean culture involves greater indirectness in communication, especially when dealing with sensitive topics such as death. In terms of preferences for end-of-life care, caregivers understand their patients' preferences and older adults expect that their adult children understand their preferences through indirect communication. This is because bringing up death in a conversation with parents is

avoided and considered disrespectful and insensitive. Therefore, indirect communication, or *noon-chi*, which is valued in Korean culture, is an important indigenous concept referring to an implicit, nonverbal method of communication by developing an awareness of, and sensitivity to, another person's nonverbal cues (Kwak & Salmon, 2007). Due to indirect communication, official verbal discussions of end-of-life care tend to be initiated by the physician, and the physician is the one who should inform patients about hospice care and why it is important to plan. In this culture, interaction with physicians plays a valuable role in end-of-life care planning and treatment options and positively influences attitudes or preferences regarding hospice care. Last, a home death is encouraged as the norm in Korean culture (Kwak & Salmon, 2007).

#### **Advance Directive Preference**

Advance directive planning is a useful tool to promote dignity and autonomy at the end-of-life and a process of planning end-of-life decisions in the event that individuals are not able to speak for themselves (Pearlman, Cole, Patrick, Starks, & Cain, 1995). Advance directive planning is the process of exploring treatment options, discussing or communicating medical treatment, and documenting preferences with a legal statement about end-of-life care (Larson & Tobin, 2000; WHO, 2011). End-of-life communication allows individuals to express their preferences for treatment at the end of life, and advanced care planning is a means of encouraging end-of-life discussions (Curtis et al., 2000; Hopp, 2000). As a process of health behavior, understanding advance directive planning is regarded as an aspect of end-of-life decision-making (Fried, Bullock, Iannone, & O'Leary, 2009).

A study found that end-of-life discussion is associated with less aggressive medical care near death and earlier hospice referral; aggressive care is associated with an inferior quality of life and worse bereavement adjustment (Wright et al., 2008). A study of adults (N=3746) 60

years of age or over who died between 2000 and 2006 found that patients who had prepared advance directives received care that was strongly associated with their preferences (Silveira, Kim, & Langa, 2010). Despite the benefits of advance care planning, Molloy, Russo, Pedlar, and Bedard (2000) pointed out that the use of advance directives in general is low, and it is not popular. Jones, Moss, and Harris-Kojetin (2011) indicate that the overall estimates of completed advance directives among community-dwelling adults in the United States range from 5% to 15%.

The factors that influence the use of advance directives for social work professionals include attitude toward decision-making in advance, preference for curative treatment, and race and ethnicity (Heyman & Gutheil, 2003). First of all, social work professionals' attitudes and their behavior regarding end-of-life decision-making were related to their knowledge and their perceived role in advance directives (Werner & Carmel, 2001). Also, their capacities to discuss advance directives may be influenced by their personal death attitudes and experiences (Steinhauser et al., 2001). A study by Heyman and Gutheil (2003) explored the attitudes of MSW students (N=267) toward end-of-life planning and the factors associated with these attitudes. This study found that factors, such as students' age, knowledge, and personal comfort with end-of-life discussions, have a significantly positive relationship on attitudes toward end-of-life planning. In addition, personal desire for aggressive treatment was shown to have a negative relationship with attitudes toward end-of-life planning.

A study, examining social workers' (N=29) personal death attitudes and experiences in relation to their advance directive communication behavior, surveyed 29 social workers and found that social workers' behavior differed by personal death attitudes, such as fear of death or death avoidant attitudes, and recent personal experiences with diagnoses of terminal illnesses

(Black, 2005). Black's (2007) survey of health care professionals (N=135) indicated that practitioners who had recent personal experience with terminal illness reported more disclosing information regarding advance directive communication behaviors.

Minority groups in the United States are less likely to utilize advance directive planning. Dupree (2000) found that African Americans are reluctant to discuss advance directives. Compared to Caucasians, Waters (1999) found that African Americans participating in focus groups held negative attitudes toward advance directives, since this population generally distrusts the health-care system and feels that advanced directives would not be carried out by health-care professionals. Furthermore, Murphy and colleagues (1996) found that older Korean Americans and older Mexican Americans are more likely to have negative attitudes toward advance care planning than older Caucasians and older African Americans. Matsumura and colleagues (2002) found that Japanese Americans showed high acculturation, and this was reflected in their more positive attitudes toward advance directives. In addition, studies on Indian Hindu immigrants regarding end-of-life care including belief and advanced directives showed that only approximately 9% of Hindus have advance directives, which is less than the American national average of 15% to 20%. This attitude was attributed to the family's decision-making tradition and a low level of knowledge regarding hospice care (Doorenbos & Nies 2003; Deshpande, Reid, & Rao, 2005).

In Asian culture, as discussed previously, initiating end-of-life communication may challenge the cultural norm that family members need to protect their parents from negative topics, such as death and dying (Kwak & Salmon, 2007). A study on end-of-life communication and completing advance directive planning, comparing Korean American and non-Hispanic White older adults ( $N = 217$ ), indicated that non-Hispanic White older adults were more likely to

engage in end-of-life communication than Korean Americans. The study also indicated that the people who were engaging in end-of-life communication were more likely to be female, have higher levels of education and income, and be more experienced with illness. Moreover, higher knowledge, stronger beliefs about the perceived severity of the illness, and greater experience with illness play an important role in end-of-life discussion and completion of advance directive planning which differs by ethnicity (Ko & Lee, 2009).

A study by Ko and Berkman (2010) qualitatively explored the role of children in end-of-life treatment planning among Korean American older adults (N=23). None of the participants in the study completed advanced directives, and the study found that older Korean Americans in this study experienced negative responses from their children when they tried to initiate end-of-life care treatment wishes; children showed refusal when it came to engaging in end-of-life communication to safeguard their parents from negative and unpleasant topics about illness and death. In addition, participants in this study believed that the important cultural factor on the decision-making process among the parents and children was filial piety. Some participants expressed that “filial piety would lead to the elder parents’ wish being honored by their children, but others were concerned that their children would interpret the obligation of filial piety as required that they do everything possible to extend their parents life regardless of the parents’ wishes” (Ko & Berkman, 2010, p. 177).

Some studies have indicated other factors, which influence end-of-life issues. The acculturation in Western culture favors end-of-life care, including hospice care (Kwak & Haley, 2005; Matsumura et al., 2002) and additionally, economic status, class or sociopolitical position, education, immigrant status, sex, age, and urban versus rural background can influence attitudes toward and preferences regarding death and dying (Crawley et al., 2000). Some scholars



conversely found that the level of acculturation into mainstream American culture has not changed the findings related to cultural influences on end-of-life preferences (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Blackhall, Murphy, Michel, Palmer, & Azen, 1999). A study supported that individuals from racial or ethnic minority backgrounds tend to turn to their traditional norms and practices, especially at the end of life, for guidance in making decisions regarding end-of-life care or treatment options (Ersek, Kawaga-Singer, Barnes, Blackhall, & Koenig, 1998). In other words, ethnicity is the primary factor influencing attitudes toward hospice care, truth-telling, and end-of-life decision-making, and other core concepts in the end-of-life care process (Berger, 1998; Cort, 2004; Kagawa-Singer & Blackhall, 2010; Koenig & Gates-Williams, 1995; Rosenfeld et al., 2007; Volker, 2005). Therefore, looking closely at the cultures and customs of different ethnic groups is important for providing effective end-of-life care.

### **Religiosity and End-of-Life Care**

Along with the impact of culture on the end-of-life care issues, another important factor to be considered is the religious affiliation of the dying individuals and their families (Steinberg, 2011). Religious beliefs help individuals make sense of the terminal illness, relieve the emotional burdens, and reduce the fear of death (Okon, 2005; Reiner, 2007). Furthermore, it has influence on the patients' preferences regarding end-of-life treatment decisions, such as prolonging life, do-not-resuscitate (DNR) instructions, hospice or palliative care, and physician assisted suicide (PAS) at one's last stage of life (Burdette, Hill, & Moulton, 2005; Trill & Holland, 1993).

Before directly discussing religious influences on end-of-life care issues, a basic point can be made that different religious affiliations have different ideas or doctrines regarding the question: "who has the authority to make decisions regarding end-of-life treatment: man or

God?” Some religious affiliations believe that man has the authority to make decisions related to death and dying, because “God has granted humanity the right of personal choice and this authority must extend to matters of life and death” (Burdette, Hill & Moulton, 2005, p. 80). Conversely, others view the process of making end-of-life decisions as encroaching upon God’s authority, believing that God exclusively holds authority over the process from life to death; so if people choose the option of physician-assisted suicide or terminal palliative care, then it is a usurpation of God’s authority (Burdette, Hill & Moulton, 2005).

Steinberg (2011) specified the difference of religious affiliations in terms of how diverse religious affiliations view end-of-life treatment based on their principles, and how they consider care options, such as suicide, assisted-suicide, euthanasia, and withdrawal of treatment. First, Islam indicates that only Allah can make decisions on life and death, so advanced directives and living wills, which are ways to make end-of-life decisions ahead of time, are not recognized in Islamic law, and suicide and assisted-suicide are forbidden. Do Not Resuscitate (DNR) orders are allowed only by physicians who are qualified to sign the DNR form (Steinberg, 2011). Second, Hindus’ view “pain and suffering as part of karma, which is the unfolding of events based on a person’s current and previous lives; pain and suffering are viewed as the state the individual is supposed to be in” (Steinberg, 2011, p 155). This belief holds that people should not avoid pain and suffering. The end-of-life care provided by a hospice or palliative care facility mainly focuses on pain relief and pain management, it contradicts the beliefs in this religion. Third, in Jewish texts, the end-of-life treatments for providing comfort and minimizing pains and sufferings are permitted, but assisted-suicide, euthanasia, and withdrawal of care is not allowed (Steinberg, 2011). Compared to other religious affiliations, Christian and Catholic doctrines have more flexible views regarding acceptance or refusal of end-of-life treatment. These religions

indicate that ordinary care, such as the provision of nutrition and hydration to patients in persistent vegetative states, must be administered (Steinberg, 2011). However, it is not necessary to provide such extraordinary care to patients when the treatment does not offer a reasonable hope of benefits or when it brings an excessive burden to the patient. As with other religions, euthanasia is prohibited in Christian and Catholic religions (Steinberg, 2011). Lastly, Buddhist views regard death as an integral part of life. The religion believes in rebirth, so they believe that death is an experience they will undergo many times. Buddhist beliefs support the ideals of the hospice movement, but they prohibit euthanasia since it is seen as an intentional killing. Withdrawal of medical intervention near a death is not seen as immoral (Keown, 2005). In summary, the religious affiliations of Islam and Hindu do not support the autonomy of individuals in making decisions regarding end-of-life issues and care, while the religious affiliations of Buddhism, Christianity, Catholicism, and Judaism have more flexible views toward choosing end-of-life treatments.

Relevant religious studies with end-of-life care preferences found that greater religiosity tends to correlate with more favorable attitudes toward life sustaining treatment over refusal of treatment (Cicirelli, 1997; Cicirelli, MacLean, & Cox, 2000; Nathan Cummings Foundation & Fetzer, 1997). Cicirelli, Maclean, and Cox (2000) conducted research to explore the relationship between religiosity and end-of-life decisions with 200 elders (N=200). The study found that older adults who were less religious placed a higher value on the quality of life and a lower value on the preservation of life; accordingly, they tended to choose the option of a hastened death. Those who were strongly religious older adults in this study preferred to experience aggressive treatment for extending life. A recent study conducted by Van Ness, Towle, O'Leary, & Fried (2008) to investigate whether religious patients are more or less likely to experience the risks

associated with potentially life-sustaining treatment supported a prior study. This study, which was performed on 226 terminally ill older adults (N=226), found that those who expressed spiritual growth were more willing to choose curative treatments than persons who did not.

Another study was conducted to explore relationships between religious affiliations including non-religious groups and attitudes on physician-assisted suicide and terminal palliative care (Burdette, Hill & Moulton, 2005). That study found that conservative Protestants, such as Southern Baptists, Pentecostals, and Evangelicals, are more opposed to both physician-assisted suicide and terminal palliative care than those with non-religious affiliations. Moderate Protestants, such as Lutherans, Methodists and Catholics, also showed greater opposition to physician-assisted suicide than non-affiliates. Additionally, the conservative Protestants and moderate Protestants were less accepting of palliative care. Liberal Protestants, Catholics, and nonaffiliated respondents were supportive of palliative care. This study emphasized that church attendance and its involvement are positively associated with a conservative attitude toward both physician-assisted suicide and terminal palliative care (Burdette, Hill & Moulton, 2005). An earlier study found that Catholics were more willing to undergo lifesaving procedures than Protestants (Mally et al., 1992). In contrast, a study by Heeren, Menon, Raskin, and Ruskin (2001), which examined the differences between Catholics and other Christians, found that Catholics were less willing to undergo lifesaving procedures than other Christians.

Balboni and colleagues (2007) conducted a study to examine religiosity and quality of life, treatment preferences, and advance care planning with 338 terminally ill patients (N=338), that were controlled for their racial/ ethnic background. The study indicated that more African Americans and Hispanics, as compared to White groups considered religion to be an important factor in end-of-life decisions. It was found that spiritual support is associated with a better

quality of life by means of feeling at peace with God and receiving religious or spiritual counsel. Also, religious belief was significantly associated with the preference of using aggressive measures to extend life. The study found “religious individuals may feel that because their illness is in divine hands, there is always hope for a miraculous intervention” (Balboni et al., 2007, p.559).

Okon (2005) pointed out that religion is an important factor for patients to sustain their hope and to cope with their illness as well as to make end-of-life decision. But for physicians or health care professionals, faith is not an important factor when they make health care decisions for advanced cancer patients, rather their religious beliefs do influence their practice. For example, physicians, nurses, and social workers who disclose a lower level of religious belief are more likely to endorse assisted suicide than those with a higher level of belief. Furthermore, those professionals who have a high or moderate level of religious belief are less likely to perform euthanasia or physician-assisted suicide, and those without affiliations are more likely to assist patients requesting physician-assisted suicide (Okon, 2005).

In summary, religious affiliations are a significant factor in choosing end-of-life care and treatment options, because an individual’s attitudes and preferences are intertwined with their religious doctrines and beliefs. The previous studies show that there are some religious affiliations, which do not allow end-of-life decisions or care itself, and people with those affiliations are more likely to prefer life sustaining treatments than non-religious people. In addition, those from diverse cultures tend to consider spirituality to be an important factor and they are more likely to choose curative care (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004). Therefore, especially among minority ethnic groups, not only the cultural but also spiritual influence on end-of-life care issues should be addressed.

### **End-of-Life Care in Korean Culture**

Korean society lacks more comprehensive understanding of death; the concept of death has been discussed and understood in terms of medical and legal perspectives, but not in terms of psychosocial aspects, and the denial of death is deeply rooted in the society (Oh, 2011). As detailed in the previous chapter, Koreans have a notable tradition of respect for elders and family-based systems, which is rooted in the Confucian teachings. Families are expected to care for older parents within the family network, and people, accordingly, are less likely to seek a formal care (Lew, 1996; Kim & Rhee, 1999; Choi, 2001; Sung, 2001). Based on the cultural expectation, the government generally encourages families to support aged parents and preserve the virtue of filial piety as a form of informal care. Pushback against the “responsibility of long-term care laid upon the family alone due to the lack of alternative” and “the stuck-in oppression in reality which does not correspond to the filial tradition” has led to an increase in government based social solutions to elder care (Seok, 2010, p188). The government’s attitude has shifted from ignorance, to relying on families, to active involvement in providing universal services for all older adults, not just for low-income groups (Seok, 2010). Government participation and involvement for effective aged care has increased and government-based programs are being developed.

Despite the cultural refusal regarding end of life care, hospice care in Korea was initiated in rural Kangrung in 1965 by the Sisters of Little Charity of Mary from Calvary Wakefield Hospital in Australia (Chung, Xu, & Kwak, 2005). The development of hospice care in Korea has progressed slowly since the 1980s, when religious and charitable organizations became interested in helping the dying. Since 2000, the development of hospice care has accelerated not only in terms of number but also in quality, with increasing emphasis on enhancing the quality of

death and end-of-life care throughout the nation (Chung et al., 2005; Lee, Ju, Kim, & Kim, 2008). The Korean government first attempted to legislate the provision of hospice care in 1998, and the attempts continue to this day; this type of formal care has not yet been officially legalized (Glass, Chen, Hwang, Ono, & Nahapetyan, 2010). In 2002, the government announced a plan for institutionalizing hospice and palliative care, supporting hospice care in earnest by financially supporting the hospice and palliative programs of the National Cancer Center. In addition, it has been developing standards and regulations for hospice and palliative care in an effort to institute such services in hospitals and nursing facilities, as well as promote physicians' education, staff training programs, and public outreach initiatives (Korean Society for Hospice and Palliative Care, 2004; Yoo, 2010). The Ministry of Health, Welfare, and Family Affairs systematically launched a 10-year national cancer control plan, which promotes hospice and palliative care through 2015 (Yoo, 2010).

Hospice services in Korea are provided in four different types of facilities: (1) a hospital setting with an independent hospice unit located in the hospital; (2) a hospital setting that does not have a separate unit for hospice care, and the services are selectively provided to terminally ill patients in general hospitals; (3) freestanding or independent hospice facilities; and (4) home hospice care (Moon, 2004). Yun and colleagues (2002) explored the characteristics of the hospice and palliative care programs in South Korea, and found that 64 hospice and palliative care programs were operating throughout the nation in 2002. The programs are classified into 40 hospital-based hospice palliative care programs and 24 non-medical hospice palliative care programs (Lee & Lee, 2005). Specifically, the medically affiliated hospice and palliative care programs are provided in university hospitals (N=20 of 40), general hospitals (N=9), private hospitals or clinics (N=3), and doctor's offices (N=8). The non-medical programs are operated

by non-profit organizations (N=9 of 24), social work institutions (N=8), volunteer-based facilities (N=4), and private institutions in cooperation with hospitals (N=3) (Yun et al., 2002). This study also revealed a religious aspect to the programs: a Buddhist organization, Won Buddhism institutions, Catholic organizations, and Christian charitable institutions operate one (1.6%), three (4.7%), 25 (39.1%), and 27 (42.2%) facilities, respectively; 8 (12.5%) facilities are operated by non-religious outfits. These results indicate that most of the hospice programs in Korea, including those offered in hospital settings, are provided by religious charity organizations (Yun et al., 2002; Moon, 2004). Lee, Joo, Kim, and Kim (2008) pointed out that from 2002 to 2007, the number of facilities that offer medical and non-medical hospice programs in Korea increased from 64 to 120. The provision of hospice programs in Korea has expanded in the last few years, but despite the continued increase in these programs, the number of care facilities is insufficient for supporting terminally ill patients and their families (Park, 2006).

In describing the hospice programs in Korea, Glass, Chen, Hwang, One, and Nahapetyan (2010) stated that “unlike medical center hospice palliative care, the service provided in the home and in freestanding facilities tend to focus on nursing care and emotional and social support programs, with limited medical services” (p. 9). Yun and colleagues (2002) investigated staff composition in a hospice setting to determine how essential interdisciplinary professionals implement the programs (medical versus non-medical scheme). This study found that only 24 of the 64 programs have professionals that are essential to an interdisciplinary team of physicians, nurses, social workers, and clergy. In 40 of the medically affiliated facilities, the personnel composition comprises doctors (87.5%), clergy (87.5%), nurses (82.5%), and social workers (62.5%). For the 20 non-medical hospice and palliative programs, the proportions of personnel are 70.8% for clergy, 54.2% for nurses, 45.8% for doctors, and 29.2% for social workers. Some



non-medical hospice and palliative facilities include only nurses and clergy, and four of the programs are operated only by volunteers (Yun et al., 2002). Although professionals who make up interdisciplinary teams for hospice care are necessary for the effective provision of holistic care to the dying and their families, the aforementioned percentages show that an interdisciplinary approach is not adopted in caring for patients. In particular, the proportion of social workers is the lowest among those of the other professionals possibly due to insufficient training and limited funding for the positions.

Compared with the situation in America, where cancer patients (35.6%) account for less than half of all hospice admissions these days (NHPCO, 2011), Korea shows that most people (96.9%) who are treated under hospice palliative care programs are cancer patients (Yun et al., 2002). Almost all of the medically affiliated hospice programs and most of the non-medical facilities provide cancer care, whereas only six of the 24 non-medical hospice palliative programs serve non-terminally ill patients suffering from chronic diseases, such as AIDS, dementia, and alcoholism. Specifically, fifty (78.1%) hospice programs are targeted toward people who have six months or less to live if their illness takes its normal course; among these programs, 45 involve caring for people who have only 3 months or less to live. Some institutions also stated that they serve patients who do not have limited life expectancy (Yun et al., 2002).

Two studies have revealed that the use of hospice care among cancer patients in Korea increased from 6.0% in 2006 to 6.3% (4,285 of 67,561) in 2007 (Lee, Joo, Kim, & Kim, 2008; Kyung, Jang, Han, & Yoon, 2010). In the year 2011, approximately 11.9% of cancer decedents (8,494 of 71,579 cancer deaths in Korea) received hospice care (Kim, 2012). The percentage of hospice use has slightly increased over the years, but only a small proportion of cancer patients have accessed such care services. The Death Statistics 2010 report, which was published by the

Korean government, showed that 86.6 % of cancer patients died in hospital, and 13.4 % died at home or in other institutions (Statistics Korea; Death statistics, 2011).

### **End-of-Life Care Education in Korea**

Hospice and palliative care necessitates collaboration among physicians, nurses, social workers, pastors, and volunteers (NHPCO, 2011). Effective collaboration entails providing appropriate education to involved professionals, as well as clarifying their roles and professional boundaries. To achieve successful education and training of hospice professionals, WHO (2007) proposed three steps for hospice and palliative education in response to organizations providing different levels of hospice and palliative services: (a) The first step is to provide basic training (20–40 hours) to health care providers who work at the primary and community levels. This initiative is designed to educate general health care providers, such as community leaders, traditional healers, and family caregivers or others who are trained to provide basic home based care. (b) The second level of education involves the provision of intermediate-level training (60–80 hours) to physicians and nurses who work at the secondary and tertiary levels. These professionals treat only cancer patients as part of specialized palliative care programs. All the physicians and nurses who administer care to such patients obtain basic training on managing pain and other symptoms, as well as on providing psychosocial support to clients. (c) As the highest level of education, the third level focuses on enhancing proficiency or providing specialized training (3–6 months) to specialist or palliative care teams at the secondary and tertiary levels. These teams also serve as national reference and training groups.

In response to the need to educate and train all health care providers in hospice and palliative care settings in Korea, the End-of-Life Care Task Force Team of the Ministry of Health and Welfare (MHW) established 60 hours of hospice education as a basic requirement for

hospice professionals in 2005 (Kang, Kim, Shin, Kim, & Lee, 2010b). A standard training program was recently officially launched for physicians, nurses, social workers, volunteers, and other individuals involved in hospice and palliative care or who work at hospice care facilities (Kang et al., 2009). Despite the fact that the number of hours spent on this standard training program matches that of the second level of specialized WHO training, in terms of substance, the program corresponds to only the first level of education and training (Kang et al., 2010b). That is, basic education and training are provided to health care workers at the basic level of training for service providers at the primary and community levels; the program does not provide specialized training to all interdisciplinary teams working in end-of-life care settings.

Kang and colleagues (2009) conducted a study to determine how many hospice professions satisfy the criterion of 60 hours of hospice education as a basic requirement established by the MHW. The researchers found that in the 46 hospice organizations supported by the Ministry of Health and Welfare (which employ 673 hospice professionals), only 41.5% of the professionals (279 of 673) satisfy the criterion. A higher percentage of nurses satisfy the requirement (177 of 378, 46.8%), whereas a low proportion of doctors comply with the standard (38 of 106, 35.8%). The proportions of social workers and clergy who satisfy the criterion are 32% (24 of 75) and 35.1% (40 of 114), respectively.

Kang and colleagues (2010a) also conducted a survey on certification and curriculum development for hospice and palliative care professionals. The authors found that professionals who belong to a hospice team commonly present a need for a certificate program and curriculum system to effectively care for terminal cancer patients and their families. The results show that 90% of the physicians ( $n = 51$ ), 84% of the nurses ( $n = 134$ ), and 89% of the social workers ( $n = 35$ ) agree that a certification system is required. With regard to the requirement for certification and a

curriculum system, most of the physicians (46%) prefer a diploma course and social workers (46%) favor a training course.

Yoo (2008) focused on a long-term care setting for the older adults to investigate the general characteristics of long-term care employees and the current status of hospice services. Among 142 long-term care staff, the results show that only 10% of them received training or education programs related to hospice care and 88.7% never received any training. When the participants were asked about whether they are familiar with hospice care, 78.2% responded that they are and 21.8% stated they had little or no understanding. Among the long-term care facilities, only 6.3% provide a formal or systematic hospice program for older adults; more than half of the workers in the long-term care facilities provide only spiritual services, whereas 35.9% do not provide any hospice care services to patients and their families. Additionally, some participants (17.6%) said that they doubt hospice care is essential to older adults (Yoo, 2008).

As indicated by the aforementioned studies, Korean society and all its affiliated professionals should exert more efforts toward end-of-life care for the dying and their families by extending hospice care services and improving staff training. In particular, social workers should more actively address such issues for effective and specialized services associated with elder care settings.

### **Attitude Study on End-of-Life Care in Korean Culture**

Lee and colleagues (2008) explored the barriers to providing hospice and palliative care in Korea. The problems identified by the study are lack of hospice and palliative institutions (42.1%), negative attitudes of patients and their families (22.2%), financial problems (11.5%), lack of support from legislation (10.0 %), referral process problems, such as lack of responsibility for referrals (5.7%), problems in determining time of referral (3.1%), problems in

identifying which cancer patients need hospice and palliative care (2.7%), doctors' negative attitudes toward hospice and palliative care (1.9%), and others (0.8%). Similarly, the reasons these professionals rarely provide hospice care are identified as follows: lack of knowledge about hospice care and the services that it covers (11.8%), the absence of a dedicated space for such services (17.6%), and insufficient funding (15.7%) (Yoo, 2008). In addition, the lack of public consensus on the need for hospice programs was identified as a barrier (Han & Lee, 2009).

Although the number of end-of-life care studies involving various professionals is limited, researchers in Korea have initiated first steps to looking into this underexplored field, focusing on investigating people's attitudes about and perceptions of end-of-life care. The studies were conducted among public and affiliated health care professionals, who are mostly nursing and medical personnel; however, few are directed toward social workers (Choi et al., 1999; Jung et al., 2010; Kim, 2011; Moon et al., 2006; Shin et al., 2010; Yoon et al., 2004).

A study exploring 337 college students' attitudes toward hospice care indicated that only 14.2% of participants could accurately explain the concept of "hospices" (Choi et al., 1999). Participants noted that they obtained information about hospices from television (49%), books (33.5%), and religious groups (12%). Kwon (2007) also examined hospice awareness and found that of the 360 medical college students surveyed, 212 (67.2%) knew little about hospice care, 19.4% indicated slight familiarity, and 48 (13.3%) reported no knowledge of it. When asked where the students had heard about hospice care, 44.3% identified television or newspapers and 129 (35.9%) stated that they learned about it from school. All the participants agree on the need for patient hospice care, with 44.7% asserting that hospices for older adults should be placed in long-term care facilities; over a quarter stated that hospices should be placed in hospitals (27.8%);

26.7% indicated that home was the best location for such services; and the remaining 0.8% provided various other suggestions.

Kim (2011) conducted a descriptive study on the perception of hospice care among 420 university nursing students in Chungcheong province. Among the participants, 90.7% responded that they are aware of hospice care and 63.9% indicated that they learned about it from books or the curriculum. In terms of experience or the practice of hospice care, only 8.3% indicated that they have practical experience with hospice patients as volunteers or as family members. In addition, 56% of the participants agree that hospice care for the dying is necessary.

Jung and colleagues (2010) examined the orientation and attitudes of university students ( $N = 798$ ) regarding hospice care. More than half of the respondents did not understand the concept of hospice care and showed no interest in it. Yoon et al. (2004) also explored public attitudes toward hospice and palliative care with 1,055 participants throughout 16 cities and local districts. The study found that approximately 40% of the participants responded that they had not heard about hospice care. With regard to a question about terminal illness, however, 57.4% of the participants reported that they intend to use hospice care and 82.3% agree with the idea of withdrawing medically futile life-sustaining treatment.

Some studies have been conducted on the affiliated health care professionals. A study involving 100 physicians and 127 nurses in a hospital setting was carried out to determine the knowledge and attitudes of hospice home care; the authors concluded that those in the medical profession show high levels of knowledge regarding the definition and philosophy of hospices (Kim, 2002). Physicians' knowledge of hospice care is acquired mostly through books, media, and education, in that order, and nurses acquire information from the school curriculum, hospital experience, and books, and media, in that order. The study also reveals, however, that the

knowledge of physicians regarding certain hospice services, such as bereavement care, is still insufficient. Kim (2002) concluded that hospice care for terminally ill patients should be promoted by increasing awareness of hospice services among not only the general population but also among medical professionals.

Moon and colleagues (2006) conducted a survey with 81 doctors to elucidate attitudes toward hospice and palliative care for terminal cancer patients. Among the participants, 37 (45.6%) know the exact definitions of hospice and palliative care, and 80 (98.8%) agree that hospice and palliative care is necessary. When asked whether they positively refer terminal cancer patients to hospital and palliative care, 55 (67.9%) respondents answered “yes” whereas 22 (27.2%) answered “no” to the question. Among those who said yes, 17 (30.9%) reported experiencing hesitation in referring patients to hospice and palliative care; the most common reason was disagreement from family members (6 of 17 “yes” respondents, 35.3%). When the “no” respondents were asked why they did not refer patients to hospice and palliative care, six (27.2%) stated that they felt a “feeling of abandoning or giving up on the patients,” while the rest indicated “lack of information on the referral procedure” as the reason (p. 98).

Kim (2007a) conducted another study to determine the perception of hospices and death among 751 staff members at “D” hospital in Seoul. Questions included those on demographic variables, the staff members’ health conditions, and their experiences with patient death and hospice services. Education on hospices, religion, and marital status were established as variables. The participants’ attitudes toward hospices were significantly correlated with experience of a patient’s or relative’s death, the experience of having been requested for consultation about death, as well as gender, marital status, and work department.

In terms of disclosing diagnoses to patients as an important factor associated with end-of-life care issues, Lee (2009) conducted a national study under the auspices of the MHW. The author recruited 3,840 participants of varying ages, including generally healthy individuals, cancer patients, families of terminal cancer patients, and doctors. Most of the respondents (generally healthy individuals, 91.8 %; patients, 91.8%; families of patients, 86.5%; and doctors, 96.4%) strongly agree on the need to disclose diagnoses to terminal cancer patients. On whether disclosure should be the doctors' obligation, the generally healthy individuals (82.8%), patients (83.2%), and families of the patients (72.3%) mostly agree, whereas only one-quarter of the doctors (26.7%) agree.

Shin and colleagues (2010) analyzed the use of hospice and palliative care units in Korea with data on 2,940 terminally ill patients in 2009. When patients registered with hospice and palliative care programs, almost every caregiver (99.6%) for the terminally ill patients recognized that the patient had a terminal illness and that the caregivers (97.3 %) knew these patients were at the end of their lives. However, only 87.6% of the patients knew about their disease and only 67.4% recognized that they were in their last moments. Two previous studies (Lee et al., 2009; Shin et al., 2010) showed that disclosing a terminal diagnosis to a patient is an issue that requires significant consideration in Korean society.

Jang, Chiriboga, Allen, Kwak, and Haley (2010) studied 675 older Korean-American adults (mean age 70.2) in the United States to investigate the predictors that influence the willingness of such adults to use hospice care. The study indicates that Korean-Americans negatively view hospice care, and only a few have precise information or knowledge about such types of services. The younger participants and those who have educational levels higher than high school are more willing to use hospice care. As the number of chronic conditions has



increased, so has the likelihood of the willingness to accept hospice care. However, having health insurance coverage is a predictor that increases this willingness. The other predictors include the ages and education levels of the patients, chronic conditions, health insurance, and acculturation (Jang et al., 2010).

Smith, Earle, and McCarthy (2009) observed that Korean-Americans have a more positive attitude toward life-sustaining treatments and receiving high-intensity treatments than does the Caucasian population. The decisions regarding hospice care broadly depend not only on the patients but also on their family members. An individual's expectation to carry out filial piety is not only based on what is accepted and valued by society, but also related to emotional bonds with parents (Ko & Lee, 2009). In terms of preference for advance health care directives among 382 Koreans, Kim (2011) revealed that the majority of Koreans in South Korea's domestic settings hold positive attitudes toward advance directives. This study also found that advance directives are preference for not using life-sustaining treatments at the end of life, a good self-rated health status, and unsatisfactory family functioning.

Regarding the composition of population by religion in South Korea, the Population and Housing Census Report (2005) indicated that 53.1 % of the Korean population has a religious affiliation, while 46.5% indicated no religious affiliation. Specifically, 43%, 34.5%, and 20.6% of those who said they had a religious affiliation indicated their religious affiliation with Buddhism, Christianity, and Catholicism, respectively. In addition small percentages of the population indicated themselves to be affiliated to Confucianism (0.4%), Won-Buddhism (0.5%) and others (1.0%) (Statistic Korea; Population and Housing Census Report, 2005).

In summary, most of the South Korea-based studies that explored the knowledge of and attitudes toward hospice care and end-of-life planning have dominantly focused on nurses and

physicians. These studies reveal that such professionals tend to lack knowledge and awareness, as well as hold unfavorable attitudes toward death, dying, and the associated health care issues. This situation gives rise to the need for further investigations on the Korean population and professionals, particularly social workers, in relation to end-of-life care given that the inherited Korean culture is characterized by a refusal to discuss death, dying issues, and end-of-life care issues.

### **Conceptual Framework**

Two conceptual frameworks are useful for exploring the relationship between end-of-life practice and the domains of the attitudes, knowledge, and skills of geriatric social workers in Korea. The first framework is learning theory, which emphasizes changes in one's attitude stemming from learning. The second is the intercultural competence model (ICM), which provides theoretical explanations about human behavior as it relates to intercultural issues.

#### **Learning Theory**

Attitude is usually defined as a disposition or tendency to respond positively or negatively toward a certain idea, object, person, or situation; it affects the choices that people make. Attitudes encompass, or are closely related to, our opinions and beliefs and are based on our experiences. Such environmental factors as culture can influence our perceptions and attitudes (Braun et al., 2000). That is, emotional and cognitive processes can be developed in a cultural context, and individuals' psychosocial processes are organized on the basis of cultural norms and values. Culture is reflected in individuals themselves or in a society's collective behavioral patterns (Kitayama, 2002).

Hovland, Janis, and Kelley's (1953) learning theory holds that opinions can result in attitude changes depending on the presence or absence of rewards. Attitudes can also be learned

from previous experiences combined with external cues and observable behaviors (Bem, 1967; Himmelfarb & Eagly, 1974). Learning theory specifically explains that attitudes change because of learning from direct experience, reading, listening, or emotional associations. These experiences tend to provide individuals opportunities to practice new opinions. Although practice alone does not lead to acceptance, attitudes likely change when one recognizes the presence or absence of rewards, such as an incentive, which can be a physical or financial reward, or other benefits. An incentive can also take a more abstract form, such as the knowledge gained from persuasive argument (Hovland et al., 1953).

### **Intercultural Competence Model**

ICM is used to explore how people acquire intercultural competence. Deardorff (2006) developed the model into a framework for intercultural competence to identify what is necessary for people from different cultural backgrounds to learn to live together; that is, the factors that are important to becoming interculturally competent. The model has been primarily employed to explore the process of teachers' intercultural competence when working with students from a variety of backgrounds and experiences (Deardorff, 2009). Scholars who employed the ICM define intercultural competence as pertaining to effective and appropriate behavior and communication in intercultural situations. The essential items that are necessary for diverse people to co-exist, as described in the ICM, are (a) attitudes, (b) knowledge, (c) skills, (d) internal outcomes, and (e) external outcomes (Deardorff, 2006).

**Attitudes.** One of necessary components is attitude because, as the ICU model explains, intercultural competence begins from an individual's attitude such as openness, respect, and curiosity. Openness and curiosity imply a willingness to risk and move beyond one's comfort zone. Curiosity sets the foundation for more creative ways to turn differences into opportunities,

and openness enables a person to view more than one perspective, which is invaluable when negotiating and mediating cultural differences (LeBaron & Pillay, 2006). These three attitudes are the bases for further development of the knowledge and skills required to acquire intercultural competence. One way to move individuals toward these requisite attitudes is to challenge assumptions. As LeBaron and Pillay (2006) noted, “dialogue with genuine curiosity is a precondition for . . . addressing cultural conflicts” (p. 94).

**Knowledge.** In terms of knowledge, cultural self-awareness is a factor. Cultural self-awareness is described in the model as the ability to describe the lens through which a person views the world, including the underlying culturally conditioned values that affect people’s behaviors and their understanding of others’ behaviors. Another important factor is culture-specific knowledge, which pertains to deep cultural knowledge, including an understanding of other world-views, sociolinguistic awareness, and historical contexts (Deardorff, 2006).

**Skills.** The skills necessary to intercultural competence include listening and observing in an educational setting where the ICM is frequently applied. Knowing how to relate and how to evaluate the knowledge that one obtains is also considered a significant determinant. The skills found in the ICM point to the importance of processes and of engaging in active reflection of (for example) teaching practice and intercultural interactions. In short, the skills in the ICM address the components involved in knowledge processing: observation, listening, evaluating, analyzing, interpreting, and relating (Deardorff, 2006).

**Internal outcomes.** Flexibility, adaptability, and empathy lead to an “internal outcome.” These components are defined as appropriate and effective behavior and communication in intercultural interactions. *Empathy* refers to understanding and responding to others in appropriate ways that satisfy others’ needs, as opposed to basing actions on assumptions of how

others want to be treated (Calloway-Thomas, 2010). The internal outcome involves aspects that occur within the individual, and individuals at this point should be able to begin to see others' perspectives and to respond to others according to the manner by which the other person desires to be treated (Deardorff, 2006).

**External outcomes.** Outcomes that manifest as behavior and communication are considered the external outcomes of intercultural competence. The model emphasizes that the definition is predicated on particular requisite elements of intercultural competence. Understanding the implications of “effective” and “appropriate” behavior and communication is also important. Specifically, *effectiveness* can be determined by the speaker, but *appropriateness* can be determined only by the listener because appropriateness is directly related to cultural sensitivity and adherence to the cultural norms of that person (Deardorff, 2006).

With these five core elements, the ICM emphasizes that the development of intercultural competence is a lifelong process, and at no point does one become fully interculturally competent. Becoming intercultural competent can take various forms. The *process of development* through self-reflection, mindfulness, and experiential learning beyond the classroom is crucial. Knowledge alone is insufficient for intercultural competence, and ultimately, the requisite attitudes of openness, curiosity, and respect remain the foundation for all else. Previous literature on intercultural competence places less emphasis on knowledge (and in fact even considers presumptions that one can develop competence solely on the basis of cultural knowledge), and focuses on fostering cultural self-awareness, interpersonal sensitivity, and an attitude of openness and learning (Juarez et al., 2006; Tervalon, & Murray-Garcia, 1998).

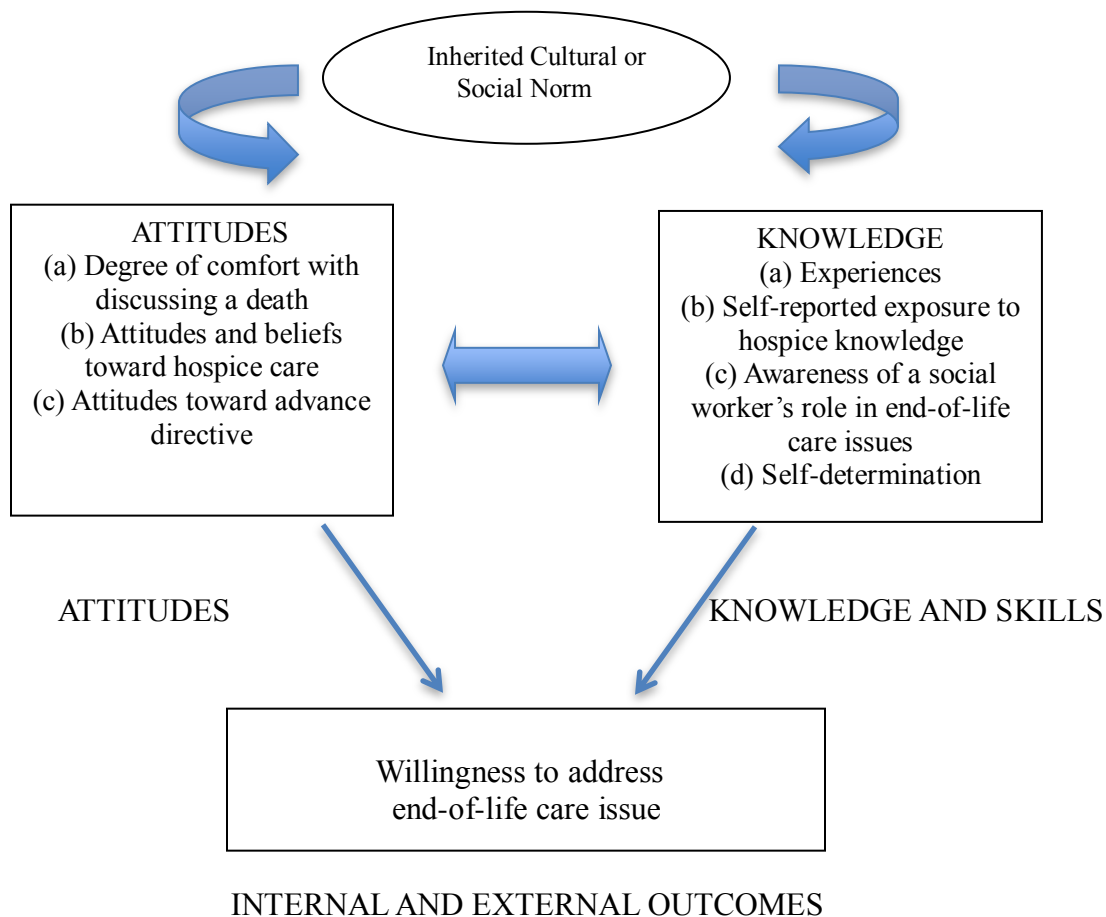
### **Intercultural Competence and End-of-Life Care**

Given the increasing interdependence of our world, intercultural competence is becoming an important factor for living together successfully. Understanding other cultures and accepting or modifying them are critical to intercultural competence. The most commonly used definition of culture is that it is an integrated pattern of human knowledge, beliefs, and behaviors that depend on the capacity for symbolic thought and social learning. Culture is also defined as the set of shared attitudes, values, goals, and practices that characterizes an institution, organization, or group (Kroeber & Kluckhohn, 1952). Using these definitions as bases, we can define culture not only by race, ethnicity, and social norms, but also by shared attitudes, values, goals, and practices. In Korean society in general and in the social work profession in particular, death and dying issues, including end-of-life care, are commonly considered unfamiliar and unfavorable topics. These are regarded as sensitive and uncomfortable to discuss, and some people view death topics as taboo. Such people are likely to have negative attitudes about using end-of-life care services.

Whether social workers understand end-of-life issues and provide end-of-life care to patients may be related to culture and individual perceptions. Perceptions are shaped by individuals' views of the world, and one's world-view is learned through socialization from childhood to adulthood and is constantly reinforced by the culture in which that person lives. Open acknowledgment and discussion of death, dying, and end-of-life care are particularly prohibited in Korean culture. In terms of service provision, nonetheless, social workers have a responsibility to care for the dying and their families, and to enable autonomy and self-determination to enhance their patients' quality of life and end-of-life care. Regardless of an individual's personal attitudes or perceptions, he/she should be interculturally competent in

coping with end-of-life issues in order to provide appropriate services and communication to the clients he/she serves. In this study, therefore, the intercultural dynamic examined is not that between individuals from different national cultures, but that between individuals with varying cultural responses to death, dying, and end-of-life care.

On the basis of the ICM, I propose the conceptual model for this study (Figure 2.)



*Figure 2.* Conceptual Framework

This study (a) categorizes independent variables for attitudes as reflected in social workers' level of comfort in discussing death. In the categorization, statements such as "I feel comfortable discussing death and dying with older adults who are in institutions" are used as

bases. The study also (b) questions whether social workers have positive, negative, or neutral attitudes toward hospice care as indicated by their cultural beliefs and values. In addition, the study uses (c) questionnaires regarding advanced directives to determine attitudes toward end-of-life planning.

The independent variable “knowledge and skills,” is broken down into categories, including an individual’s (a) self-reported exposure to hospice knowledge, (b) what role the social workers’ awareness of end-of-life care plays in the provision of such services, and (c) how social workers view self-determination in their practice. Social workers also answer questions related to their awareness of their roles as they relate to end-of-life care in terms of psychosocial support and assessment. Given that Korean culture focuses on family-based decision making, participants are asked about whether they comply with professional values of self-determination or autonomy in their practice. As a dependent variable with internal and external outcomes, the issue of whether social workers are willing to provide end-of-life care is addressed.

The learning theory framework and the ICM are adopted to explore individual attitudes and behaviors about end-of-life care on the basis of the assumption that Koreans are likely to have negative attitudes toward end-of-life issues because of cultural norms and beliefs. Consistent with the framework, teaching people about end-of-life care and the ways in which such care benefits older people can be the reward that prompts changes in negative attitudes. Ultimately, social workers may demonstrate changed attitudes and behaviors toward end-of-life care and its practice.

This chapter presented an overall review of the contextual background of end-of-life care and identified issues related to cultural diversity in terms of death and dying. The chapter also introduced the conceptual model for this study. Chapter III discusses the research methodology



and how the study progressed, including the research questions, design, sample, data collection and instruments, measurements, and statistical procedures.

## CHAPTER III

### RESEARCH METHODOLOGY

This chapter presents a discussion of research methodology as follows: 1) the research questions and hypotheses, 2) the research design, sampling process, and data collection, and 3) the instruments and measurements. Lastly, this chapter presents the statistical approaches to analysis of the collected data.

#### Research Questions

The following research questions and several specific hypotheses are formulated on the basis of the previously discussed empirical studies, and a theoretical or conceptual model of Learning Theory and Intercultural Competence Model (ICM).

**Question 1.** What socio-demographic characteristics (gender, age, education, marital status, living arrangements, religious affiliation, level of licensure, type of work facility, type of service, and nature of work) of geriatrics/gerontological social workers in South Korea are significant determinants of willingness to address end-of-life issues?

**Question 2.** What are the characteristics or tendencies of these social workers regarding end-of-life care issues or predictor variables?

**Question 3.** What are the statistically significant predictor variables among the end-of-life issues to influence the social workers' willingness to address end-of-life care issues?

For questions two and three, predictor variables in end-of-life care issues in this study are defined as work experience, awareness of hospice care, level of knowledge and attitudes about

hospice care, level of comfort about discussing death, awareness of social workers' role in end-of-life care, self-determination, and advance directives.

**Question 4.** How do social workers consider self-determination or autonomy, end-of-life decision makers, and disclosure of terminal diagnoses, and what are their preferences among those variables associated with Korean culture?

### **Hypotheses**

**HY1:** Social workers with a high level of knowledge about hospice care are likely to be willing or intend to address end-of-life issues.

**HY2:** Social workers with positive attitudes and beliefs regarding hospice care are likely to be willing or intend to address end-of-life care issues.

**HY3:** Social workers who are comfortable discussing dying are likely to be willing to address end-of-life issues.

**HY4:** Social workers who minimally emphasize concepts concerning self-determination and patient rights are likely to prefer family-based decision-making (collectivism) rather than depend solely on patient self-determination (individualism).

**HY5:** Social workers with positive attitudes toward end-of life care planning are willing or intend to address end-of-life care issues.

**HY6:** Social workers who have less positive attitudes toward end-of-life care planning are less likely to be willing or intend to address end-of-life care planning.

**HY7:** Social workers who are willing to complete an advance directive for themselves are likely to encourage or help clients to do the same.

### **Research Design and Sampling Methods**

The research design for this study is a cross-sectional survey designed for descriptive and explanatory purpose(s). Two hundred forty-six participants (N=246) who are geriatric/gerontological social workers were surveyed in South Korea. The primary purposes of this study were to explore the attitudes and tendencies of social workers regarding end-of-life care issues and to identify factors influencing willingness to provide end-of-life care.

The target population was geriatric/gerontological social workers working in the metropolitan areas of Seoul and the Kyunggi region, where most long-term care facilities are centrally located in South Korea (See *Figure 4*). Non-probability sampling method, that is, cluster snowball sampling (referral sampling) was used to recruit potential participants. Initially, four social work professionals: a social worker, an agency director, an administrator, and a professor at each of the institutions of geriatric/gerontology were contacted and agreed to participate. These initial professionals provided referrals to social workers in different institutions of geriatric/gerontology. On the basis of these referrals, potential study participants and agencies registered with the MHW were contacted by phone to ascertain whether the potential recruits were interested in participating in the end-of-life care study; initial contact was mostly made with the director of a social work agency. Then arrangements were made for personal visits with a verbal consent. Depending on the proximity of the potential participants to the study facilities and their preferences, mail surveys or onsite surveys (in agencies) were selectively administered.



Figure 3. Research sites in South Korea

The qualifications for social work in Korea are categorized into three grades: A first-grade social worker defines a person who has earned a bachelor's (BSW) or master's degree in social work (MSW), and then passed the national examination for a first-grade social work license. A second-grade social worker indicates those who have only completed the BSW and MSW without a first-grade license. A third-grade social worker is one who has completed a two-year social work program or who has professional experience in social work and has completed a 24-week training program assigned by the MHW (Korea Association of Social Workers, 2011) without a BSW or MSW degree. Eligibility criteria required for this study are as follows: (1) ability and willingness to provide informed consent; (2) licensed social worker (only for first- and second-grade professionals; third-grade social workers were excluded, since they rarely

work in the agencies registered with the MHW); (3) part-time and full-time workers at gerontological, geriatric, or any aging-related field associated with social work; and (4) male or female subjects aged 21 years or older.

### **Data Collection and Procedures**

Participants who agreed to study participation were surveyed by agency studies or mailing. Before initiating the survey, a Korean version of the introductory letter to afford a better understanding about the purpose of this study was provided to the participants. The letter explained the need for and importance of an end-of-life care study in social work, along with the purpose of the study, emphasizing the rapidly increasing aging population in Korean domestic settings. It also described participants' right to stop or refuse to participate in the survey and a confidentiality clause. A consent form was provided to the participants and approximately 30 minutes was estimated for the completion of the onsite self-administered questionnaires. With a total of 245 participants in this study, an on-site survey (n=107) and a mail survey with pre-paid return label (n=138) were selectively administered at gerontology/geriatric institutions.

### **Sample Size and Power Calculation**

A sample power analysis for this study was conducted to determine the sample size required for sufficient power to detect meaningful relationships between dependent and independent variables. The statistical power was calculated for multivariate regression with Cohen's effect size measures. Cohen's effect size for multiple regression analysis includes small (.02), medium (.13), and large (.26) sizes. In this study, with 15 predictors, an  $R^2$  of .13 (medium-sized effect), a significance level of .05 (alpha), and a power of .80 ( $1 - \beta = .80$ ), 158 (N) cases were required.

### **Human Subjects**

The study was conducted in accordance with the protocol approved by the University of Georgia Internal Review Board (IRB). Each participant was informed about the purpose of the study, its potential advantages and disadvantages, and the participants' right to refuse to participate in or withdraw from the survey. Each participant and the participating institutions were assured of confidentiality. In addition, the researcher's phone numbers and those of the University of Georgia IRB were provided in case the participants needed to contact us.

### **Instrument Translation**

A self-administered questionnaire was developed for this study to gather information on the characteristics of geriatric/gerontological social workers involved in end-of-life care in Korean domestic settings. All of the scales in the questionnaire were initially developed in English after scholarly review and then translated into a Korean version. The questionnaire was back-translated into English to increase the accuracy of the language equivalence (Brislin et al., 1973; Sperber, 2004; Van der Vijver & Leung, 1997). Both the original and the translated questionnaires were checked by bilingual doctoral students in the Departments of Social Work and Education at the University of Georgia. In addition, four Korean social workers in South Korea checked and reviewed the Korean version of the questionnaire to ensure culturally validated wording and to better comprehension.

### **Measurement**

The instrument scales were developed on the basis of previous studies and included culturally sensitive scales from previous empirical end-of-life care studies on minority ethnic groups. The structured questionnaire consisted of seven sections: (a) experience with hospice care; (b) self-reported exposure to knowledge, and attitudes and beliefs regarding hospice care

(Part I: Hospice philosophy, and Part II: Cultural values and beliefs); (c) degree of comfort with death related communications; (d) awareness of a social worker's role in end-of-life care; (e) understanding and preferences regarding patients' self-determination and autonomy; (f) attitudes and willingness toward end-of-life planning and advance directives; and (g) participant's demographic characteristics.

### **Dependent Variable**

The likelihood or intention of providing services related to death and dying was assessed with a question. The participants were asked to respond using a five-point Likert scale (1 = strongly disagree to 5 = strongly agree), indicating that the higher rating means more willingness to provide the services.

### **Independent Variables**

#### **Experiences Related to Hospice Care**

In the first section of the questionnaire (a descriptive overview of all participants' experiences with older adults and end-of-life care), the participants were asked how long they have worked with older adults, with four response categories. The following questions were asked to assess awareness of end-of-life care: "Have you ever heard of hospice and palliative care? How or where did you hear about them? Have you worked with the terminally ill?" The participants were also asked about whether they have ever attended a class or received formal training related to death, dying, and end-of-life care.

#### **Self-reported Exposure to Hospice Knowledge**

Knowledge level about hospice care was measured through evaluation of the respondents' knowledge of hospice care. In this study, "knowledge" pertains to basic knowledge of hospice care service, its philosophy, and the team approach; the knowledge scale was operationalized



from the information provided by the National Hospice and Palliative Care Organization (2010) and WHO (2011). The knowledge scale for palliative and hospice care consisted of seven items and also uses the five-point Likert scale (1 = strongly disagree to 5 = strongly agree). Scores range from 7 to 35, with a high score indicating a high level of knowledge regarding hospice care. Based on a pilot study carried out on social work students, the reliability coefficient of the scale was .72.

### **Attitudes toward Hospice Care**

The Attitude Scale of Hospice Care (ASHC), which was purposely developed for this study, was used to measure the attitudes of Korean social workers regarding hospice care. It comprises two subsections: (1) Part I on hospice philosophy (questions numbered 1 to 10), and (2) Part II on cultural values and beliefs (questions numbered 11 to 19). Regarding Part I, this questionnaire was modified from the Hospice Philosophy Scale (HPS) to assess the respondents' attitudes toward hospice philosophy (Gerbino, 1994); for the 10-item HPS, the developed questionnaire has an internal consistency reliability coefficient alpha of .81. A study using the HPS scale shows that, with 424 oncology social workers, a Cronbach's alpha of .83 was derived (Becker, 2004). In the current work, the HPS with a 10-item attitude inventory uses a five-point Likert scale (1 = strongly disagree to 5 = strongly agree).

Regarding Part II on cultural values and beliefs, the items in the second section were modified from the Hospice Beliefs and Attitudes Scales, with a .74 Cronbach's alpha for eight items (Johnson, Kuchibhatla, & Tulsky, 2009), the Hospice Barriers Scale (Reese et al., 1999), and the North Carolina AARP End-of-Life Survey (2003). The identified factors are based on knowledge of cultural values and beliefs, as well as on misunderstandings and prejudices regarding hospice care stemming from previous ethnic studies on end-of-life care. These factors

include filial duty and family responsibility to provide end-of-life care in relation to culture (McLaughlin & Braun, 1998; Glass et al., 2010; Lapine et al., 2001; Kangwa-Singer & Blackhall, 2010; Karim et al., 2000); misconceptions and lack of knowledge regarding hospice care (Kwak & Salmon, 2007; Reese et al., 1999; Shrank et al., 2005); and awareness of, attitudes toward, and willingness to provide hospice care (Jang, Chiriboga, Allen, Kwak, & Haley, 2010; Ludke & Smucker, 2007; Moon et al., 1998). In addition, a question on treatment preferences; palliative versus life-sustaining treatment was added with reference to a study by Smith, Earle, and McCarthy (2009).

The ASHC, including both Part I and Part II for this study, consists of a 19-item attitude inventory that uses a five-point Likert scale (1= strongly disagree to 5 = strongly agree). In terms of the response scale, *strongly agree* indicates a positive attitude toward hospice care, whereas *strongly disagree* indicates a negative attitude toward hospice care, except in the case of some negatively worded questions. Among the 19 items, the negative questions (questions 11–14 and 16–19) were reverse coded. Scores on the ASHC range from 19 to 95, with higher scores signifying more favorable attitudes toward the principles of hospice care and more positive attitudes regarding cultural belief and values. The reliability coefficient for the scale with 10 items in a study on Asians was .73, and the reliability coefficient of the modified scale with seven items was .75.

### **Comfort in Death Discussion**

To measure a social worker's level of comfort in discussing death and dying, three response questions were provided to the participants using a five-point Likert scale (1 = strongly disagree to 5 = strongly agree). The questions were as follows: (a) "I feel comfortable discussing the topic of death and dying in general," (b) "I feel comfortable discussing death and dying with

older adults,” and (c) “I worry that my client feels unpleasant or upset when I discuss death and dying.” One question (c) was reverse coded, because a high score under this item indicates uncomfortable feelings, unlike those obtained from the two other items. Those items in the section about comfort were developed on the basis of previous research findings. For instance, minority populations tend to feel uncomfortable discussing death and dying (Johnson et al., 2008). Especially in Korean culture, discussing death is regarded as a sensitive topic; bringing up death in a conversation is avoided, and considered disrespectful and insensitive (Kwak & Salmon, 2007).

### **Awareness of the Social Worker’s Role**

To measure social workers’ role in end-of-life care, which is defined in this study as psychosocial and emotional support, participants were asked to respond to the following using a five-point Likert scale (1 = strongly disagree to 5 = strongly agree): 1) “As a geriatric social worker, I have a responsibility to provide support for clients’ end-of-life issues,” 2) “Are you ready to help a dying client and their family in terms of psychosocial or psychological support?” And 3) if participants indicated that they did not feel a responsibility to provide end-of-life care, they were asked to answer “who should be engaged in these issues?”

### **Professional Values Regarding Self-Determination in Korean Domestic Settings**

In determining respect for self-determination or autonomy in end-of-life care, the participants were asked to choose who should be involved in decision making: (1) the client alone, (2) both the client and his/her family, (3) only the family members, but with the client informed, and (4) only the family members, without informing the client (with examples of reasons for not informing the client). For the second option, a follow-up question was asked: “Which family member should be involved?” (with options such as wife/husband or partner,

adult son, adult daughter, close relatives, and significant others such as friends or a priest). To assess how Korean social workers understand and emphasize self-determination in general practice, two statements were asked of participants. A five-point Likert scale (1 = strongly disagree to 5 = strongly agree) was used.

These questions were developed in light of previous literature in this field. For example, Asians tend not to consider self-determination or autonomy meaningful and empowering, and family decision-making is similar to the end-of-life decision-making process (Blackhall et al., 1999; Lapine et al., 2001; Kangwa-Singer & Blackhall, 2010; Krakauer et al., 2002; Kreling et al., 2010; Kwak & Haley, 2005). In addition, the social workers were asked about their preferences regarding disclosure of terminal illness or truth telling associated with self-determination.

### **End-of-Life Planning or Advance Directive Planning**

The Scale of End-of-Life Planning (SELP) was modified from the Values and Beliefs scale used by Bullock (2011). The original scale (Bullock, 2011) comprises 20 items with different response categories; the reliability for end-of-life decisions is  $r = .74$ . The wording of items and response categories was modified to ensure conformity and congruence among the response items. Along with nine items from the original scale, the SELP for this study consists of 11 items with two additional items, which are about whether the respondents are willing to complete advance direct planning both for their own future and for their clients. Following a brief description of advance directive planning, the response categories ranged from 1 (strongly disagree) to 5 (strongly agree). The summed scores of the response categories ranged from 13 to 65, with a high score indicating a considerably positive attitude about end-of-life care planning (advance directive planning). Some of the items (1, 5, 7, 9, 11) were reverse coded, because

higher score of the items indicate a negative attitude toward end-of-life care planning or advance directive planning. This scale was based on existing knowledge derived from previous ethnic studies on advance directive planning (Bullock, 2011; Ludke & Smucker, 2007; Johnson et al., 2008; Reese et al., 1999; Shrank et al., 2005; Smith et al., 2009; Tennstedt, 2002). A pilot study of 102 social work students revealed an SELP Cronbach's alpha of .76.

### **Data Analysis and Statistical Analyses**

To derive answers to the research questions, four statistical approaches were employed for data analysis: descriptive analysis, ANOVA, correlation analysis, and multivariate regression analysis, using the SPSS software package (SPSS 17 version). For questions 1 and 2, descriptive analysis was performed to depict the characteristics of each independent and dependent variable, along with demographic descriptive variables. The descriptive analysis provided the mean, frequency, and distribution of knowledge and experiences, attitudes, comfort levels, awareness of a social worker's role, professional values regarding self-determination and attitudes toward advance directive planning, and willingness to provide end-of-life care. In addition, to explore the relationship stated in each hypothesis between attitude and knowledge, and that between willingness to complete advance directive planning for themselves (social workers) and willingness to promote advance directive planning for clients, correlation analysis was performed.

For question 3, both factor analysis and reliability analysis were performed to verify the validity and reliability of each scale before regression analysis. Also, the variables were tested on whether they were independent of one another via a collinearity diagnosis process to satisfy the assumption for multivariate regression (Pedhazur, 1997). Based on the result of the multicollinearity diagnosis, regression was then performed to analyze the relationship between

the following explanatory variables: (a) previous experience and level of knowledge, (b) attitude, (c) level of comfort, (d) attitude toward advance directives, (e) awareness of the social worker's role, and (f) self-determination and a responsive variable (willingness to address end-of-life issues). More detail in the process of regression analysis will be presented in the next chapter.

This chapter has presented the research questions and hypotheses, study design, sampling process, and research methods. The next chapter will present the research findings derived by statistical analyses.

## **CHAPTER IV**

### **RESULTS**

This chapter presents the results of the research in three sections. The first section describes the frequencies and descriptive statistics for all variables, including the socio-demographic variables, as well as the independent and dependent variables. The second section discusses the effect that the socio-demographic variables have on the willingness of social workers to address end-of-life care. This section also includes an analysis of the correlation in an attempt to measure the relation between two or more variables. The last section reports the significant predictor variables of the willingness to provide end-of-life care.

#### **Descriptive Analysis**

##### **Sample Characteristics**

A total of 246 social workers who currently work at geriatric/gerontological social work institutions in South Korea participated in this study. Table 1 presented the socio-demographic characteristics of the participants; 71.1% (n=175) of the sample was female and 28.9% (n=71) was male. The average age of the participants was 35.7 years of age and there was a range of 21 to 63 years. All of the social workers in this study held a college-level degree. Specifically, 22.4% (n=55) of the social workers finished a two year college-level degree program, 62.6% (n=154) completed a four-year undergraduate program, and 15% (n=37) indicated they had a graduate degree in social work. In terms of social work license qualifications, 55.7% (n=137) of respondents had a first-grade social work license and 41.9% (n=103) had a second-grade license; only 5 respondents (.4%) did not report what type of social work license they had. The majority

(n=204) of the sample reported that they were not currently living with their parents. Over half of the sample (53.3%) reported being married, while the rest (46.7%) identified as unmarried or single.

Regarding religious identification, 41.5 % (n = 102) were Christian, 28.9% (n=71) were Agnostic, 15.4 % (n=38) were Catholic, 13% (n=32) were Buddhist, and 1.2% (n=3) were others. Of the participants, 14.2 % (n=35) stated that they worked at nursing homes or nursing hospitals, 12.6% (n=31) reported that they worked at home care delivery centers, 56.1% (n=138) reported that they worked at senior leisure or integrated centers, 0.4% (n=1) reported that they worked at general hospitals, and 16.7 % (n=41) reported that they worked at other social work institutions, such as government-based administrative facilities and disability agencies for older adults. Approximately half of the participants (50.8%) indicated that they were direct services providers to the older adults; the remaining participants (49.2%) indicated that they indirectly serve older adults. The various titles of the participant at the institution are as follows: social workers (78.5%), case managers (6.5%), counselors (0.4%), administrators (4.5%), executive directors (5.7%), and others (3.7%); two respondents did not answer.

Table 1

*Characteristics of the Sample (N = 246)*

Variable	Group	Number (%)	Mean (SD)
Age	<i>Range 21–63</i>		35.5 (9.90)
Gender	<i>Male</i>	71 (28.9%)	
	<i>Female</i>	175 (71.1%)	
Education	<i>Two-year college</i>	55 (22.4%)	
	<i>Four-year</i>	154 (62.4%)	



Variable	Group	Number (%)	Mean (SD)
	<i>undergraduate</i>	37 (15%)	
	<i>Graduate school</i>		
License	<i>First grade</i>	137 (55.7%)	
	<i>Second grade</i>	103 (41.9%)	
	<i>Missing data (unanswered)</i>	5 (0.4%)	
Living with old adults	<i>Living with elders</i>	42 (17.1%)	
	<i>Not living with elders</i>	204 (82.9%)	
Marital status	<i>Married</i>	131 (53.3%)	
	<i>Unmarried</i>	115 (46.7%)	
Religion	<i>Christian</i>	102 (41.5%)	
	<i>Buddhist</i>	32 (13%)	
	<i>Catholic</i>	38 (15.4%)	
	<i>Agnostic</i>	71 (28.9%)	
	<i>Others</i>	3 (1.2%)	
Type of facility	<i>Nursing home and hospital</i>	35 (14.2%)	
	<i>Home care delivery</i>	31 (12.6%)	
	<i>Senior center</i>	138 (56.1%)	
	<i>General hospital</i>	1 (0.4%)	
	<i>Others</i>	41 (16.7%)	
Service position	<i>Direct services</i>	125 (50.8%)	
	<i>Indirect services</i>	121 (49.2%)	

Variable	Group	Number (%)	Mean (SD)
Nature of Work	<i>Social worker</i>	193 (78.5%)	
	<i>Case manager</i>	16 (6.5%)	
	<i>Counselor</i>	1 (0.4%)	
	<i>Administrator</i>	11 (4.5%)	
	<i>Executive director</i>	14 (5.7%)	
	<i>Others</i>	9 (3.7%)	
	<i>Not answered</i>	2 (0.8%)	

**Experience with end-of-life care.** As summarized in Table 2, 41.1% (n=101), 25.6% (n=63), 22% (n=54), and 11.4%(n=28) of the participants reported that they worked with older adults for 1–2 years, 3–4 years, 5–10 years, and more than 10 years, respectively. In this sample, 66.7 % (n=164) of respondents have worked with older adults for fewer than 5 years. Regarding being aware of hospice care, 79.7% (n=196) of respondents reported having heard about hospice care and 17.1% (n=42) reported that they had good knowledge about hospice care, but 3.2% (n=8) indicated that they did not know and had never heard about this type of service. Responding to a multiple choice questionnaire, only the participants who have ever heard about the hospice were asked to choose all choices that applied to how they learned about hospice care among. The participants reported that they had learned through a class in school (N=99); followed by special training on social work (n=78); from the radio, television, newspapers, and websites (n=76); through direct or indirect experience (n=47); from other health professionals (n=39); and from other means (n=9).

As described in Table 2, most of the geriatric/gerontological social workers (83.3%) in this study reported that they did not have any experience working with terminally ill patients;

16.7% (n=41) reported having provided care to such patients. The following are services provided to clients as reported by the participants: resolution of ethical dilemmas (4.1%); symptom management (3.3%); navigation of resources (2.8%); advance directive planning (2.8%); and provision of emotional support (13%). In addition, 22% (N=54) of the participants in this study had received end-of-life care training.

Table 2

*Experience with End-of-Life Care*

Variable	Group	Number (%)
Work experience with older adults	<i>1–2 years</i>	101 (41.1%)
	<i>3–4 years</i>	63 (25.6%)
	<i>5–10 years</i>	54 (22%)
	<i>More than 10 years</i>	28 (11.4%)
Awareness of hospice care	<i>No awareness</i>	8 (3.2%)
	<i>Moderately knowledgeable</i>	196 (79.7%)
	<i>Highly knowledgeable</i>	42 (17.1%)
Learning platforms (multiple items)	<i>1) Direct/indirect experience</i>	47 (19.1%)
	<i>2) Class in school</i>	99 (40.2%)
	<i>3) Training in SW profession</i>	78 (31.7%)
	<i>4) Radio, TV, newspapers, or websites</i>	76 (30.9%)
	<i>5) Other health care professionals</i>	39 (15.9%)
	<i>6) Others</i>	9 (3.7%)

Variable	Group	Number (%)
Have you worked with end-of-life care clients?	<i>Yes</i>	41 (16.7%)
	<i>No</i>	205 (83.3%)
Services provided (multiple items)	<i>1) Symptom management</i>	8 (3.3%)
	<i>2) Solving ethical dilemmas</i>	10 (4.1%)
	<i>3) Navigating resources</i>	7 (2.8%)
	<i>4) Advance directive planning</i>	7 (2.8%)
	<i>5) Providing emotional support</i>	32 (13%)
Received end-of-life care training	<i>Yes</i>	54 (22%)
	<i>No</i>	192 (78%)

**Self-reported exposure to knowledge on hospice care.** This section of knowledge scale consisted of 7 items that explored the level of knowledge among the participants regarding hospice care. The descriptive statistics for the knowledge scale are summarized in Table 3. The following five items have a mean score of around 4 or higher with a scale ranging from 1 (inaccurate knowledge level) to 5 (accurate knowledge level). 1. Definition of hospice care (HC) (M = 4.41, SD = .63), 2. Goal of HC (M = 4.35, SD = .67), 3. Hospice is performed by an interdisciplinary team (M = 3.97, SD = .95), 4. Focus symptom management (M = 3.90, SD = .97), and 5. Hospice serves patients and their family (M = 4.16, SD = .85). The item with the lowest mean score (M = 3.71, SD = .98) was knowledge about who has eligibility to access hospice care; the correct answer is patients with 6 months or less to live. The total knowledge scale scores range from 7 to 35, with a high score indicating a high level of knowledge regarding hospice care. Specifically, those who scored over 21 were considered to have an adequate knowledge of hospice care. Overall, these results indicate that participants in this study of

geriatric/gerontological social workers were more likely to have a relatively high-level knowledge regarding hospice care ( $M = 28.353$ ,  $SD = 3.91$ ).

To ensure the validity of the knowledge scale, which consisted of seven items, factor analysis and principle component analysis with Varimax rotation of seven items were conducted on data gathered from 246 participants. An examination of the Kaiser-Meyer Olkin measure of sampling adequacy suggested that the sample was factorable ( $KBO = .70$ ). The result of an orthogonal rotation indicated that all items in the scale were more than 0.50 loading score and yield two-factor solution, which meant that none of the items were excluded from regression analysis. The reliability analysis with seven items knowledge scale has a Cronbach's alpha of .74, which indicates acceptable reliability.

Table 3

*Descriptive Statistics for the Knowledge Scale on Hospice Care (N = 246)*

Knowledge Scale	Minimum	Maximum	Mean (median)	SD
Definition of hospice care (HC)	2.0	5.0	4.418	.63
Goal of HC	2.0	5.0	4.353	.67
HC is performed by an interdisciplinary team	1.0	5.0	3.975	.95
HC is for those whose life expectancy is 6 months or less	1.0	5.0	3.715	.98
HC is more focused on symptom management than trying to cure	1.0	5.0	3.906	.97
Hospice serve patients and family	2.0	5.0	4.162	.85

Knowledge Scale	Minimum	Maximum	Mean (median)	SD
HC extends to bereavement services of family members after patient death	1.0	5.0	3.821	1.04
<i>Total Knowledge Scale with 7 items</i>	18	35	28.353	3.916

**Attitude scale part I: Hospice philosophy.** This attitude scale explored participants' attitudes regarding hospice philosophy; whether they have a positive attitude or are in agreement with hospice philosophy. The descriptive statistics of attitude scale part I which consisted of 10 items is presented in Table 4. Among the 10 items, the respondents mostly agreed that patients should prepare mentally and spiritually for death ( $M = 4.59$ ,  $SD = .54$ ); followed by death is a normal part of life ( $M = 4.55$ ,  $SD = .59$ ); and that patients and family must work together ( $M = 4.463$ ,  $SD = .62$ ). Conversely, the respondents agreed the least on the notion that an interdisciplinary approach provides the best care to dying patients ( $M = 3.52$ ,  $SD = .91$ ). The total scores for an attitude scale part I ranged from 10 to 50; a high score indicated a positive attitude or strong agreement toward hospice philosophy. After factor and reliability analysis were performed, none of the 10 items were excluded, and the reliability coefficient of the attitude scale part I was .759.

**Attitude scale part II on cultural value and belief.** The section of attitude scale part II presents participants' attitude on hospice care in respect to their cultural values and beliefs. The results of this scale consisted of nine items, which are shown in Table 5. Among the nine items, the respondents are less likely to agree on the following negative items because these items have a mean score of around 4: "it is not proper for patients' families to allow cancer patients to

receive hospice care as a formal service” ( $M = 4.26$ ,  $SD = .85$ ), “people who receive hospice care have given up all hope of living” ( $M = 4.08$ ,  $SD = 1.00$ ), and “people receiving hospice care die at a time before they should have” ( $M = 4.09$ ,  $SD = .94$ ).

In contrast, the respondents are likely to agree on the following statement, with a low mean score of less than 3: “with hospice care, you do not receive treatment to stay alive” ( $M = 2.60$ ,  $SD = 1.09$ ) and “I would be best cared for by my family” ( $M = 2.43$ ,  $SD = 1.10$ ). Given that this score was reverse coded, the mean score of “hospice care is not important to my family because I will take care of them if the need arises” which is 3.90 ( $SD = .94$ ), indicated that hospice care is important to families. The respondents are less likely to use curative treatment for terminal illnesses ( $M = 3.73$ ,  $SD = 1.14$ ) and show more willingness to opt for hospice care ( $M = 3.73$ ,  $SD = 1.07$ ). In terms of willingness to use hospice care when they face a terminal illness, the respondents showed a positive attitude ( $M = 3.74$ ,  $SD = 1.07$ ), but not a strong willingness.

In particular, except for “willingness to provide hospice care,” all the other items in this scale were negative questions that were reverse coded. The reliability analysis for the attitude scale part II exhibited a Cronbach’s alpha of .683, which indicates questionable reliability for this instrument. In order to enhance the reliability score, researchers excluded two items from the scale. Finally, the reliability coefficient of the scale with only 7 of the items considered in further statistical analysis was .744. The mean score of the scale with the 7 items is 26.90 ( $SD = 4.44$ ), with total scores ranging from 7 to 35, which indicated a positive attitude and less cultural bias regarding hospice care.

Table 4

*Descriptive Statistics for Attitude Scale Part I on Hospice Philosophy (N = 246)*

Attitude Scale I	Minimum	Maximum	Mean (median)	SD
Death is a normal part of life.	2.00	5.00	4.552	.59
Mentally and spiritually preparing for death is necessary.	3.00	5.00	4.593	.54
Home care maximizes patient dignity.	1.00	5.00	3.833	.97
Death is the final stage of life.	1.00	5.00	3.837	1.11
Achieving death is important.	1.00	5.00	4.345	.71
An interdisciplinary approach is the best for hospice care.	1.00	5.00	3.528	.91
Death with dignity is central to hospice care.	2.00	5.00	4.223	.69
Patients should be able to live life as fully as possible while suffering from terminal illnesses.	2.00	5.00	4.398	.67
Hospice care does not extend life or promote dying.	1.00	5.00	4.178	.88
Patients and families must work together.	2.00	5.00	4.463	.62
<i>Total Attitude scale I with 10-items</i>	<i>30</i>	<i>50</i>	<i>41.95</i> <i>(42.00)</i>	<i>4.46</i>



Table 5

*Descriptive Statistics for Attitude Scale II: Cultural Prejudice (N = 246)*

Attitude Scale II	Minimum	Maximum	Mean (median)	SD
If I had a terminal illness, I would want hospice care.	1.00	5.00	3.73 (4)	1.07
I would be best cared for by my family. *	1.00	5.00	2.43 (2)	1.10
With hospice care, you do not receive treatment to alive. *	1.00	5.00	2.60(2.5)	1.09
Hospice care means give up all hope of living. *	1.00	5.00	4.08 (4)	1.00
People receiving hospice care die before they should. *	1.00	5.00	4.09 (4)	.94
Hospice care is unpopular in Korean culture. *	1.00	5.00	3.06 (3)	1.08
I want to use all opportunities to live as long as I can, even if it is painful. *	1.00	5.00	3.73 (4)	1.14
It is not proper for patients' families to allow cancer patients to receive hospice care. *	1.00	5.00	4.26 (4)	.85
Hospice care is not important to my family because I will take care of them. *	1.00	5.00	3.90 (4)	.94
Total Attitude scale II with 7 items	11	35	26.90 (27.00)	4.44

\* Indicates reverse coded questions: a high mean score indicates a negative attitude toward statements.

**Comfort in discussing death and dying.** This section assessed participants' comfort levels in death discussion. The descriptive statistics of the comfort in discussing death and dying is shown in Table 6. The mean score of comfort in discussing death is generally 3.16 (SD = 1.07). Comfort in terms of having this discussion with older patients has a mean score of 2.91 (SD = 1.05). A question about feelings of anxiety over making older patients feel unpleasant or upset when discussing death and dying exhibits a mean score of 3.69 (SD = 3.50). Overall, the respondents showed neutral attitudes on discussing the topic of death and dying in general, but the results of the level of comfort, particularly with older adults, indicate that the respondents are more likely to exhibit an unfavorable attitude and experience worry over patients feeling upset and unpleasant.

Table 6

*Descriptive Statistics for Comfort Level with Death Discussion (N = 246)*

	Minimum	Maximum	Mean	SD
I feel comfortable discussing the topic of death and dying in general.	1.00	5.00	3.16 (3)	1.07
I feel comfortable discussing death and dying with older adults who are in institutions	1.00	5.00	2.91 (3)	1.05
I worry that my clients feel unpleasant or upset when I discuss death and dying.	1.00	5.00	3.69 (4)	3.50

**Social worker's role and the need and willingness to provide end-of-life care.** This section describes how participants recognize the needs of end-of-life care in geriatric/gerontological institutions and how they perceive their responsibility in end-of-life care

issues. Table 7 summarizes the descriptive statistics for social workers' role in end-of-life care. In response to the need for end-of-life care services in gerontological and geriatric institutions in South Korea, the respondents are more likely to agree with the need for such services ( $M = 4.18$ ,  $SD = .73$ ). The mean score of the respondents' preparedness in providing psychosocial and emotional support to older clients is 2.55 ( $SD = .99$ ), and the overall mean of willingness to provide the services is 3.74 ( $SD = .85$ ), with a high score indicating more willingness or strong agreement. The mean score of social workers' responsibility in end-of-life care is 4.05 out of 5 ( $SD = .73$ ), with a high score indicating strong agreement. The respondents reported that family members (70.3%), clergy (42.7%), doctors (41.1%), nurses (27.2%), and other personnel, such as end-of-life counselors or experts (13%), should have a responsibility to address end-of-life care.

Table 7

*Descriptive Statistics for Social Worker's Role and the Need and Willingness to Provide End-of-Life Care (N = 246)*

	Minimum	Maximum	Mean (median)	SD
Need for end-of-life care	2	5	4.18 (4)	.73
Social worker's responsibility	1	5	4.05 (4)	.74
Who else should have responsibility for those issues?				
Doctor	101			
Nurse	(41.1%)			
Clergyman	67 (27.2%)			
Family member	105(42.7%)			

	Minimum	Maximum	Mean (median)	SD
Others	173 (70.3%) 32 (13%)			
I feel that I am ready to help dying clients and their families with psychosocial and emotional support.	1	5	2.55 (2.5)	.99
I am willing to provide psychosocial and emotional support if needed	1	5	3.75 (4)	.85

**The decision making process.** The descriptive statistics in determining respect for self-determination or autonomy in end-of-life care are summarized in Table 8. The results show that 44% of the respondents believe clients should make their own decisions, and 49.2% deem joint decision-making between clients and their families as the most sensible option. In addition, among the respondents who chose joint decision-making, 48.3% prefer wives/husbands or partners, 30.9% prefer adult sons, 29.3% favor adult daughters, 9.3% favor significant others, and 6.9% prefer close relatives as the individuals who should be involved in the decision-making process. Of the respondents, 5.3% stated that only family members should be involved in the decision-making process and that the patients should know that such decisions are being made. Also, 2% of respondents answered that only family members should be involved, but that patients should not be informed to shield them from fear of death (1.2%) and to prevent such information from possibly exacerbating the patients' health conditions (1.2%).

Table 8

*Descriptive Statistics for Who Should be Involved in the Decision-Making Process (N = 246)*

Variable	Group	Number (%)
Client alone		109 (44.3%)
Client and family		121 (49.2%)
	<i>Wife/husband</i>	119 (48.3%)
	<i>Adult son</i>	76 (30.9%)
	<i>Adult daughter</i>	72(29.3%)
	<i>Close relatives</i>	17 (6.9%)
	<i>Significant others</i>	23 (9.3%)
Only family, informing the client		13 (5.3%)
Only family, without informing the client		5 (2.0%)
	<i>1) So as not to cause feelings of abandonment</i>	0 (0%)
	<i>2) So as not to inspire feelings of fear regarding a death</i>	3 (1.2%)
	<i>3) So as not to worsen patient's health condition.</i>	3 (1.2%)

**Preference regarding truth telling.** In this section, participants rated one's preferences regarding disclosure of terminal illness or truth telling, and Table 9 illustrates the distribution of the mean scores of social workers' preference. With a five-point scale of 1 (strongly disagree) to 5 (strongly agree), the mean score regarding one's willingness to know about his or her terminal diagnosis or exact information was 4.42 (SD = .78). The mean score of letting a family member

who is terminally ill know about his or her terminal illness was 3.46 (SD = .99). The mean scores of “I want a doctor to relay exact information beforehand” and “I want my family member to relay exact information beforehand” are 4.23 (SD = .82) and 2.94 (SD = 1.15), respectively. The mean scores of emphasis on self-determination as an ethical principle in social work practice and being apprehensive about conflict in self-determination are 4.26 (SD = .71) and 4.00 (SD = .79), respectively.

Table 9

*Descriptive Statistics for Truthful Disclosure (N = 246)*

	Minimum	Maximum	Mean (median)	SD
I want to have exact information regarding my terminal illness.	2.00	5.00	4.42 (5)	.78
I want the doctor to tell me about my terminal illness.	1.00	5.00	4.23 (4)	.82
I want my family to tell me about my terminal illness.	1.00	5.00	2.94 (3)	1.17
I will convey exact information to my family regarding terminal illnesses.	1.00	5.00	3.46 (3)	.99
Self-determination is an important principle.	2.00	5.00	4.26 (4)	.71
When self-determination results in conflict, I feel troubled.	1.00	5.00	4.00 (4)	.79

**End-of-life care planning.** As shown in Table 10, most (73.2%) of the participants were not aware of advance directives, while 22.4% indicated they were moderately aware, and 4.5% stated that they were highly knowledgeable about advance directives. When it came to being aware of the medical technologies that are used to assist patients in the final stages of life,

89.8%, 75.2%, 79.7%, and 74% of the respondents were knowledgeable about cardiopulmonary resuscitation, mechanical ventilation, dialysis, and tube feeding, respectively. 6.9% of the respondents reported they had no knowledge of the aforementioned technologies.

Table 10

*Descriptive Statistics for Awareness of Advance Directive Planning (N = 246)*

Variable	Group	Number (%)
Awareness of advance directive	<i>No awareness</i>	180 (73.2%)
		55 (22.4%)
	<i>Moderately knowledgeable</i>	11 (4.5%)
	<i>Highly knowledgeable</i>	
Medical technologies you know (multiple choice)	<i>1) Cardiopulmonary resuscitation</i>	221 (89.8%)
		185 (75.2%)
	<i>2) Mechanical ventilation</i>	196 (79.7%)
	<i>3) Dialysis</i>	182 (74%)
	<i>4) Tube feeding</i>	17 (6.9%)
	<i>5) None of the above</i>	

The descriptive statistics of social workers' attitudes regarding advance directive planning is presented in Table 11. Scale scores range from 1 (low) to 5 (high), with a high score indicating a positive attitude toward advance directive planning. The first five items (1, 5, 7, 9, and 11) of negative question in this scale consisted of 13 items that were reverse coded because the high scores of these items indicated a negative attitude. With the negative questions, the mean score was 4.03 ( $SD = 1.06$ ) for "discussing death brings misfortune," 3.69 ( $SD = .97$ ) for "I

prefer that someone close to me make important decisions for me,” 4.16 ( $SD = .96$ ) for “planning for or communicating about death can accelerate its occurrence,” and 4.04 ( $SD = .98$ ) for “end-of-life planning is unnecessary because God will take care of everything.” The results indicate that the higher the score, the stronger the disagreement; in other words, the respondents are more likely to disagree with the aforementioned statements.

In contrast, the mean scores indicate that the respondents are more likely to agree with the following statements: “making decisions on the basis of one’s own wishes is important” ( $M = 4.44$ ,  $SD = .66$ ), “planning for the future is important” ( $M = 4.54$ ,  $SD = .58$ ), and “my wish should be given priority if conflicts exist” ( $M = 4.16$ ,  $SD = .81$ ). The summed mean score of 13 items is 49.89 ( $SD = 4.70$ ), ranging from 13 to 65.

Table 11

*Descriptive Statistics for Attitude Regarding Advance Directive Planning (N = 246)*

	Minimum	Maximum	Mean	SD
Discussing death brings misfortune. *	1.00	5.00	4.03	1.06
I prefer someone to make the decisions for me. *	1.00	5.00	3.69	.97
Planning for death can accelerate its occurrence. *	1.00	5.00	4.16	.96
Completing advance directives will give doctors a reason to stop caring for me. *	1.00	5.00	2.82	1.06
End-of-life care planning is unnecessary because God will take care of everything. *	1.00	5.00	4.04	.98
Making decisions on the basis of my wishes is important.	2.00	5.00	4.44	.66
Involving family or friends in decision-making is	1.00	5.00	3.71	.91



	Minimum	Maximum	Mean	SD
important.				
If conflicts exist, my wishes should be given priority.	1.00	5.00	4.16	.81
Planning for the future is important.	2.00	5.00	4.54	.58
Completing advance directives will help ensure my wishes are followed.	1.00	5.00	3.72	.89
Without completing advance directives, my family may not do what is best for me when the time comes.	1.00	5.00	3.36	1.01
I am willing to complete advance directives for myself.	1.00	5.00	3.55	.88
I am willing to provide or encourage advance directive planning to patients who I am working with.	1.00	5.00	3.61	.81
Attitude scale for advance directive planning (N = 245)	37	63	49.89	4.70

\* indicates reversely coded questions: a high mean score indicates negative attitudes toward the statements.

### Univariate Analyses

An independent t-test with variables of two groups and analysis of variance (ANOVA) with variables of three or more groups was performed to test multiple comparisons between groups or among groups.

#### Effect of Social Workers' Characteristics on Willingness to Provide End-of-Life Care

The mean score of gender was 3.83 for male social workers (M = 3.83) and 3.72 for female. The mean difference showed that males exhibit higher mean scores for willingness to provide end-of-life care than female social workers, but this difference was not found to be

significant between the two groups. Age showed a significant positive correlation between the age of social worker and the willingness to provide end-of-life care ( $r = .143, p = .025$ ), meaning older social workers were more willing to provide end-of-life care. No significant relationship was found between social workers' educational levels and intention to provide end-of-life care. However, the mean difference on the three educational groups found that those who completed graduate-level education ( $M = 4.02, SD = .76$ ) were more willing to provide end-of-life care than those who had a college-level education [i.e., the participants who completed 2-year ( $M = 3.74, SD = .94$ ) and 4-year ( $M = 3.68, SD = .82$ ) college programs]. Social work qualifications ( $N=240$ ) also exhibited different mean scores: social workers with first-grade licenses ( $M = 3.78$ ) were more willing to provide end-of-life care than those with second-grade licenses ( $M = 3.70$ ). Nevertheless, no significant relationship was found between the two subgroups. Regarding living arrangements, the mean difference showed that social workers currently living with older adults ( $M = 3.95$ ) were more willing to provide end-of-life care than those who were not ( $M = 3.71$ ), but significant difference was not found between these two variables.

Table 12

*Effects of Social Workers' Characteristics on Willingness to Provide End-of-Life Care (N = 246)*

Variable	Group	Mean (SD)	t-value
Gender	<i>Male</i>	3.83 (.75)	$t = .925$
	<i>Female</i>	3.72 (.88)	
Age*			$r = .143$
Education	<i>2-year college</i>	3.74 (.94)	$F = 2.386$
	<i>4-year college</i>	3.68 (.82)	

Variable	Group	Mean (SD)	t-value
	<i>Graduate school</i>	4.02 (.76)	
Social Work License (N=240)	<i>First grade</i>	3.78 (.84)	F = .521
	<i>Second grade</i>	3.70 (.84)	
Living arrangements	<i>Living with older adults</i>	3.95 (.73)	$t = 1.680$
	<i>Not living with older adults</i>	3.71 (.87)	
Marital status*	<i>Married</i>	3.85 (.82)	$t = 2.028$
	<i>Unmarried</i>	3.63 (.87)	
Religious affiliation *	<i>Christian</i>	3.82 (.82)	F = 3.084
	<i>Buddhist</i>	3.37 (.70)	
	<i>Catholic</i>	3.55 (1.00)	
	<i>Agnostic</i>	3.91 (.80)	
	<i>Others</i>	4.00 (1.00)	
Type of Facilities **	<i>Nursing home or nursing hospital</i>	4.08 (.88)	F = 4.117
	<i>Home care delivery</i>	3.96 (.83)	
	<i>Senior center</i>	3.60 (.84)	
	<i>Others</i>	3.80 (.78)	
Service position	<i>Direct services</i>	3.77 (.86)	$t = .448$
	<i>Indirect services</i>	3.72 (.84)	

Variable	Group	Mean (SD)	t-value
Nature of work	<i>Social worker</i>	3.74 (.86)	F = 1.133
	<i>Case manager</i>	3.62 (.80)	
	<i>Counselor</i>	3.00	
	<i>Administrator</i>	4.09 (.70)	
	<i>Executive director</i>	3.92 (.61)	
	<i>Others</i>	3.33 (1.11)	

Note: \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Difference in marital status was found to be significant on the willingness to provide end-of-life care ( $t = 2.028$ ,  $p < .01$ ). The married ( $M = 3.85$ ,  $SD = .82$ ) were more willing to provide end-of-life care than unmarried social workers ( $M = 3.63$ ). Regarding religious affiliation, Agnostic social workers ( $M = 3.91$ ) showed the highest mean score, followed by Christians (3.83), Catholics (3.55), and Buddhists (3.37). In this order, the results of mean score categorized as other affiliations were excluded because the respondents did not share specific affiliations. The result of ANOVA ( $N=246$ ) indicated that religious affiliation has a statistically significant effect on the willingness of social worker to provide end-of-life care ( $F(4, 241) = 3.084$ ,  $p < .017$ ), and the result of multiple comparisons showed significant differences between the following pairs: Christianity and Buddhism, Buddhism and Agnosticism, Catholic and Agnosticism, at levels of  $p = .009$ ,  $p = .003$ , and  $p = .032$ , respectively. The mean difference on the type of facilities was found to be statistically significant among the groups. Social workers who worked at nursing and rehabilitation centers or nursing homes exhibited the highest level of willingness ( $M = 4.08$ ); followed by those who worked in general hospitals ( $M = 4.00$ ); home care facilities, daycare centers, or delivery centers, as well as those who provide home visits or

work as home helpers ( $M = 3.96$ ); social workers who are assigned to facilities for the disabled, including older adults ( $M = 3.80$ ); and those who work at senior integrated centers ( $M = 3.60$ ). As described in Table 12, the results of ANOVA indicated that the type of facilities was a significant factor on the willingness to provide end-of-life care ( $F(3, 242) = 4.117, p = .007$ ). Furthermore, by doing multiple comparisons between the facilities, the following pairs were significantly different at the level of alpha: nursing home and senior center and home care delivery and senior center, with  $.002$  and  $.028$ , respectively. The mean difference of service position showed that participants who provide direct services to older clients ( $M = 3.77, SD = .86$ ) have slightly higher level of willingness than those who provide indirect services ( $M = 3.72, SD = .84$ ), but the position was not a statistically significant factor. Lastly, although the nature of work or name of work was not significant related to the willingness to provide end-of-life care, the mean difference showed that administrators ( $M = 4.09, SD = .70$ ) and executive directives ( $M = 3.92, SD = .61$ ) showed more willingness than social workers ( $M = 3.74, SD = .86$ ) and counselors ( $M = 3.62, SD = .80$ ).

Overall, the result of the independent t-test or analysis of variance (ANOVA) indicated that marital status, religious affiliation, and type of facilities have a significant effect on the level of willingness to provide end-of-life care.

Table 13 presents the effects of social workers' experiences (e.g., years of service, experience with older adults, and previous experience with end-of-life care issues) with regard to their willingness to offer end-of-life care services. The results of ANOVA indicate that the more of experience, the stronger the influence on the level of willingness. The mean score of workers with more than 10 years' experience ( $M = 4.10$ ) indicates the highest level of willingness. The rest of the scores for this scale follow this order: social workers with 5–10 years' experience ( $M$

= 3.79), > 3–5 years' experience (M = 3.71), and > 1–2 years' experience (M = 3.65). But those differences did not indicate a statistically significant relationship.

The result of an independent t-test indicated that social workers' previous experiences working with terminally ill patients were statistically significant on their willingness to provide end-of-life care ( $t = 5.205, p < .001$ ). Social workers in this study who had previous work experience with terminally ill patients (M = 4.21) are more willing than those with no experience (M = 3.65). In addition, a significant relationship is also found between attending hospice care training or classes and willingness to provide psychosocial and emotional support ( $t = 3.395, p = .001$ ). Social workers who have received any kind of official workshop training, such as hospice training, or who have attended workshops or classes, showed more willingness to provide psychosocial and emotional support (M = 4.09) than those who have not undergone any type of training (M = 3.65). Finally, the social workers who were more likely to agree with the needs for end-of-life care services in geriatric/gerontological institutions exhibited a high level of willingness to provide such services ( $F(3, 242) = 16.705, p < .001$ ). Based on multiple comparisons, the following pairs exhibited a significant difference: no need and strongly need ( $p = .010$ ), neutral and need ( $p = .015$ ), neutral and strongly need ( $p < .001$ ), and need and strongly need ( $p < .001$ ).

Table 13

*Effect of Social Workers' Experiences on Willingness to Provide End-Of-Life Care (N = 246)*

Variable	Group	Mean (SD)	t-value
Work experience with older adults	<i>1–2 years</i>	3.65 (.95)	F = 2.193
	<i>3–5 years</i>	3.71(.79)	
	<i>5–10 years</i>	3.79 (.73)	

Variable	Group	Mean (SD)	t-value
	<i>More than 10 years</i>	4.10 (.73)	
Work experience with terminally ill patients***	<i>With experience</i>	4.21 (.57)	$t = 5.203$
	<i>No experience</i>	3.65 (.86)	
Attended hospice training **	<i>Yes</i>	4.09 (.68)	$t = 3.395$
	<i>No</i>	3.65 (.87)	
Need for end-of-life care ***	<i>No need</i>	3.33 (1.21)	$F = 16.705$
	<i>Neutral</i>	3.20 (.71)	
	<i>Expressed need</i>	3.59 (.77)	
	<i>Strong need</i>	4.19 (.77)	

Note. \* $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

### Correlational Analysis

To test the mutual relation between two variables and the willingness to provide end-of-life care and to confirm the research hypothesis of this study, a correlational analysis was performed. Table 14 presents correlations, whether positive or negative, as well as how strongly pairs of variables were related or not related. With a dependent variable, the willingness to provide end-of-life care, knowledge as one of predictors in this study indicated that there is a positive relationship with Pearson correlation ( $r = .106$ ), indicating more knowledge leads to more willingness to provide the services, but there was no statistical significance between the variables ( $p = .098$ ). Social worker's attitudes, both attitude scale part I regarding hospice philosophy ( $r = .224, p < .001$ ) and part II regarding cultural belief and value ( $r = .184, p = .184$ ),

show a statistically significant positive relationship with willingness to provide end-of-life care, but the correlation coefficient indicates that it is not strong. In addition, a variable of comfort level in discussing death shows statistically significant positive relationship with willingness to provide end-of-life care ( $r = .249, p < .001$ ).

Table 14

*Correlation of Independent Variables on Willingness for Providing EOL Care (N= 246)*

Variable		Knowledge	Attitude I	Attitude II	Comfort
Willingness of	Pearson's $r$	$r = .106$	$r = .224^{**}$	$r = .184^{**}$	$r = .249^{**}$
EOL care	Sig. (2-tailed)	.098	.000	.004	.000

\*\* . Correlation is significant at the 0.01 level (2-tailed).

As presented in Table 15, the relation between social workers' attitudes toward advance directive planning and their willingness to encourage or provide advance directive planning services for oneself ( $r = .624, p < .001$ ) and for older adults ( $r = .606, p < .001$ ) was found to have a statistically significant positive correlation with relatively strong correlation. In addition, the correlation between willingness of advance directive for themselves and with older adults was also statistically significant ( $r = .595, p < .001$ ).

Table 15

*Correlation of Attitude on Advance Directive and Willingness for Providing AD*

Variable		Attitude on AD	Willingness of AD for oneself	Willingness of AD with Elders
Attitude on	Pearson's $r$	1	$r = .624^{**}$	$r = .606^{**}$



Variable		Attitude on AD	Willingness of AD for oneself	Willingness of AD with Elders
Advance Directive (AD)	Sig. (2-tailed)		.000	.000
	N	245	245	245
Willingness of AD	Pearson's <i>r</i>	$r = .624^{**}$	1	$r = .595^{**}$
	Sig. (2-tailed)	.000		.000
	N	245	246	246
Willingness of AD with Elders	Pearson's <i>r</i>	$r = .606^{**}$	$r = .595^{**}$	1
	Sig. (2-tailed)	.000	.000	
	N	245	246	246

\*\* . Correlation is significant at the 0.01 level (2-tailed).

### Regression Analysis

A multiple regression analysis was performed to test the effect of predictor variables that are related to social workers' willingness to provide end-of-life care in South Korea (Table 16). Prior to the analysis, two nominal variables, working experiences with terminally ill clients and attending hospice care training, were dummy coded. Conducting a multiple regression analyses, multicollinearity, or very high intercorrelations among predictor variables, was examined to meet underlying assumptions for regression analysis (Pedhazur, 1997). In collected data for this study, it was found that there is a great deal of correlation between the predictor variables. Hence, the order of entry of the independent variables into regression analysis greatly affects what is deemed statistically significant. To address this issue, an orthogonal factor analysis was performed, and then two factors in this study resulted (see Table 16). In Table 16, the significant

loadings, which are greater than .5, are in bold. Factor 1 is essentially a knowledge/attitude factor, and the second is an experience component. Accordingly, for regression analysis, the first factor was labeled a knowledge/attitude factor, and the second was named an experience/comfort factor that is based on significant loadings. Since the factor scores in the factor analysis can be utilized as independent variables, the score was used for regression analysis as the independent variables (DiStefano, Zhn, & Mindrila, 2009). Finally, multiple regression analysis was used by regression willingness scores to provide end-of-life care among social workers on these independent variables: (1) attitude and knowledge and (2) experience.

Table 16

*Factor Analysis with Predictor Variables*

Rotated Component Matrix <sup>a</sup>		
	Component	
	1 Attitude and Knowledge	2 Experience
Knowledge on hospice	<b>.718</b>	
Attitude Scale I	<b>.802</b>	
Responsibility to provide end-of-life care	<b>.627</b>	
Self-Determination	<b>.593</b>	.326
Need EOL care	.564	.462
Attitude Scale II	.420	.306

Rotated Component Matrix <sup>a</sup>		
	Component	
	1	2
	Attitude and Knowledge	Experience
Work experience with terminally ill/ cancer clients		<b>.760</b>
Attend Hospice Care Training		<b>.668</b>
Comfort on death discussion		<b>.510</b>

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

In this regression model, the result indicated that knowledge and attitude as well as experience were significant and able to explain 19.4 % of the variance in the willingness to provide end-of-life care ( $F [2, 241] = 30.290, p < .001$ ). The positive regression coefficient ( $B = .261, \beta = .319, t [241] = 5.545, p < .001$ ) for knowledge and attitude indicated that the participant who had a higher level of knowledge and positive attitude about hospice care was more likely to have a greater willingness to provide end-of-life care. The positive regression coefficient for experience ( $B = .257, \beta = .315, t [241] = 5.462, p < .001$ ) indicated that the participants with more experience working with terminally ill patients and attending hospice care training were more likely to have a higher level of willingness to provide end-of-life care. This regression model indicated that knowledge/attitude ( $\beta = .319$ ) is a slightly more important predictor than experience ( $\beta = .315$ ). In short, this regression analysis indicated that both

knowledge/attitude and experience regressed on the willingness of geriatric/gerontological social workers to provide end-of-life care and was statistically significant and positively associated with willingness.

Table 17

*Coefficients of Predictor Variables in Regression Analysis (N = 246)*

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	3.775	.047		80.298	.000
	1. Knowledge/ attitude	.261	.047	<b>.319</b>	5.545	<b>.000</b>
	2. Experience	.257	.047	<b>.315</b>	5.462	<b>.000</b>

a. Independent variables: 1. Knowledge, attitude, and responsibility to provide EOL care. 2. Work experiences, receiving EOL training and comfort in EOL

b. Dependent Variable: I am willing to provide end-of-life care in appropriate facilities if needed.

Model:  $R = .448$ ,  $R^2 = .201$ , Adj  $R^2 = .194$ ,  $p < .001$ .

In summary, based on the ANOVA and multivariate regression analysis presented in this chapter, the characteristics of South Korean social workers, such as age, marital status, religious affiliation, and type of facilities they are working in, were significantly related to their willingness of provide end-of-life care. In addition, level of knowledge and attitude about hospice care, and working experience with terminally ill patients and attending hospice care training were both identified as predictors of increased willingness to provide end-of-life care.

## **CHAPTER V**

### **IMPLICATIONS AND DISCUSSION**

This chapter comprises a summary of the study, a summary of the confirmed research hypotheses, and a discussion of the results, which are compared and contrasted with previous empirical studies, including interpretation of expected and unexpected findings as presented in Chapter IV. In addition, this chapter considers implications for the social work profession, including practice and education. Lastly, it suggests a direction for future study, along with a review of the limitations of this study.

Considering both the demographic shift toward a graying Korean society and an unfamiliarity with end-of-life care as a formal service associated with Korean culture, the primary purpose of this study is to explore the attitudes and tendencies of geriatric/gerontological social workers regarding end-of-life care issues and their willingness or intention to provide end-of-life care. It aims also to identify significant factors influencing willingness to provide such care in the Korean domestic setting. The research design for this study is a cross-sectional survey designed for descriptive and explanatory purposes in response to four research questions. Two hundred and forty-six people (N=246) participated in this study.

#### **Hypotheses Testing**

Each research hypothesis examined the relationship between variables presented in the statement. This section discusses whether the results of this study confirm the hypotheses or not.

**HY1:** Social workers with a high level of knowledge about hospice care are more willing to or intend to address end-of-life issues.

The hypothesis was not confirmed in this study since the result was not found to be statistically significant between the two variables ( $p = .098$ ).

**HY2:** Social workers with positive attitudes and beliefs regarding hospice care are more willing to or intend to address end-of-life care issues.

The hypothesis was confirmed in this study, which found that social workers' attitude to hospice care, both attitude scale part I regarding hospice philosophy ( $r = .224, p < .001$ ) and attitude part II regarding cultural beliefs and values ( $r = .184, p = .184$ ), showed a statistically significant relationship with willingness to provide end-of-life care. The results confirmed that those who have a more positive attitude to hospice care are more likely to have a higher level of willingness to provide end-of-life care.

**HY3:** Social workers who are comfortable discussing dying are more likely to be willing to address end-of-life issues.

The hypothesis was confirmed in this study. The result showed that feeling more comfortable about discussing death, dying, and end-of-life care is correlated with a higher level of willingness to provide such care ( $r = .249, p < .001$ ).

**HY4:** Social workers who minimally emphasize concepts of self-determination and patient rights are likely to prefer family-based decision-making (collectivism) rather than relying solely on patient self-determination (individualism).

The hypothesis was not statistically confirmed in this study. The relationship between emphasizing the concept of self-determination and preferring family-based decision-making was found to be negative ( $r = -.086$ ), meaning that those who emphasize self-determination are less likely to choose family-based decision-making. However, no statistically significant relationship was found between the two variables ( $p = .181$ ).

**HY5:** Social workers with positive attitudes toward end-of life care planning are more willing to or intend to address end-of-life care issues.

This hypothesis was confirmed in this study, which indicated that those who show more positive attitudes to end-of-life care planning or advance directive planning are more likely to be willing to provide end-of-life care ( $r = .240, p < .001$ ). The relationship between attitude and willingness to address the issues was found to be statistically significant.

**HY6:** Social workers who have less positive attitudes toward end-of-life care planning are less likely to be willing or have less intention to provide end-of-life care planning.

This hypothesis was confirmed in the study, which indicated that social workers' more positive attitude toward advance directive planning was correlated with more willingness to encourage or provide such services for themselves ( $r = .624, p < .001$ ) and for older adults ( $r = .606, p < .001$ ). The attitude was statistically significant with regard to willingness both for themselves and for older adults.

**HY7:** Social workers who are willing to complete an advance directive for themselves are likely to encourage clients to do the same.

This hypothesis was confirmed in this study. Correlational analysis between willingness to complete an advance directive for oneself and willingness to do the same for older adults indicated a statistically significant relationship between the two variables ( $r = .595, p < .001$ ). The results of ANOVA were also statistically significant ( $F [4,241] = 40.580, p < .001$ ).

## **Summary of Results**

### **Experiences Related to Hospice Care**

This study found that almost all the social workers (96.8%) had heard about hospice care, but only 17.1% of them reported that they had knowledge about or were familiar with hospice

care. Previous studies regarding awareness of hospice care with the general public in the Korean domestic setting indicated that approximately 60% of respondents were aware of hospice care (Yoon et al., 2004), and more than half reported knowing about such care (Jung et al., 2010). In the medical profession, studies indicated that 86.6 % of medical students (Kwon, 2007) and 90.7% of nursing students (Kim, 2011) were aware of hospice care. Compared with previous studies, this study found the highest percentage of respondents who were aware of hospice care. However, the rate of being knowledgeable about and having familiarity with (17.1%) hospice care in this study was no different from previous studies; 19.4% of medical students reported slight familiarity (Kwon, 2007), and only 14.2% of college students could accurately explain the concept of hospice (Choi et al., 1999). Essentially, compared with other professionals' knowledgeability regarding hospice care, 45.6% of doctors (Moon et al., 2006) and 78.2% of employees in long-term care facilities for older adults (Yoo, 2008), this study showed a low rate (17.1%) of being knowledgeable about the care.

With regard to end-of-life care training, 22% of the sample in this study had received training, confirming previous study findings; a low proportion of social workers in Korea received end-of-life care training (Kang, 2009; Yoo, 2008) and supported the need for education and training for social workers related to end-of-life care (Kang, Kim, Shin, Kim, & Lee, 2010 a). In terms of ways of learning about hospice care, the result of this study is consistent with previous studies, although the ranked order is slightly different (Choi et al., 2009; Kim, 2002; Kwon, 2007; Kim, 2011); education at school (40.2%) or through special training in social work (31.7%), and books, radio, television, newspapers, and websites (30.9%) were identified as popular ways of learning. In addition, most of the geriatric/gerontological social workers (83.3%) in this study reported no experience of working with terminally ill people, while a small



proportion (16.7%) had provided such care services as emotional support (13%), resolution of ethical dilemmas (4.1%), symptom management (3.3%), navigation of resources (2.8%), and advance directive planning (2.8%), in that order. These results may suggest that social workers in geriatric/gerontological institutions tend to provide more emotional support than other services, but that finding is inconsistent with findings from previous studies, which showed that social workers in medical or long-term care settings were more likely to provide administrative services such as paperwork, insurance, and linking available resources (Lee, 1998).

### **Knowledge about and Attitudes toward Hospice Care**

Scholars have repeatedly found a lack of understanding and insufficient knowledge regarding hospice care as well as a positive attitude toward life-sustaining and curative treatment, within the Korean and Korean-American community, owing to cultural factors derived from Confucian ideals, as discussed in Chapter II (Jang, Chiriboga, Allen, Kwak, & Haley, 2010; Kwak & Salmon, 2007; Lee, 1998; Lee et al., 2008; Moon, Lubben, & Villa, 1998; Smith, Earle, & McCarthy, 2009; Yoo, 2008). By contrast and unexpectedly, this study found that participant geriatric/gerontological social workers had relatively high-level knowledge regarding hospice care ( $M = 28.353$ ,  $SD = 3.91$ ). In other words, 96.8% ( $n=238$ ) of participants showed a mean score of 22 or higher, when the total score was categorized into three levels: exact knowledge (total mean score from 22 to 35), minimal knowledge (21), and inaccurate knowledge (7 to 20).

The overall mean score for attitude scale part I shows that geriatric/ gerontological social workers in South Korea tend to have a positive attitude toward or strong agreement with the hospice philosophy ( $M = 41.95$ ,  $SD = 4.46$ ). In addition, based on the results of part II of the attitude scale, which consisted of 7 items, social workers in this study were more likely to hold a positive attitude, that is, they presented less cultural bias regarding hospice care ( $M = 26.90$ ,  $SD$

= 4.44). These two unexpected findings do not accord with previous empirical research, which highlights an unfavorable cultural attitude toward death, dying, and end-of-life care associated with Asian culture. For instance, the Confucian ideal, which permeates Asian culture, emphasizes family responsibility to take care of older parents, within the family network. In this culture, informal care is preferred for older adults, including end-of-life care, so fewer people seek formal care (Lew, 1996; Kim & Rhee, 1999; Choi, 2001; Sung, 2001). Furthermore, while previous studies maintained that Asian people tend to hold unfavorable and insensitive attitudes toward hospice and palliative care (Jung et al., 2011; Kim, 2002; Kim, 2011; Moon et al., 2006; Shin et al., 2010; Yoon et al., 2004), this study shows relatively positive attitudes about hospice care.

With regard to breaking with cultural traditions and expectations, this study supports some other studies, which indicate that the cultural impact of Confucianism in Korean society has been weakened and changed owing to increasing Westernization and growing individualization among citizens (Kim et al., 2000). Also, the study confirmed that perceptions about death are more open, preparing for death has become more active, and people tend to pursue the concept of “dying well” (Kang et al., 2011; Kim, 2011). In addition, in terms of treatment preference in the last stage of one’s life (curative treatment versus palliative treatment), this study found that the respondents are less likely to use curative treatment for terminal illnesses, which is consistent with common practice among older Korean adults in a domestic setting (Kim, 2011).

### **Attitude toward Advance Care Planning**

This study found that most (73.2%) of the South Korean geriatric/gerontological social workers are unaware of what advance directives are. In terms of medical technologies that may

be used to assist patients who are in the final stages of life, the respondents reported they are relatively knowledgeable about cardiopulmonary resuscitation (89.8%), mechanical ventilation (75.2%), dialysis (79.7%), and tube feeding (74%). However, 6.9% of the participants reported no knowledge at all of the aforementioned technologies. Although most of the sample are unaware of advance directives, the attitude scale toward end-of-life care planning showed that participants were more likely to have a relatively positive attitude, with a mean score of 49.89 (SD = 4.70), ranging from 0 to 65 with 13 items.

The finding of limited awareness of advance directives is consistent with previous studies (Doorenbos & Nies 2003; Deshpande, Reid, & Rao, 2005; Kwak & Salmon, 2007; Ko & Berkman, 2010); not only Americans but also other ethnic groups have insufficient knowledge and a low rate of awareness. Hence, it seems that informing people about advance directives is an issue that crosses cultures. Also this finding of attitude toward end-of-life care planning is consistent with a recent study, which found that Koreans tended to have a positive attitude toward a comfortable death and preferred to avoid any unnecessary pain caused by curative treatment. Moreover, they agreed that advance directives would ensure respect for their own wishes regarding the process of dying (Kim, 2011).

By contrast with this study, some studies found that older Korean Americans are more likely to have negative attitudes toward advance care planning, based on relatively inaccurate knowledge (Murphy et al., 1996). Specific factors identified in previous empirical studies included reluctance or refusal to engage in communication about end-of-life care in general and the family decision-making tradition; in particular, adult children were unlikely to discuss end-of-life care planning with their older parents, thus avoiding the topic of the advance directive (Doorenbos & Nies 2003; Deshpande, Reid, & Rao, 2005; Kwak & Salmon, 2007; Ko & Berkman, 2010).

### **Being Comfortable about Discussing Death**

Much of the literature asserts that people in Asian cultures tend to have fear, discomfort, or unpleasant feelings about any discussion related to death, dying, or end-of-life care. In a culture that denies death, they tend to view death and dying as a taboo topic, and to discuss it is likely to be regarded as disrespectful and insensitive (Kwak & Salmon, 2007; Oh, 2011). One study found that people in Korean culture tend to communicate indirectly, employing an implicit, nonverbal method of communication that is based on a highly developed awareness of, and sensitivity to, another person's nonverbal cues (Kwak & Salmon, 2007). Consistent with these previous studies, this study indicates that respondents are less likely to be comfortable talking about death in general ( $M = 3.16$ ,  $SD = 1.07$ ). In particular, participants in this study were likely to feel uncomfortable about discussing death when they were talking to older adults ( $M = 2.91$ ,  $SD = 1.05$ ). To be specific, 35.4% ( $n=87$ ) of participants showed uncomfortable feeling with death discussion while 26.8% ( $n=66$ ) indicated that they feel comfortable about discussion death with older adults. Also a large number (37.8%,  $n=93$ ) of participants answered that they are not sure. Overall, this study found that the respondents did not exhibit a favorable attitude toward discussing death a finding that is consistent with a study conducted in the U.S with ethnic minority groups (Johnson et al., 2008).

### **The Social Worker's Role in End-of-Life Care**

Regarding social workers' opinions about the need for end-of-life care in geriatric/gerontological institutions, overall they were likely to agree on this need ( $M = 4.18$ ,  $SD = .73$ ). They also acknowledged their responsibility to address such end-of-life care issues as psychological, psychosocial, and emotional support (4.05,  $SD = .73$ ). End-of-life care issues, for a significant proportion of older people, have been predominantly considered part of the role of

hospital or medical social workers who work at health care institutions (Damron-Rodriguez, Villa, Tseng, & Lubben, 1997). However, this study showed positive attitudes toward extending social workers' role in end-of-life care to the general geriatric/gerontological field, concurring with the idea that caring for dying individuals and their families must not be limited to the health care setting, but rather should extend to health and mental health agencies, hospitals, hospices, home care, nursing homes, and other age-related fields (NASW, 2004). Not only did social workers regard themselves as responsible persons in end-of-life care issues but a majority (70.3%) reported on family members (70.3%) should be involved in end-of-life care, followed by clergy (42.7%), doctors (41.1%), nurses (27.2%), and other end-of-life counselors or experts (13%). In addition, although social workers in this study agreed on the need for end-of-life care and their responsibility to address the care issue, they reported that they were unprepared to provide this service to older clients ( $M = 2.55$ ,  $SD = .99$ ). This finding demonstrates the absence of social work education and training pertaining to death, dying, and end-of-life care in the Korean domestic setting, along with insufficient attention from the social work profession (Kang, Kim, Shin, Kim, & Lee, 2010 a).

### **End-of-Life Care Decision-Making**

In Korean culture, initiating end-of-life communication and utilizing advance directives tend to be regarded as a challenge. This is because of the cultural norm and tradition in Korean society that death is a taboo topic, a preference for indirect communication so-called *noon-chi*; the cultural value of denial; secrecy about prognoses; and a collective, family-centered system in end-of-life care decision-making (Blackhall et al., 1999, 2001; Fan, 2006; Glass et al., 2010; Park & Chesla, 2007; Kwak & Salmon, 2007; McLaughlin & Braun, 1998). Family members are likely to override the dying person's decision, because of their devotion or loyalty to the family,

family harmony and solidarity, family reciprocity, and filial piety, which includes the value of respecting and caring for elders and obeying one's parents (Blackhall et al., 2001; Smith & Hung, 2012). In accord with these studies, 49.2% of social workers in this study deemed family-based decision-making between clients and their families the most sensible option when clients need to make an end-of-life care decision. In addition, among the respondents who selected joint decision-making with the family, most preferred to involve a family member such as a spouse (48.3%), adult son (30.9%), or adult daughter (29.3%) in the process; this was consistent with previous studies (Fan, 2006; Park & Chesla, 2007).

In contrast with cultural expectations in Asian culture, including Korean culture, the study found that 44% of respondents reported that the autonomy or self-determination of the client should be maintained in the end-of-life care decision which is consistent with previous relevant studies, which addressed the importance of self-determination in end-of-life care decisions (Cagel & Kovacs, 2009; Mezey, Mitty, Rappaport, & Ramsey, 1997, WHO, 2011). One possible explanation is that those respondents who chose self-determination were more likely to emphasize the patient's right to make his or her own decision and also more likely to agree to participate in study. In addition, this study discovered strong agreement with certain statements, namely "making decisions on the basis of one's own wishes is important" ( $M = 4.44$ ,  $SD = .66$ ), "planning for the future is important" ( $M = 4.54$ ,  $SD = .58$ ), and "my wish should be given priority if conflicts exist" ( $M = 4.16$ ,  $SD = .81$ ); these findings confirm the view that Korean people also emphasize the right of an individual to make her or his decision according to his or her wishes regarding the process of dying; this was consistent with a study conducted in the Korean domestic setting (Kim, 2011). Considering ethical principles in the social work

profession, overall social workers in this study placed a strong emphasis on self-determination ( $M = 4.26$ ,  $SD = .71$ ) as an ethical principle in social work practice.

Unlike the above findings, 5.3% of the participants stated that the process of decision-making in end-of-life care should directly involve only family members, not clients, although the family member should inform the patient about such decisions. By contrast, 2% of respondents reported that end-of-life care decisions should be made by family members only, without informing clients, to shield them from the fear of death (1.2%) and to prevent such information from possibly exacerbating the patients' health conditions (1.2%).

### **Preference for Telling the Truth**

This study found that participants prefer to get accurate information and have a strong wish to know everything regarding a serious or terminally ill diagnosis ( $M = 4.42$ ,  $SD = .78$ ). This finding is consistent with the preference of White Americans regarding disclosure of terminal illness; they want to know what to expect physically, based on precise information, and want to maintain their right to make independent decisions (Duffy et al., 2006).

Although respondents in this study exhibited a strong wish to know about their own terminal illness, they demonstrated little agreement on how to convey bad news to a family member who suffered from incurable cancer or another terminal illness ( $M = 3.46$ ,  $SD = .99$ ). This finding confirmed the fact that family members in Asian culture may attempt to keep knowledge of impending death from a loved one to avoid emotional distress and preserve the ability of the soul to obtain liberation, and so they hesitate to disclose a terminal diagnosis (Kwak & Salmon, 2007; Koenig, & Gates-Williams, 1995; Orona, Koenig, & Davis, 1994). This finding may also explain why patients are less likely to recognize when they are in their last moments of life if they have been registered with a hospice or for palliative care, whereas almost

every caregiver is well aware that the patient is near death (Shin, 2010). In addition, in regard to becoming aware of bad news, participants said they would prefer a doctor to give them accurate information, rather than hearing it from a family member.

In connection with disclosing a terminal diagnosis or telling the truth to terminally ill patients, this study found a difference between when participants in this study become terminally ill and when participants have a terminally ill family member. In other words, they want precise information about their own terminal illness, but are less likely to let a family member know such information. Also, they felt that conveying the bad news to a client or family member should be the role of a doctor, not a family member. Similar findings came from a recent study conducted in the Korean domestic setting (Lee, 2009).

### **Overall Willingness to Provide Hospice Care, Complete an Advance Directive, or Provide End-of-Life Care**

Based on ANOVA and t-tests, social workers' characteristics such as age, marital status, religious affiliations, and type of facilities where social workers work have a significant effect on the level of willingness to provide end-of-life care. Consistent with previous studies, older social workers were more likely to show a high willingness to provide end-of-life care than younger ones (Reese et al., 2005; Simons & Park-Lee, 2009). It was found that married social workers were more willing to provide end-of-life care than unmarried ones. In this study, two variables; age and marital status of social workers showed a statistically positive correlation ( $r = .63, p < .001$ ), meaning older social workers were more likely to be married. The previous studies found that non-religious people were more likely to have positive attitudes toward end-of-life care issues and prefer palliative care than those who were more religious (Balboni et al., 2007; Cicirelli, 1997; Cicirelli et al., 2000; Van Ness et al., 2008). Consistent with previous studies, this



study confirmed that non-religious people indicated the highest willingness with regard to end-of-life care issues compared to those who reported religious beliefs. In addition, as expected social workers who work at home care facilities and at nursing homes where most services are for frail older adults and dying patients showed more willingness to address end-of-life issues than those who work at senior integrated centers.

This study found that social workers' attitude and comfort toward end-of-life care issues have a statistically significant positive correlation in regard to willingness of social worker to address end-of-life care. Also, this study indicated that positive attitudes toward advance directive planning were strongly and positively correlated with willingness of providing advance directive. The results of this study confirmed and supported previous studies; more positive attitude or increasing level of death acceptance and increasing comfort feeling or decreasing anxiety toward death and dying are all correlated with willingness of providing the end-of-life care (Black, 2005; Black, 2007; Heyman & Gutheil, 2003; Sanders & McFarland, 2005; Simons & Park-Lee, 2009). In addition, regarding providing or encouraging advance directives for older adults in gerontology/geriatric institutions, approximately half of participants answered that they are willing to address this issue while the other half indicated that they are still not sure or that they are not willing to provide this service.

### **Summary of Findings**

This section presents a summary of the conclusions from the research questions. The purpose of this study was to answer four questions:

- 1) What socio-demographic characteristics (gender, age, education, marital status, living arrangements, religious affiliation, level of licensure, type of work facility and service) of social workers are significant determinants of willingness to address end-of-life issues?

2) What are the characteristics or tendencies (in relation to end-of-life care issues such as work experience, awareness of hospice care, level of knowledge and attitudes about hospice care, level of comfort about discussing death, awareness of the social worker's role in end-of-life care, self-determination, and advance directives) of South Korean social workers involved in geriatrics/gerontology?

3) What are the characteristic factors (experience, self-reported exposure to hospice knowledge, attitude and beliefs about hospice care, level of comfort in discussing death, emphasizing the notion of self-determination, attitude toward end-of-life care planning, awareness of the social worker's role in end-of-life care) that influence South Korean social workers' willingness to address end-of-life care issues?

4) How do social workers regard self-determination or autonomy and disclosure of terminal diagnosis, and what preferences for end-of-life decision-making are associated with Korean culture?

First, social workers' characteristics such as age, marital status, religious affiliations, and type of facilities where social workers are currently working have a significant effect on the level of willingness to provide end-of-life care. Older social workers were more likely to show a high willingness to provide end-of-life care than younger ones. Married social workers were more willing to provide end-of-life care than unmarried ones. Regarding religious affiliations, this study found that the highest willingness with regard to end-of-life care issues was exhibited by agnostic social workers, followed by Christians, Catholics, and Buddhists, in that order. Regarding the types of geriatric/gerontological facilities, those who work at nursing and rehabilitation centers or nursing homes with frail older adults and dying patients exhibited the highest level of willingness to address end-of-life. The second highest level of willingness was

found in home care facilities, daycare centers, or delivery centers, as well as among those who provided home visits or worked as home helpers. Social workers who were assigned to facilities for the disabled, including older adults ( $M = 3.80$ ) had the third highest level of willingness. Lastly, those who worked at senior integrated centers with a physically diverse range of older adults, ranging from frail to healthy, showed the least willingness to provide end-of-life care.

Second, the characteristics or tendencies that acted as predictors of willingness to provide end-of-life care were discussed in detail in previous section on the results of this study. In brief, almost all social workers have heard about hospice care but only a small number were knowledgeable about or familiar with such care. Approximately a quarter of the social workers in this study received end-of-life care training, although they had little experience of working with terminally ill patients. Geriatric/gerontological social workers in this study were more likely to have a basic accurate conception of hospice care and to show a positive attitude toward or agreement with the hospice philosophy. In addition, social workers were more likely to regard hospice care positively, with fewer of the cultural biases or prejudices that are deeply rooted in Asian culture. They were also less likely to prefer curative treatment for patients faced with a terminal illness. However, as expected, social workers in this study did not feel comfortable about discussing death, dying, and end-of-life care with older adults.

In this study, social workers agreed with the need for end-of-life care in geriatric/gerontological institutions, and they thought they had a responsibility to address end-of-life care. In response to a question “who else additionally should be involved in end-of-life care?” a large proportion of respondents agreed that family members (70.3%) should also be involved in end-of-life care issues, followed by other health professionals (nurses and doctors) and spiritual professionals. Most of the geriatric/gerontological social workers (73.2%) in South

Korea were unaware of advance directives, but overall social workers in this study were more likely to have a positive attitude toward end-of-life care planning by a patient stating a wish or preference for end-of-life care in the event that they are incapable of speaking.

Third, the statistically significant factors that have an impact on willingness to provide end-of-life care among social workers, based on regression analysis, were identified as knowledge about hospice care, attitudes toward hospice care, previous work experience, and attending trainings.

Fourth, almost all the geriatric/gerontological social workers, 194 in number, answered an open-ended question regarding the definition of self-determination with such phrases as one's right to make a decision, or one's right to make a decision without any pressure from others, no interference in making a decision for oneself, etc. Regarding how they view self-determination in their practice, social workers in this study strongly emphasized self-determination as an ethical principle. Approximately half emphasized self-determination in one's decision about end-of-life care, while the other half deem joint decision-making between clients and their families the most sensible option.

### **Implications for Social Work Education and Policy**

Enhancing the quality of one's life, including the quality of end-of-life care, is a major area in which social workers should be involved and have expertise. Specifically, social workers play an important role in providing psychological, psychosocial, and emotional support in academic and clinical settings for clients who face acute or long-term situations involving life-limiting illness, dying, death, grief, and bereavement (Benzoff, 2003, 2008; Cagle & Kovacs, 2009, 2011; Sanders & McFarland, 2005). End-of-life care is evidently not for all social workers, but there is no doubt that all social workers are at risk of experiencing a client death regardless of

their client populations. In particular, in the case of America, for those working in geriatric services and/or with older populations, knowledge about death and dying is considered required knowledge. This was identified as one of the five basic competencies for practice by geriatric social workers (Council on Social Work Education [CSWE], 2000, 2001). Furthermore, the NASW (2004) recommended that training gerontology workers in the area of death and dying should be required to provide the best possible quality of care and effectively and appropriately help older clients in end-of-life care issues, regardless of their practice settings. As service providers, needless to say, all social workers should be knowledgeable and skillful in giving assistance at all stages of the dying process, with illness-related issues, manifestations of pain, advance directives, and the range of settings that provide care at the end of life (NASW, 2004).

A previous survey to assess the quality of end-of-life care across 40 countries reported that South Korea ranked 34<sup>th</sup>, indicating that one of the factors that impact on the quality of end-of-care there was the lack of training and education (Economist Intelligence Unit, 2010). Consistent with the previous survey, the present study reveals that geriatric/gerontological social workers tend to lack professional knowledge, owing to an absence of education and training in end-of-life care issues. For example, few of the respondents answered that they were knowledgeable about hospice care, and most indicated that they were not aware of advance directives. The results of this study also highlight the importance of relevant work experience to increase one's willingness to provide end-of-life care to older adults. In other words, social workers who have received relevant training or education and have experience of working in end-of-life care are more likely to be willing to provide such care, as well as having a high degree of knowledge and positive attitudes on such issues as hospice care and advance care planning. Based on the theoretical models presented in this study, education or training and direct

experience were also shown to be the way to achieve intercultural competency when faced with culturally unfamiliar situations or issues such as death, hospice care, advance directives, and so on. Therefore, this study confirms the finding of previous studies: that education is an effective strategy for helping social work professionals to be more prepared for end-of-life situation in practice; accordingly death education is important for effective services (Christ & Sormanti, 1999; Kovacs & Bronstein, 1999; Kramer, 1998; Kramer, Hovland-Scafe, & Pacourek, 2003). Also this study supports the finding that education is indicated as the means of providing better end-of-life care.

In the case of America, in social work schools, 64 % of 260 baccalaureate social work programs and 60 % of 98 graduate social work programs integrated general content on death and dying into the Human Behavior and the Social Environment course or into a gerontology course (Dickinson, Sumner, & Frederick, 1992). There is only superficial education regarding the content of grief and loss in miscellaneous courses, so social work professionals may feel unprepared for addressing end-of-life situations (Christ & Sormanti, 1999; Kramer, 1998; Kramer, Hovland-Scafe, & Pacourek, 2003). Similarly, In Korea, there is not a required course to teach comprehensive understanding regarding death and dying. Rather, the content of death and dying is predominantly discussed when discussing late adulthood in a required course related to human behaviors or an elective gerontology course (Park et al., 2010). Thus, offering a compulsory course on death and dying to all social work students in the formal social work curriculum might be an effective way to impart better understanding and skills before they take up practice.

For social workers who currently work at social work institutions, one possible way for them to enhance their knowledge and skills is to voluntarily undertake continuing education by

enrolling in non-credit-granting courses on death and dying. In addition, the Korean Association of Social Welfare (KASW) (2011) currently provides compulsory annual refresher education or training to all social workers who are currently working at social work agencies. All social workers must complete this education, which is provided through e-learning. The course is divided into five sections; the first two are compulsory, while the last three are elective. The sections are: 1) social work ethics and values, 2) social work practice, 3) social work policy and law, 4) social work administration, and 5) social work research. As this training system is mandatory for all social workers, adding a section on death and dying might yield more effective outcomes.

As well as educating social work professionals, it is important to simultaneously provide education to older adults and their families who visit geriatric/gerontological institutions or even to the general public. This study indicates that social workers feel uncomfortable talking about death with older adults and worry that older clients may also feel distressed or upset when the subject is raised. Since historically in Korean culture talking about death and dying is taboo, people generally feel uncomfortable and worried about doing so (Oh, 2011). Therefore, a campaign of enlightenment is recommended by developing resources, and disseminating information on end-of-life care issues, via the media and by other means, to the general public. This would contribute to broader acceptance and understanding of end-of-life care and might be critical to the success of end-of-life care practice. Also, a public education campaign carried out in collaboration with other professionals such as doctors, nurses, social workers, and religious leaders along with community organizations would produce more effective outcomes, since end-of-life care is ideally performed by an interdisciplinary team.

The social workers' code of ethics in Korea identifies patient autonomy and self-determination as part of the profession's core values (Korea Association of Social Workers; Code of Ethics, 2011). The self-determination is generally understood as clients' right to make their own decisions and to determine the type of medical treatment they wish. However, due to the role of Korean culture, this study assumed that historically people expect or prefer collectivism or family decision-making; that is, decision-making based on family orientation rather than client autonomy may be norm in this kinship-focused culture (McCormick, 2011).

Unexpectedly, this study provides evidence that these kinds of study assumptions derived from Korean cultural expectation are not universal within this culture. Almost all the social workers answered that self-determination is an important ethical principle in social work practice, and almost half of the respondents preferred more self-determination and focused on the client's right to make his or her own decision. By contrast, half of the respondents believed that the family should be involved in decision-making and that family decision-making should be maintained with regard to end-of-life care. In regard to decision-making in end-of-life care, this finding indicates that there is no universal true answer, since it depends on personal and family preferences rather than being distinguished by belonging to a culture (Western culture versus Asian culture).

To address this issue, the social work profession, in which self-determination is a core value that must be maintained, should turn its attention to the ethical issues or the conflicts that may arise. McCormick (2011) pointed out that social workers are likely to face challenges when supporting families that wish to keep cultural traditions at the end of life, while also maintaining their obligation to follow social work ethical principles and relevant laws regarding patient autonomy in decision making in practice (McCormick, 2011). Accordingly, the social work



profession should carefully consider how social workers should understand or apply this professional value in Korean culture, and in particular what they should do for older clients and their families who do not value self-determination so highly. In addition, it is necessary to empirically explore whether decision-making based on family orientation is improperly giving more power or control to the family than patients might wish. Meanwhile, social work professionals and practitioners should be listening and understanding clients' preferences or wishes without making cultural bias or professional assumptions and while respecting individuality and diversity. Bioethics and competency training regarding autonomy in decision-making will be valuable for social workers (McCormick, 2011).

Another issue is disclosure of a diagnosis or telling the truth about an impending death. In Asian culture, disclosure of a cancer diagnosis may be less likely in terminal cases; people prefer not to talk about death until the last minute of a family member's life (Kwak & Salmon, 2007). Accordingly, many dying individuals in Asian culture are unlikely to be officially told that they are dying (Shin et al., 2010). Respondents in this study reported that they would hesitate to let a family member who is suffering from a terminal illness know about the diagnosis or talk about death. By contrast, however, this study indicates that respondents faced with their own terminal illness would want to know exactly what the diagnosis is, even when the prognosis is death. These contradictory findings highlight the discrepancy between knowing about a diagnosis or terminal illness for oneself and telling the truth or disclosing a terminally ill diagnosis to a family member. In the social work profession, without disclosure of diagnosis to a patient, the right of self-determination cannot be employed, and achieving death with dignity might be difficult, since the patient is unable to prepare for death mentally and spiritually. Social work professionals therefore need to take the time to communicate with clients and family members and should

actively encourage family interaction, serving as mediators and advocates to ensure self-determination as a right of the client.

Lastly, while the practical and specific implications of this study are straightforward, they cannot stand alone. Policy must support reform, by developing or modifying social work education in order to inculcate positive attitudes toward and knowledge about death and dying. Reform should occur both in the academic curriculum and in the mandatory training undertaken by those in the social work profession. Moreover, policy should support continuous education by offering benefits, cost rewards, or scholarships to those who enroll voluntarily.

### **Limitations of Study**

A number of important findings came out of this study, which, however, was subject to a number of limitations in generalizing its findings. First, the survey instruments used were originally developed and implemented in Western countries. Although the scales were developed and employed with minority ethnic groups, mainly Black and Asian populations, they were not culturally validated for Korean domestic settings. In addition, although efforts to ensure language equivalence were made via translation and back translation, cultural validation including culturally sensitive interpretation requires more than translation of the words. Also, although previous literature and a pilot study established the acceptable reliability of the testing measurements, the construct validity was not tested. Without looking at construct validity, the theoretical relationship between variables could not be examined (DeVellis, 2003). In addition, since this study directly asked respondents to disclose their willingness to provide end-of-life care in response to future demands, social workers may have proffered the professionally desirable answer. In view of these limitations regarding measurement, readers should interpret the study outcomes with caution.

Second, this study's non-probability sampling method, specifically the referral sampling process, was a limitation in the generalizability of findings to the population at large. That is, this study does not represent all geriatric/gerontological social workers in Korea. Also, the study was conducted in a metropolitan area of Korea; different regions may yield different outcomes. For instance, social workers in the central city have more opportunities to access training or workshops to learn about end-of-life care than those who live in rural areas. Exposure to education and practical experiences in the city may also have increased their knowledge on this topic and enhanced positive attitudes. Thus, it is important for any future study to employ a probability sampling method to increase generalizability, and to broaden the geographic spread of the study in order to increase representativeness. Further, given that participants were volunteers, social workers who declined to participate may have different perceptions or attitudes toward end-of-life care issues.

Third, a cross-sectional design is a limitation, since the nature of the design did not provide information about changes in attitude over time. Multiple observations at different times could yield different findings, which may contribute to better understanding about end-of-life care issues.

Fourth, with regard to the questionnaires employed in this study, there is a need to cite detailed instances in certain questions. In response to a question regarding "who or which family member should be involved in the decision-making process," this study only gave a spouse, adult son, adult daughter, and relatives or others as examples of family members. Previous studies of end-of-life care in Asian culture indicated that the sibling order as well as the gender of children is an important factor that influences decision-making. However, this study did not ask respondents about what sibling order of children or what gender of children they preferred in the

decision-making process; specifically, whether they preferred to confer with their elder son rather than with their other children. Therefore, future studies should investigate this issue to gather more detailed information regarding the preference of family involvement in the decision-making process about end-of-life care in Korean culture.

Fifth, regarding medical technologies that may be used on dying people in the questionnaires, this study simply asked about the definition of each technology; there is need to add better measures of knowledge of, in particular, cardiopulmonary resuscitation (CPR) as applied to older adults in emergent situations.

Last, this study examined the attitudes and tendencies of geriatric/gerontological social workers regarding end-of-life care issues and their willingness or intention to provide end-of-life care. This study found that only 22% (n=54) of 245 participants answered that they had received end-of-life care training or education, and only 16.7% (n=41) had experience of working in end-of-life situations. Based on the results regarding lack of education and experience, one of the limitations is linked to the problem of participants responding to the specificity of the survey.

### **Strengths of Study**

Although several methodological weaknesses are inherent in this study, there are some strengths, which contribute to the existing literature. With culturally diverse populations, there is a paucity of information on this end-of-life care topic. That is, end-of-life care issues in Asian culture and with Asian populations are understudied and underexplored, especially since, to our knowledge, none of the end-of-life care studies in Korean domestic settings was conducted with geriatric/gerontological social workers. Accordingly, this study expands the body of knowledge about end-of-life care issues and will broaden our understanding about the Korean population, including Koreans living abroad. In the social work profession in particular, the study provides a

picture of how social workers view end-of-life care and their responsibilities in this care, and how they might prepare for a future aging society.

### **Directions for Future Studies**

The main purposes of this study were to explore the attitudes and tendencies of geriatric/gerontological social workers regarding end-of-life care issues and their willingness or intention to provide end-of-life care, and to identify significant factors influencing willingness to provide this care in the Korean domestic setting. Based on the findings, some recommendations or suggestions for future study are presented in this section.

First, as discussed previously, the notion of self-determination or autonomous decision-making, which is emphasized in Western culture and end-of-life care philosophy, does not equally apply to all cultures. At the same time, the cultural value that emphasizes family decision-making can lead to discord with the professional social work value of self-determination. Therefore, future studies should investigate how such ethical principles are understood and applied in different cultures and how social workers handle these issues in their practice. Also, studies could seek to discover whether cultural expectations still exist or whether they have now dwindled or vanished.

Second, this study explored social workers' attitudes regarding end-of-life care in Korean domestic settings. Future studies should explore social workers' attitudes or tendencies with other ethnic or cultural populations. In particular, Korean-American social workers who are working in America should be studied to explore the comparison between them and Koreans and whether social workers in America maintain their cultural values or beliefs in their practice. In addition, by controlling ethnicity, future studies should investigate the similarities and differences between or among ethnic groups; American versus Korean, Korean versus Korean-

American, African-American versus Asian-American, between Asians (Korean versus Chinese or Japanese), etc.

Third, focusing on Korean domestic settings, this study was designed to gather and evaluate social workers' attitudes and willingness to provide and the need for end-of-life care at geriatric/gerontological institutions, as a preliminary study for provision of end-of-life care. The next step should be to consider the barriers that exist in geriatric/gerontological institutions to providing end-of-life care and to identify a realistic environment for social work practice related to such care.

Fourth, this study revealed that those who completed graduate-level education were more willing to provide end-of-life care than those who had a college-level education [i.e., the participants who completed 2-year and 4-year college programs]. To further address these differences among social work programs, future study should investigate the social work curriculum of BSW and MSW degrees related to end-of-life care, and death and dying, as well as how different social work curricula impact students' preparedness and willingness of address end-of-life care.

Fifth, this study included five different types of geriatric/gerontological facilities, namely a nursing home, nursing hospital, home care, senior integrated center, and aging-related institution. Institutions such as senior integrated centers serve relatively healthy older adults, while nursing homes care for frail older adults. Therefore, a future study should consider each type of facility offering long-term care to identify the characteristics or tendencies related to end-of-life care issues that exist within them.

Sixth, in regard to religious affiliation, agnostic in this study was regarded as "non-religion" which included not only agnostic (as the absence of religious belief) and atheist (as the

rejection of religious belief), but also people who just answered none or no religious preference. Therefore, future study with a sharp distinction of between agnostic and atheist will be useful for deep understanding of the effect of religious affiliations in regard to end-of-life care issues.

Lastly, culturally appropriate instruments should be developed and used in future studies. A similar study should be undertaken with other ethnic populations to ensure reliability and validity of measurement and of the instrument scales.

### **Conclusion**

This dissertation has examined the attitudes and tendencies of geriatric/gerontological social workers regarding end-of-life care issues and their willingness or intention to provide end-of-life care. It has identified significant factors influencing willingness to provide such care in a large metropolitan area of South Korea. Consistent with the existing literature, the findings of this study indicate that geriatric/gerontological social workers have little or no education or training on end-of-life care issues, and lack awareness and knowledge, especially about advance directives. The social workers in this study were likely to agree on the need for end-of-life care in geriatric/gerontological institutions and show a willingness to address end-of-life care issues for older adults. However, they feel they are not prepared to provide psychological, psychosocial, or emotional support within the area of death and dying.

Contrary to cultural expectations, overall respondents were likely to have a positive attitude toward hospice care and planning for future end-of-life care, and they showed a preference not to use life-sustaining treatment during the last stage of life. Regarding EOL care planning, approximately half of the participants answered that they are willing to provide or encourage advance directives for older adults in gerontology/geriatric institutions, but the other half indicated that they are not sure or that they are not willing to provide this service. One of the

important finding is that respondents expressed emphasis on self-determination in end-of-life care decision-making and the principle that the patient's wish is regarded as the most important factor when there are conflicts between the patient and a family member. By contrast, consistent with cultural values and expectations, half the respondents in this study prefer a family decision-making process, and some even want to exclude the patient from the process to protect him or her from feelings of fear or abandonment. In addition, because of the cultural importance of the topic of death and dying, social workers generally feel uncomfortable talking about death with elders and worry that such a discussion might cause distress to older adults.

This study refocuses and readdresses the issue of end-of-life care decision-making (individualism versus collectivism) and disclosure of diagnosis of a terminal illness. It also raises concern about the discrepancy between social workers' professional values, the ethical principle of self-determination, and the traditions of Korean culture. The findings of this study suggest the need for an educational and informational program for social workers to achieve competency in end-of-life care, as well as education for the general public, in order to bring the topic of death and dying into the public arena and promote familiarity with the concept and practice of end-of-life care.



## REFERENCES

- Altilio, T., Otis-Green, S., & Dahlin, C. M. (2008). Applying the national quality forum preferred practices for palliative and hospice care: a social work perspective. *Journal of Social Work in End-of-Life & Palliative Care, 4(1)*, 3-16.
- Asch-Goodkin, J. (2000). The virtues of hospice. *Patient Care, 34(21)*, 72.
- Balboni, T., Vanderwerker, L., Block, S., Paulk, M., Lathan, C., Peteet, J., & Prigerson, H. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology, 25(5)*, 555-560.
- Barker, R. L. (1991). *Social work dictionary*. Silver Spring, Md.: National Association of Social Workers, NASW Press.
- Becker, J. E. (2004). Oncology social workers' attitude toward hospice care and referral behavior. *Health & Social Work, 29(1)*, 36-45.
- Bem, Daryl J. (1967). Self-perception: An alternative interpretation of cognitive dissonance phenomena. *Psychological Review, 74(3)*, 183-200.
- Berzoff, J. (Ed.). (2003). *Living with dying: A handbook for end-of-life healthcare practitioners*. New York: Columbia University Press.
- Benzoff, J. (2008). Working at the end of life: providing clinically based psychosocial care. *Clinical Social Work Journal, 36(2)*, 177-184.
- Beresford, L. (1997). The future of hospice in a reformed American health care system: What are the real questions? *Hospice Journal, 2(2)*, 85-91.

- Beresford, P., Adshead, L., & Croft, S. (2007). *Palliative care, social work and service users: Making life possible*. Philadelphia: Jessica Kingsley Publishers.
- Berger, J. T. (1998). Culture and ethnicity in clinical care. *Archives of Internal Medicine*, *158(19)*, 2085.
- Berkman, B., & D'Ambruoso, S. (2006). *Handbook of social work in health and Aging*. Berkman, B., & D'Ambruoso, S. (Eds.). Oxford; New York: Oxford University Press.
- Berkman, B., Gardner, D., Zodikoff, B., & Harootyan, L. (2006). Social work and aging in the emerging health care world. *Journal of Gerontological Social Work*, *48(1-2)*, 203-217.
- Bern-Klug, M. (2010). *Transforming palliative care in nursing homes: The social work role*. New York: Columbia University Press.
- Bern-Klug, M., Gessert, C., & Forbes, S. (2001). The need to resolve assumptions about end-of-life practice: Implications for social work practice. *Health & Social Work*, *26(1)*, 38-47.
- Black, K. K. (2005). Social workers' personal death attitudes, experiences, and advance directive communication behavior. *Journal of Social Work In End-of-Life & Palliative Care*, *1(3)*, 21-35.
- Black, K. K. (2007). Health Care Professionals' Death Attitudes, Experiences, and Advance Directive Communication Behavior. *Death Studies*, *31(6)*, 563-572.
- Blackhall, L., Frank, G., Murphy, S., & Michel, V. (2001). Bioethics in a different tongue: the case of truth-telling. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, *78(1)*, 59-71.
- Blackhall, L., Frank, G., Murphy, S., Michel, V., Palmer, J., & Azen, S. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine*, *48(12)*, 1779-1789.

- Blackhall, L., Murphy, S., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *Journal of the American Medical Association, 274*(10), 820-825.
- Born, W., Greiner, K., Sylvia, E., Butler, J., & Ahluwalia, J. (2004). Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *Journal of Palliative Medicine, 7*(2), 247-256.
- Braun, K., Pietsch, J. H., & Blanchette, P. L. (2000). *Cultural issues in end-of-life decision making*. Kathryn L. Braun, James H. Pietsch, Patricia L. Blanchette. (Eds.). Thousand Oaks, CA: Sage Publications.
- Brislin, R., Lonner, W., & Thorndike, R. (1973) *Cross-cultural research methods*. New York: Wiley.
- Brock, D. B., & Foley, D. J. (1998). Demography and epidemiology of dying in the U.S. with emphasis on deaths of older persons. *Hospice Journal, 13*(1/2), 49-60.
- Bullock, K. (2011). The Influence of Culture on End-of-Life Decision Making. *Journal of Social Work In End-Of-Life & Palliative Care, 7*(1), 83-98.
- Bum, H. J. (2010, Jan 27). Trial applying health insurance to hospice care, *Naeil News Paper*. Retrieved, October 10, 2012, from <http://www.naeil.com/News/economy/ViewNews.asp?num=522009&sid=E&tid=4>
- Burdette, A. M., Hill, T. D., & Moulton, B. E. (2005). Religion and attitudes toward physician-assisted suicide and terminal palliative care. *Journal for the Scientific Study of Religion, 44*(1), 79-93.
- Burrs, F. A. (1995). The African American experience: Breaking the barriers to hospices. *Hospice Journal, 10*(2), 15-18.

- Byrce, C. L., Lowenstein, G., Arnold, R. M., Schooler, J., Wax, R. S., & Angus, D. C. (2004). Quality of death: Assessing the importance placed on end-of-life treatment in the intensive-care unit. *Medical care*, 42(5), 423-431.
- Cagle, J. G., & Kovacs, P. J. (2009). Education: A complex and empowering social work intervention at the end of life. *Health & Social Work*, 34(1), 17-27.
- Cagle, J. G., & Kovacs, P. J. (2011). Informal caregivers of cancer patients: perceptions about preparedness and support during hospice care. *Journal of Gerontological Social Work*, 54(1), 92-115.
- Calloway-Thomas, C. (2010). *Empathy in the global world: An intercultural perspective*. Thousand Oaks, CA: Sage Publications.
- Center for Gerontology and Health Care Research, (2001). Facts On Dying: Policy relevant data on care at the end of life. Retrieved, March 26, 2012, from <http://www.chcr.brown.edu/dying/brownatlas.htm>
- Centers for Medicare & Medicaid Services. (2012). Medicare & You. Medical Handbook. U.S. Department of Health and Human Services. Retrieved April 01, 2012, from <http://www.medicare.gov/publications/pubs/pdf/10050.pdf>
- Choi, S. (2009). Aging Society Issue in Korea. *Asian Social Work and Policy Review* 3, 63-83.
- Choi, S. J. (2001). Changing attitudes to filial piety in Asian countries. Paper presented at 17th World Congress of International Association of Gerontology. Vancouver, Canada, July 1-6.
- Choi, Y. S., Shin, J. M., Lee, Y. M., Lee, H. L., Hong, M. H., Kim, J. S., & Yeom, C. H. (1999). The college students' attitude toward terminal care and euthanasia. *Korean J Hosp Palliat Care*, 2(1), 16-22.

- Christ, G., & Blacker, S. (2005). The profession of social work in palliative and end-of-life care. *Journal of Palliative Medicine, 8*(2), 415-417.
- Christ, G. H., & Sormanti, M. M. (1999). Advancing social work practice in end-of-life care. *Social Work In Health Care, 30*(2), 81-99.
- Christopher, A. K., & Stephen, R. C. (2005). NHPCO Practice Report: National Associations Survey: Advancing hospice and palliative care Worldwide. *Journal of Pain & Symptom Management, 30*386-30388.
- Chung, B. Y., Xu, Y., & Kwak, C. (2005). Hospice and hospice care in Korea: Evolution, current status, and challenges. *Home Health Care Management & Practice, 18*(1), 73–77.
- Cicarelli, V. G. (1997). Relationship of psychosocial and background variables to older adults' end-of-life decisions. *Psychology and Aging, 12*, 72–83.
- Cicarelli, V. G. (2000). Older adults' ethnicity, fear of death, and end-of-life decisions. In A. Tomer (Ed.), *Death attitudes and the older adult: Theories, concepts, and applications* (pp. 175–191). Philadelphia: Taylor & Francis.
- Cicarelli, V. G., MacLean, A., & Cox, L. S. (2000). Hastening Death: A Comparison of Two End-of-Life Decisions. *Death Studies, 24*(5), 401-419.
- Civil Act (2009). Code, 933, Korea Law, South Korea.
- Clark, D. (2004). The international observatory on end of life care: A new initiative to support palliative care development around the world. *Journal of Pain & Palliative Care Pharmacotherapy, 17*(3/4), 231-238.
- Clark, D (2007). End-of-life care around the world: Achievements to death and challenges remaining. *Omega, 58*(1), 101-110.

- Clark, D., & Wright, M. (2007). The international observatory on end of life care: A global view of palliative care development. *Journal of Pain and Symptom Management, 33*(5), 542-546.
- Code of Ethics of the National Association of Social Workers. (2005). *Journal of Aggression, Maltreatment & Trauma, 11*(3), 395-422.
- Compton, B., & Galaway, B. (1999). *Social work processes*. Pacific Grove: Brooks/Cole Publishing.
- Cort, M. (2004). Cultural mistrust and use of hospice care: Challenges and remedies. *Journal of Palliative Medicine, 7*(1), 63-71.
- Council on Social Work Education [CSWE]. (2000). CSWE/SAGE-SW National aging competencies survey report.
- Council on Social Work Education [CSWE]. (2001). *Educational policy and accreditation standards*. Alexandria, VA.
- Crawley, L. (2002). Palliative care in African American communities. *Journal of Palliative Medicine, 5*(5), 775-779.
- Crawley, L. M. (2005). Racial, cultural, and ethnic factors influencing end-of-life care. *Journal of Palliative Medicine, 8*(Suppl.1), S58-S69.
- Crawley, L. M., Marshall, P. A., Lo, B., & Koenig, B. A. (2002). Strategies for culturally effective end-of-life care. *Annals of Internal Medicine, 136*, 673-679.
- Crawley, L. L., Payne, R. R., Bolden, J. J., Payne, T. T., Washington, P. P., Williams, S. S., & The Initiative to Improve Palliative and End-of-Life Care in the African American, C. (2000). Palliative and End-of-Life Care in the African American Community. *The Journal of American Medical Association, 284*2518-2521.

- Csikai, E. (2004). Social workers' participation in the resolution of ethical dilemmas in hospice care. *Health & Social Work, 29*(1), 67-76.
- Csikai, E. L., & Bass, K. (2000). Health care social workers views of ethical issues, practice, and policy in end-of-life care. *Social Work in Health Care, 32*(2), 1-22.
- Curtis, L. (2010). Empowering, Educating, and Advocating: How Social Workers Can Help Churches Integrate End of Life Care into Congregational Life. *Social Work & Christianity, 37*(2), 128-141.
- Curtis, J. R., Patrick, D. L., Caldwell, E. E., Greenlee, H. H., Collier, A. C., Curtis, J. R., & ... Collier, A. C. (2000). Communication about End-of-Life Care. *Archives of Internal Medicine, 160*1690-1696.
- Damron-Rodriguez, J., Villa, V., Tseng, H., & Lubben, J. E. (1997). Demographic and organizational influences on the development of gerontological social work curriculum. *Gerontology & Geriatrics Education, 17*(3), 3-18.
- Daratsos, L. (2006). Roles of Social Workers in Palliative and End of Life Care. Barbara Berkman, Sarah D'Ambruso, (Ed), *Handbook of social work in health and aging*. Oxford; New York: Oxford University Press.
- Deardorff, D. K. (2006). The identification and assessment of intercultural competence as a student outcome of internationalization at institutions of higher education in the United States. *Journal of Studies in International Education, 10* (3), 241-266.
- Deardorff, D. K. (Ed). (2009). *The SAGE handbook of intercultural competence*. Thousand Oaks, CA: Sage Publication.
- de Pentheny O'Kelly, C., Urch, C., & Brown, E. A. (2011). The impact of culture and religion on truth telling at the end of life. *Nephrology Dialysis Transplantation, 26*(12), 3838-3842.

- Deshpande, O., Reid, M. C., & Rao, A. S. (2005). Attitudes of Asian-Indian Hindus toward end-of-life care. *J Am Geriatr Soc*, *53*(1), 131-135.
- Dickinson, G. E., Sumner, E. D., & Frederick, L. M. (1992). Death education in selected health professions. *Death Studies*, 15281-298.
- DiStefano, C., Zhu, M., & Mindrila, D (2009). Understanding and using factor scores: considerations for the applied researcher. *Practical Assessment, Research & Evaluation*, *14*(20), 1-11.
- Doorenbos, A. Z., & Nies, M. A. (2003). The use of advance directives in a population of Asian Indian Hindus. *J Transcult Nurs*, *14*(1), 17-24.
- Duffy, S. A., Jackson, F. C., Schim, S. M., Ronis, D. L., & Fowler, K. E. (2006). Racial/ethnic preferences, sex preferences, and perceived discrimination related to end-of-life care. *Journal of the American Geriatrics Society*, *54*(1), 150-157.
- Dupree, C. (2000). The attitudes of Black Americans toward advance directives. *Journal of Transcultural Nursing*, *11*(1), 12-18.
- Economist Intelligence Unit, (2010). *The Quality of Death; Ranking End-of-Life Care across the World*. Lien Foundation. London: The Economist.
- Emanuel, E., & Emanuel, L. (1998). The promise of a good death. *Lancet*, *351* Suppl 2SII21-SII29.
- Ersek, M., Kawaga-Singer, M., Barnes, D., Blackhall, L., & Koenig, B.A. (1998). Multicultural considerations in the use of advance directives. *Oncology Nursing Forum*, *25*, 1683-1690.
- Fan, R. R. (2006). Confucian Filial Piety and Long Term Care for Aged Parents. *Healthcare Ethics Committee Forum*, *18*(1), 1-17.



- Field, M. J., & Cassel, C. K. (2010). *Approaching death: Improving care at the end of life*. In D. E. Meier, S. L. Isaacs, R. G. Hughes, D. E. Meier, S. L. Isaacs, R. G. Hughes (Eds.), *Palliative care: Transforming the care of serious illness* (pp. 79-91). San Francisco, CA US: Jossey-Bass.
- Flory, J., Young-Xu, Y., Gurol, I., Levinsky, N., Ash, A., & Emanuel, E. (2004). Place of death: U.S. trends since 1980. *Health Affairs, 23*(3), 194-200.
- Foley, K. M., & Gelband, H. (2001). *Improving palliative care for cancer* [Report of the Institute of Medicine Task Force]. Washington, DC: National Academies Press.
- Fried, T. R., Bullock, K., Iannone, L., & O'Leary, J. R. (2009). Understanding advance care planning as a process of health behavior change. *Journal of the American Geriatric Society, 57*(9), 1547–1555.
- Gatrell, A. C., Harman, J. C., Francis, B. J., Thomas, C., Morris, S. M., & McIlmurray, M. (2003). Place of death: An analysis of cancer death in part of North West England. *Journal of Public Health Medicine, 25*, 53–58.
- Gerbino, S. B. (1994). *Burnout among hospice social workers*. Unpublished doctoral dissertation, New York University, School of Social Work.
- Glass, A. P., Chen, L., Hwang, E., Ono, Y., & Nahapetyan, L. (2010). A cross-cultural comparison of hospice development in Japan, South Korea, and Taiwan. *Journal of Cross-Cultural Gerontology, 25*(1), 1-19.
- Goodridge, D., Bond, J. B., Cameron, C., & McKean, E. (2005). End-of-life care in a nursing home: A study of family, nurse and healthcare aide perspectives. *International Journal of Palliative Nursing, 11*(5), 226– 232.

- Gordon, A. K. (1996). Hospice and minorities: A national study of organizational access and practice. *The Hospice Journal, 11*(1), 49–70.
- Gostin, L. (1995). Informed consent, cultural sensitivity, and respect for persons. *JAMA: The Journal of The American Medical Association, 274*(10), 844-845.
- Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine, 18*, 460–467.
- Grunier, A., Mor, V., Weitzen, S., Truchil, R., Teno, J., Roy, J. (2007). Where people die: A multilevel approach to understanding influences on site of death in America. *Med Care Res Rev 64*(4), 351–78.
- Gutheil, I., & Souza, M. (2006). Psychosocial service at end of life. In Berkman, B. (Ed.), *Handbook of social work in health and aging* (pp325-334). New York, NY US: Oxford University Press.
- Gwyther, L. P., Altilio, T., Blacker, S., Christ, G., Csikai, E. L., Hooyman, N., et al. (2005). Social work competencies in palliative and end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care, 1*(1), 87–120.
- Haas, J. S., Earle, C. C., Cray, J. E., Brawarsky, P., Neville, B. A., Acevedo-Garcia, D., & Williams, D. R. (2007). Lower Use of Hospice by Cancer Patients who live in Minority Versus White Areas. *Journal of General Internal Medicine, 22*(3), 396-399.
- Han, J. Y., & Lee, N. Y. (2009). Nursing students' attitude toward death and perception on hospice care. *Korean Journal of Hospice Palliative Care, 9*(2), 95-103.
- Happ, M. B., Capezuti, E., Strumpf, N. E., Wagner, L., Cunningham, S., Evans, L., & Maislin, G. (2002). Advance care planning and end-of-life care for hospitalized nursing home residents. *JAGS, 50*(5), 829-835.

- Harper, B. C. (1995). Report from the National Task Force on Access to Hospice Care by Minority Groups. *Hospice Journal*, 10(2), 1-9.
- Hart, A., Kohlwes, R. J., Deyo, R., Rhoades, L.A., & Bowen, D. J. (2003). Hospice patients' attitudes regarding spiritual discussions with their doctors. *American Journal of hospice & palliative care*, 20(2), 135-139.
- Heeren, O., Menon, A., Raskin, A., & Ruskin, P. (2001). Religion and end of life treatment preferences among geriatric patients. *International Journal of Geriatric Psychiatry*, 16(2), 203-208.
- Heyman, J. C., & Gutheil, I. A. (2003). Attitudes of social work students toward end-of-life planning. *Educational Gerontology*, 29(4), 313-326.
- Hill, R. R. (2007). "Clinical pharmacy services in a home-based palliative care program". *Am J Health Syst Pharm* 64 (8): 806-810.
- Himmelfarb, S., & Eagly, A. H. (Eds) (1974). *Readings in attitude change*. New York: Wiley
- Hopp, F. P. (2000). Preferences for surrogate decision maker, informal communication, and advance directives among community-dwelling elders: Result from a national study. *Gerontologist*, 40(4), 449-457.
- Hospice Association of America [HAA] (2009). Hospice Facts & Statistics. Retrieved from <http://www.nahc.org/facts/HospiceStats10.pdf>
- Hospice and Palliative Care of Greensboro [HPCG] (2007). Defining Hospice & Palliative Care Medicine. Retrieved from, <http://www.hospicegso.org/medical-providers>
- Holland, J. C. (Ed.). (1998). *Psycho-oncology*. New York: Oxford University Press.
- Holland, L., & Rogich, L. E. (1980). Dealing with grief in the emergency room. *Health Soci Work*, 5(2): 12-17.

- Hovland, C. I., Janis, I. L., & Kelley, H. H. (1953). *Communication and Persuasion*. New Haven: Yale University Press.
- Howe, J. L., & Daratsos, L. (2006). Roles of social workers in palliative and end-of-life care  
In Berkman, B. (Ed.), *Handbook of social work in health and aging (pp315-324)*. New York, NY US: Oxford University Press.
- International Observatory on End of Life Care (2006). International Observatory on Palliative Care. Retrieved October 2, 2011, from, <http://www.lancs.ac.uk/shm/research/ioelc/>
- Jang, Y., Chiriboga, D. A., Allen, J. Y., Kwak, J., & Haley, W. E. (2010). Willingness of older Korean-American adults to use hospice. *Journal of the American Geriatrics Society, 58(2)*, 352-56.
- Jennings, B., Ryndes, T., D'Onofrio, C., & Baily, M. (2003). Access to Hospice Care: Expanding Boundaries, Overcoming Barriers. Hastings Center Report, 3-7.
- Jones, A. L., Moss, A. J., & Harris-Kojetin, L. D. (2011). Use of advance directives in long-term care populations. NCHS data brief, no 54. Hyattsville, MD: National Center for Health Statistics. Retrieved October 1, 2012, from <http://www.cdc.gov/nchs/data/databriefs/db54.pdf>
- Johnson, K., Kuchibhatla, M., & Tulsky, J. (2008). What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of the American Geriatrics Society, 56(10)*, 1953-1958.
- Johnson, K., Kuchibhatla, M., & Tulsky, J. (2009). Racial differences in self-reported exposure to information about hospice care. *Journal of Palliative Medicine, 12*, 921-927.

Juarez, J. A., Marvel, K., Brezinski, K. L., Glazner, C., Towbin, M. M., & Lawton, S. (2006).

Bridging the gap: A curriculum to teach residents cultural humility. *Family Medicine*, 38, 97-102.

Jung, H. Y., Jung, K. T., Hwang, W. D., Kim, Y. S., An, J. H., Kim, D. H.,... & Kim, E. H.

(2010). A study on university students' orientation and attitudes on hospice: To develop Homo Humanitas Thanatology. *A study of Northeast Asia Culture*, 22, 153-168.

Kagawa-Singer, M., & Blackhall, L. (2001). Negotiating cross-cultural issues at the end of life:

"You got to go where he lives". *JAMA: The Journal of the American Medical Association*, 286(23), 2993-3001.

Kagawa-Singer, M., & Blackhall, L. J. (2010). Negotiating cross-cultural issues at the end of life:

'You got to go where he lives'. In D. E. Meier, S. L. Isaacs, R. G. Hughes, D. E. Meier, S. L. Isaacs, R. G. Hughes (Eds.), *Palliative care: Transforming the care of serious illness* (pp. 329-347). San Francisco, CA: Jossey-Bass.

Kahana, B., Dan, A., Kahana, E., & Kercher, K. (2004). The personal and social context of

planning for end-of-life care. *Journal of the American Geriatrics Society*, 52, 1163-1167.

Kang, J. A., Kim, D. Y., Shin, D. Y., Kim, S. Y., & Lee, S. N. (2010a). A survey on the

certification and curriculum development for hospice and palliative care professionals.

*Korean J Hops Palliat Care*, 13(1), 32-40.

Kang, J. A., Koh, S. J., Yoo, Y. S., Choi, Y. S., Choi, J. Y.,...& Shin, D. W. (2010b).

Development of the standard hospice and palliative care education program in Korea:

Result from the demonstration project. *Journal of Palliative Medicine*, 13(6), 703-710.

- Kang, K. A., Lee, K. S., Park, G. W., Kim, Y. H., Jang, M. J. & Lee, E. (2011). Community dwellers' perception of past life recollection and preparation for death. *Korean J Hosp Palliat Care*, 14(2), 81-90.
- Kang, J. A., Shin, D. Y., Hwang, E. J., Kim, H. Y., An, S. H., & Yoo, Y. S. (2009). Hospice Education among Hospice Professionals and Its Regional Variations in Korea; Outcomes from a 2008 Hospice Palliative Care Institutions Support Project. *Korean J Hosp Palliat Care*, 12(3), 132-138.
- Karim, K., Bailey, M., & Tunna, K. (2000). Non-white ethnicity and the provision of specialist care services: factors affecting doctors' referral patterns. *Palliat Med*, 14, 471-8.
- Kramer, B. J. (1998). Preparing social workers for the inevitable: a preliminary investigation of a course on grief, death, and loss. *Journal of Social Work Education*, 34(2), 211-228.
- Kramer, B. J., Hovland-Scafe, C., & Pacourek, L. (2003). Analysis of end-of-life content in social work textbooks. *Journal of Social Work Education*, 39(2), 299-320.
- Kauh, T. O. (1997). Intergenerational relations: older Korean American's experiences. *Journal of Cross-Cultural Gerontology*, 12, 245-271.
- Kearl, M. (2000). Kearl's guide to the sociology of death: Death across time and space.  
Retrieved from <http://www.trinity.edu/~mkearl/death-1.html>
- Keown, D. (2005). End of life: the Buddhist view. *Lancet*, 366(9489), 952-955.
- Kiesler, C., Collins, B., & Miller, N. (1969). *Attitude change*. New York: Wiley.
- Kim, C. S. & Rhee, K. (1999). Living Arrangements in Old Age: Views of Elderly and Middle Aged Adults in Korea. *Hallym International Journal of Aging*, 1, 95-111.
- Kim, J. H. (2011). Perception of hospice among nursing university student's in Chungcheong province. Unpublished master's thesis, Hanyang University, Seoul, South Korea.

- Kim, M. J. (2007a). A study on hospital staff's perception of death and hospice. *Korea J Hops Palliat Care*, 7(2), 15-25.
- Kim, M. J. (2007b). A study in intensive care unit nurses' perception of and attitudes towards death, Unpublished master's thesis, Kyunghee University, Seoul, South Korea
- Kim, O. K. (2002). A study of medical profession's knowledge and attitudes to hospice home care. *Korean J Hops Palliat Care*, 2(2), 28-48.
- Kim, S. H. (2011). Factors influencing preferences of Korea people toward advance directives. *Nursing Ethics*, 18(4), 505-513.
- Kim, S. K., Chang, K. S., Lee, H. S., Chung, K. S., Cho, A. J., & Song, I. J. (2000). *The change of family in Korea*. Korea institute for health and affairs.
- Kitayama, S. (2002). Culture and basic psychological processes--Toward a system view of culture: Comment on Oyserman et al. (2002). *Psychological Bulletin*, 128 (1), 89-96.
- Klagsbrun, S. C. (1971). Communications in the treatment of terminal cancer. *American Journal of Nursing*, 71(5), 944-948.
- Ko, E. E., & Berkman, C. S. (2010). Role of children in end-of-life treatment planning among Korean American older adults. *Journal of Social Work in End-of-Life & Palliative Care*, 6(3-4), 164-184.
- Ko, E., & Lee, J. (2009). End-of-life communication: Ethnic differences between Korean-American and Non-Hispanic White older adults. *Journal of Aging and Health*, 21(7), 967-984.
- Koenig, B., & Gates-Williams, J. (1995). Understanding cultural difference in caring for dying patients. *The Western Journal of Medicine*, 163(3), 244-249.

Korea Association of Social Workers [KASW]. (2011). Code of Ethics.

Retrieved from, <http://www.welfare.net/site/ViewMoralCode.action>

Korea Association of Social Workers [KASW], (2011). The qualification of social worker in Korea.

Retrieved August 1, 2011, from,

<http://lic.welfare.net/lic/ViewCertCriteriaPerGrade.action>

Korean Society for Hospice and Palliative Care [KSHPC]. (2004). Hospice agency.

Retrieved from <http://www.hospicecare.co.kr>.

Kovacs, P. J., & Bronstein, L. R. (1999). Preparation for oncology settings: what hospice social workers say they need. *Health & Social Work, 24(1)*, 57-64.

Krakauer, E. L., Crenner, C., & Fox, K. (2002). Barriers to optimum end-of-life care for minority patients. *Journal of the American Geriatrics Society, 50(1)*, 182-190.

Kramer, B. J. (1998). Preparing social workers for the inevitable: A preliminary investigation of a course on grief, death, and loss. *Journal of Social Work Education, 34(2)*, 211-277.

Kramer, B. J. (2002). *End-of-life care content guidelines for social work*. Madison: University of Wisconsin School of Social Work.

Kramer, B. J., Pacourek, L., & Hovland-Scafe, C. (2003). Analysis of end-of-life content in social work textbooks. *Journal of Social Work Education, 39*, 299-320.

Kreling, B. S. (2010). 'The worst thing about hospice is that they talk about death: contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliative Medicine, 24(4)*, 427-434.

Kreling, B., Selsky, C., Perret-Gentil, M., Huerta, E. E., & Mandelblatt, J. S. (2010). The worst thing about hospice is that they talk about death': contrasting hospice decisions and



- experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliative Medicine*, 24(4), 427-434.
- Kroeber, A., & Kluckhohn, C. (1952). *Culture: A Critical Review of Concepts and Definitions*. Cambridge, Mass.
- Kulys, R., & Davis, M. (1986). An Analysis of Social Services in Hospices. *Social Work*, 31(6), 448-456.
- Kumasaka, L. (1996). My pain is Gods will. *The American Journal of Nursing*, 96(6), 45-47.
- Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45(5), 634-641.
- Kwak, J., Haley, W. E., & Chiriboga, D. A. (2008). Racial differences in hospice use and in-hospital death among Medicare and Medicaid dual-eligible nursing home residents. *The Gerontologist*, 48(1), 32-41.
- Kwak, J., & Salmon, J. R. (2007). Attitudes and preferences of Korean-American older adults and caregivers on end-of-life care. *J Am Geriatr Soc*, 55(11), 1867-1872
- Kwon, B. K. (2007). A study on medical students' perception of death and hospice. Unpublished master's thesis, Kyunghee University, Seoul, South Korea.
- Kwon, S (2012). Presentation at the 23<sup>rd</sup> Annual Southeastern Student Mentoring Conference in Gerontology & Geriatrics, "Careers in Aging," Atlanta, GA, USA, March 30–31, 2012
- Kwon, S (2012). Poster presented at the 12<sup>th</sup> Annual Interdisciplinary Conference, The University of Georgia, Athens, GA, USA
- Kyung, M. H., Jang, Y. M., Han, K. H., Yoon, Y. H. (2010). Current status and activation plan of hospice palliative care in Korea-based on hospice palliative care facilities surveys. *Korean J Hosp Palliat Care*, 13(3), 143-152.

- Lacey, D. (2002). Skilled Nursing Home Social Workers and End-of-Life Decision-Making for Nursing Home Residents with Dementia. Unpublished dissertation. State University of New York at Albany, NY.
- Lacey, D. (2005). Nursing home social worker skills and end-of-life planning. *Social Work in Health Care, 40(4)*, 19-40.
- Lacey, D. (2006). End-of-Life Decision Making for Nursing Home Residents with Dementia: A Survey of Nursing Home Social Services Staff. *Health & Social Work, 31(3)*, 189.
- Lapine, A., Wang-Cheng, R., Goldstein, M., Nooney, A., Lamb, G., & Derse, A. (2001). When cultures clash: physician, patient, and family wishes in truth disclosure for dying patients. *Journal of Palliative Medicine, 4(4)*, 475-480.
- Larson, D. G., & Tobin, D. R. (2000). End-of-life conversations. *Journal of American Medical Association, 284(12)*, 1573-1578.
- LeBaron, M., & Pillay, V. (2006). *Conflict across cultures: A unique experience of bridging difference*. Yarmouth, ME: Intercultural Press
- Lee, K. J. (1998). An approach and intervention of clinical social work to develop the hospice care in Korea. Unpublished master's Thesis, JungYang University, South Korea.
- Lee, K. S. (2009). Standardization of management guideline and development of efficient health care delivery system on hospice palliative medicine. Health Care Insurance, Ministry of Health and Welfare, South Korea.
- Lee, K. S, Joo, J., Kim, J. H, & Kim, K. Y. (2008). Current Status and challenge of hospice palliative care in Korea. *Korean J Hosp Palliat Care, 11*, 196-205.
- Lee, W. H. & Lee, C. G. (2005). Development of a clinical protocol for home hospice care for Koreans. *Yonsei Medical Journal, 46(1)*, 8-20.

- Lee, Y. S. (2001). The qualification and role of hospice social worker. *Korean Journal Hospice Palliative Care*, 4(1).
- Lee, Y. S. (2008). Current status of palliative social worker education: Hospice & palliative care professional workshop for planning standard training program delivery. National Cancer Center, Korea.
- Lew, S. K. (1995). *Filial piety and human society: in filial piety and future society* [Hyo-wa Mirae-sahoe] (pp. 19-36), Kyunggido, Korea: The Academic of Korea Studies
- Ling, J. (2010). Ranking palliative and end-of-life care. *International Journal of Palliative Nursing*, 16(8), 367.
- Longman, P. (2010). Global aging. *Foreign Policy*, (182), 52-58.
- Low, J. K. (1997). Religious orientation and pain management. *The American Journal of Occupational Therapy*, 51(2), 215-219.
- Ludke, R., & Smucker, D. (2007). Racial differences in the willingness to use hospice services. *Journal of Palliative Medicine*, 10(6), 1329-1337.
- Luptak, M. (2004) 'Social Work and End-of-life Care for Older People: A Historical Perspective.' *Health and Social Work*, 29(1), 7-15.
- Luptak, M. (2006) End-of-life care preferences of older adults and family members who care for them. *Journal of Social Work in End-of-Life and Palliative Care*, 2(3), 23-44.
- Lutz, W. (2008). The coming acceleration of global population ageing. *Nature*, 451(7179), 716-769.
- Mally, T. R., Wigton, R. S., Meeske, J., Tape, T. G. (1992). The influence of treatment descriptions on advance medical directive decisions. *J Am Geriatr Soc* 40, 1255-1260.

- Matsumura, S., Bito, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa-Singer, M., & Wenger, N. (2002). Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. *Journal of General Internal Medicine, 17*(7), 531-539.
- McCormick, A. J. (2011). Self-determination, the right to die, and culture: A literature review. *Social Work, 56*(2), 119-128.
- McCormick, A., Curtis, J., Stowell-Weiss, P., Toms, C., & Engelberg, R. (2010). Improving social work in intensive care unit palliative care: results of a quality improvement intervention. *Journal of Palliative Medicine, 13*(3), 297-304.
- McDermott, E. (2005). *Advocating hospice and palliative care: Challenges, contexts, and changes*. Report of the 2nd Global Summit of National Hospice and Palliative Care Associations, March 2005, Seoul, Korea. Lancaster, UK: International Observatory on End of Life Care.
- Retrieved from, [http://www.eolc-observatory.net/global/pdf/NHPCA\\_2.pdf](http://www.eolc-observatory.net/global/pdf/NHPCA_2.pdf).
- McDermott, G. (2010). State of World Population 2009: A Summary. *Issues, 91*(1), 37-39.
- McLaughlin, L. A., & Braun K. L. (1998) Asian and Pacific Islander cultural values: Considerations for health care decision-making. *Health Social Work, 23*(2), 116-26.
- McWhinney, I. R., Bass, M. J., & Orr, V. (1995). Factors associated with location of death (home or hospital) of patients referred to a palliative care team. *Canadian Medical Association Journal, 152*, 361-367.
- Mezey, M., Dubler, N., Mitty, E., & Brody, A. (2002). What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? *Gerontologist, 42*(5), 4254-4267.

- Mezey, M., Mitty, E., Rappaport, M., & Ramsey, G. (1997). Implementation of the patient self-determination act (PSDA) in nursing homes in New York City. *J Am Geriatr Soc* 45, 43–49.
- Michaelsen, J. Krasnik, A., Nielsen, A., Norredam, M., & Torres, A. M. (2004): Health professionals' knowledge, attitudes, and experience in relation to immigrant patients: a questionnaire study at a Danish hospital. *Scandinavian Journal of Public Health*, 32, 287.
- Ministry of Health and Welfare and Family Affairs. (2007). Main contents of the LTCI for the elderly. Seoul: Ministry for Health, Welfare, and Family Affairs.
- Ministry for Health, Welfare, and Family Affairs. (2009). Performances and the future tasks after one year from the implementation of the LTCI. Seoul: Ministry for Health, Welfare, and Family Affairs.
- Ministry of Health, Welfare, and Family Affairs (2010). Cancer statistics. Seoul: Ministry for Health, Welfare, and Family Affairs.
- Retrieved from, <http://www.cancer.go.kr/cms/statics/incidence/index.html>
- Mitchell, S. L., Teno, J. M., Miller, S. C., & Mor, V. (2005). National study of the location of death for older persons with dementia. *Journal of the American Geriatrics Society*, 53(2), 299-305.
- Mitty, E. L. (2001). Ethnicity and end-of-life decision-making. *Reflections on Nursing Leadership*, 27(1), 28.
- Moller, D. W. (1996). *Confronting death: value, institutions and human mortality*. New York: Oxford University Press.
- Molloy, D., Russo, R., Pedlar, D., & Bédard, M. (2000). Implementation of advance directives among community-dwelling veterans. *Gerontologist*, 40(2), 213-217.

- Moon, A., Lubben, J., & Villa, V. (1998). Awareness and utilization of community long-term care services by elderly Korean and non-Hispanic White Americans... including commentary by Cho PJ. *Gerontologist*, 38(3), 309- 319.
- Moon, D. H., Lee, M. A., Ko, S. J., Choi, Y. S., Kim, S. H., & Yeom, C. H. (2006). Doctor's attitude toward hospice and palliative care for terminal cancer patients. *Korean J Hosp Palliat Care*, 9(2), 93-100.
- Moon, H. (2004). A study on the activation program of Korean hospice management. Unpublished master's Thesis, Chosun University, South Korea.
- Munn, J., & Zimmerman, S. (2006). Defining a good death for residents of long-term care: Family members speak. *Journal of Social Work and End of Life and Palliative Care*, 2(3), 45-59.
- Munn, J., Zimmerman, S., Hanson, L., Williams, C., Sloane, P., Clip, E., Tulsky, J & Steinhauser, K (2007) 'Measuring the Quality of Dying in Long-term Care', *Journal of the American Geriatrics Society* 55(9): 1371-9.
- Murphy, S. T., Palmer, J. M., Azen, S., Frank, G., Michel, V., & Blackhall, L. J. (1996). Ethnicity and advance directives. *Journal of Law and Medical Ethics*, 24, 108-117.
- Nathan Cummings Foundation & Fetzer, I. (1997). Spiritual beliefs and the dying process. A report on a national survey.
- National Association of Social Workers [NASW] (2004) *Standards for Social Work Practice in Palliative and End-of-life Care*. Washington, DC: NASW. Retrieved from, <http://www.socialworkers.org/practice/bereavement/standards/101503.asp?back=yes>
- National Center for Health Statistics (US). Health, United States, 2010: With Special Feature on Death and Dying. Hyattsville (MD): National Center for Health Statistics (US); 2011

Feb. Special Feature on Death and Dying. Available from:

<http://www.ncbi.nlm.nih.gov/books/NBK54374/>

National Consensus Project for Quality Palliative Care (NCP). Clinical Practice Guidelines for Quality Palliative Care (2009). Retrieved October 22, 2012 from,

[http://www.nationalconsensusproject.org/Guidelines\\_Download2.aspx](http://www.nationalconsensusproject.org/Guidelines_Download2.aspx)

<http://www.nationalconsensusproject.org/guideline.pdf>

National Hospice Organization. (1998). *National Hospice Organization Committee on Medicare Hospice Benefit and End-of-Life Care: Highlights of the Final Report*. Arlington, VA: Author.

National Hospice Organization (2010). Hospice factsheet, Arlington, VA: Author. Retrieved from, [http://www.nhpco.org/files/public/statistics\\_research/2011\\_facts\\_figures.pdf](http://www.nhpco.org/files/public/statistics_research/2011_facts_figures.pdf)

National Hospice and Palliative Care Organization [NHPCO] (2011). NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, January 2012.

<http://www.nhpco.org/i4a/pages/index.cfm?pageid=5994>

[http://www.nhpco.org/files/public/Statistics\\_Research/2011\\_Facts\\_Figures.pdf](http://www.nhpco.org/files/public/Statistics_Research/2011_Facts_Figures.pdf)

National Hospice and Palliative Care Organization (2011). The Hospice Team.

Retrieved from, <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3357>

National Hospice Organization (2010). Hospice factsheet, Arlington, VA: Author

National Health Insurance Corporation. (2009). Long-term care insurance for the elderly monthly statistics report, June 2009

Neubauer, B. J., & Hamilton, C. L. (1990). Racial differences in attitudes toward hospice care. *The Hospice Journal*, 6(1), 37-48.

- Ngo-Metzger, Q., McCarthy, E. P., Burns, R. B., Davis, R. B., Li, F. P., & Phillips, R.S. (2003). Older Asian Americans and Pacific islanders dying of cancer use hospice less frequently than older white patients. *American Journal of Medicine*, *115*(1), 47.
- Noggle, B. J. (1995). Identifying and meeting need of ethnic minority patients. *The Hospice Journal*, *10*(2), 85–93.
- Nuyen, A. T. (2004). The contemporary relevance of the Confucian idea of filial piety. *Journal of Chinese Philosophy*, *31*(4), 433-450.
- O'Brien, L., Grisso, J., Maislin, G., LaPann, K., Krotki, K., Greco, P., & ... Evans, L. (1995). Nursing home residents' preferences for life-sustaining treatments. *JAMA: The Journal of the American Medical Association*, *274*(22), 1775-1779.
- Oh, J. T. (2011). Our society lacks greatly in understanding death. *Korean Hosp Palliat Care*, *14*(3), 131-137.
- Okon, T. R. (2005). Palliative Care Review: Spiritual, Religious, and Existential Aspects of Palliative Care. *Journal of Palliative Medicine*, *8*(2), 392-414.
- Orloff, S. F., Quance, K., Perszyk, S., Flowers, W.J., & Veale, E. (2004). Psychosocial and spiritual needs of the child and family. In B.S. Carter & M. Levetown (Eds.). *Palliative care for infants, children, and adolescents: A practical handbook* (pp. 141-162). Baltimore: Johns Hopkins University Press.
- Orona, C., Koenig, B., & Davis, A. (1994). Cultural aspects of nondisclosure. Cambridge Quarterly Of Healthcare Ethics: CQ: *The International Journal of Healthcare Ethics Committees*, *3*(3), 338-346.



- Otis-Green, S., Lucas, S., Spolum, M., Ferrell, B., & Grant, M. (2008). Promoting excellence in pain management and palliative care for social workers. *Journal of Social Work In End-of-Life & Palliative Care*, 4(2), 120-134.
- Palliative Care and End-of-Life Care (2011). National Voluntary Consensus Standards for Palliative Care and End-of-Life Care. Retrieved from, [http://www.qualityforum.org/Projects/Palliative\\_Care\\_and\\_End-of-Life\\_Care.aspx](http://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx)
- Park, M., & Chesla, C. (2007). Revisiting Confucianism as a conceptual framework for Asian family study. *Journal of Family Nursing*, 13(3), 293-311.
- Park, S. M. (2006). Current status on care and management of terminal cancer patients and its future direction. *Korean Hosp Palliat Care*, summer symposium.
- Park, Y., Hwang, S., Choi, Y., Kim, H., Kim, H., Cheon, Y., . . . Lee, H. (2005). Development a curriculum for care manager in long-term care facilities. *Korean Journal of Care Work*, 1, 89-117
- Patrick, D. L., Engelberg, r. A., & Curties, J. R., (2001). Evaluating the quality of death of dying. *Journal of Pain and Symptom Management*, 22(3), 717-726.
- Pearlman, R. A., Cole, W. G., Patrick, D. L., Starks, H. E., & Cain, K. C. (1995). Advance care planning: eliciting patient preferences for life-sustaining treatment. *Excerpta Medica International Congress Series*, 1076353-362.
- Pfeifer, M., Sidorov, J., Smith, A., Boero, J., Evans, A., & Settle, M. (1994). The discussion of end-of-life medical care by primary care patients and physicians: a multicenter study using structured qualitative interviews. The EOL Study Group. *Journal of General Internal Medicine*, 9(2), 82-88.

- Pritchard, R. S., Fisher, E. S., Teno, J. M., Sharp, S. M., Reding, D. J., Knaus, W. A., et al. (1998). Influence of patient preferences and local health system characteristics on the place of death. *Journal of American Geriatrics Society*, *46*, 1242–1250.
- Raymer, M. (1996). Social workers: Death and dying - How social workers help-The role of social work in hospice and palliative care. Retrieved from, [http://www.helpstartshere.org/health\\_and\\_wellness/death\\_and\\_dying/how\\_social\\_workers\\_help/how\\_social\\_workers\\_help.html](http://www.helpstartshere.org/health_and_wellness/death_and_dying/how_social_workers_help/how_social_workers_help.html)
- Raymer, M. (2011). Death and dying-how social workers help-the role of social work in hospice and palliative care. Retrieved from, <http://www.helpstartshere.org/health-and-wellness/death-and-dying-how-social-workers-help-the-role-of-social-work-in-hospice-and-palliative-care.html>
- Reamer, F. G. (1998). The Evolution of Social Work Ethics. *Social Work*, *43*(6), 488-500.
- Reese, D. D. (1995). Testing of a causal model: Acceptance of death in hospice patients. *Omega: Journal of Death and Dying*, *32*(2), 81-92.
- Reese, D. (2000). The role of primary caregiver denial in inpatient placement during home hospice care. *The Hospice Journal*, *15*(1), 15-33.
- Reese, D., Ahern, R., Nair, S., O'Faire, J., & Warren, C. (1999). Hospice access and use by African Americans: addressing cultural and institutional barriers through participatory action research. *Social Work*, *44*(6), 549-559.
- Reese, D. J., Chan, C. W., Perry, D. C., Wiersgalla, D., & Schlinger, J. M. (2005). Beliefs, Death Anxiety, Denial, and Treatment Preferences in End-of-Life Care: A Comparison of Social Work Students, Community Residents, and Medical Students. *Journal of Social Work In End-of-Life & Palliative Care*, *1*(1), 23-47.

- Reese, D. J., & Sontag, M. A. (2001). Successful interprofessional collaboration on the hospice team. *Health & Social Work, 26*(3), 167-175.
- Reiner, S. M. (2007). Religious and spiritual beliefs: an avenue to explore end-of-life issues. *ADULTSPAN Journal, 6*(2), 111-118.
- Reith, M., & Payne, M. (2009). *Social work in end-of-life and palliative care*. Chicago: Lyceum Books Inc.
- Rhodes, R., Teno, J., & Welch, L. (2006). Access to hospice for African Americans: are they informed about the option of hospice? *Journal of Palliative Medicine, 9*(2), 268-272.
- Rhymes, J. (1996). Barriers to effective palliative care of terminal patients. An international perspective. *Clinics in Geriatric Medicine, 12*(2), 407-416.
- Rodriguez, K., Barnato, A., & Arnold, R. (2007). Perceptions and utilization of palliative care services in acute care hospitals. *Journal of Palliative Medicine, 10*(2), 99-110.
- Rosenfeld, P., Dennis, J., Hanen, S., Henriquez, E., Schwartz, T., Correoso, L., Murtaugh, C., & Fleishman, A. (2007). Are there racial differences in attitudes toward hospice care?: A study of hospice-eligible patients at the visiting nurse service of New York. *American Journal of Hospice and palliative care, 20*(10), 1-9.
- Rosler, O.E. (1987). A rational and moral and spiritual dilemma. In: *Personal and Spiritual Development in the World of Cultural Diversity* (G.E. Lasker and K. Hiwaki, eds.), 5, 61-66.
- Schim, S., Jackson, F., Seely, S., Grunow, K., & Baker, J. (2000). Knowledge and attitudes of home care nurses toward hospice referral. *Journal of Nursing Administration, 30*(5), 273-277.

- Seale, C. (2000) 'Changing Patterns of Death and Dying', *Social Science and Medicine* 51, 917–30.
- Searight, H., & Gafford, J. (2005). "It's like playing with your destiny": Bosnian immigrants' views of advance directives and end-of-life decision-making. *Journal of Immigrant Health*, 7(3), 195-203.
- Seo, M., Tamura, K., Morioka, E., & Shijo, H. (2000). Impact of medical round on patients' and residents' perceptions at a university hospital in Japan. *Medical Education*, 34(5), 409-411.
- Seok, J. E. (2010). Public long-term care insurance for the elderly in Korea: Design, characteristics, and tasks. *Social Work in Public Health*, 25(2), 185-209.
- Sepúlveda, C., Marlin, A., Yoshida, T., & Ullrich, A. (2002). Palliative Care: The World Health Organization's Global Perspective. *Journal of Pain and Symptom Management*, 24(2), 91-96.
- Shepherd Johnson, L. (2003). Facilitating spiritual meaning-making for the individual with a diagnosis of a terminal illness. *Counseling And Values*, 47(3), 230-240.
- Shin, D. W., Choi, J. Y., Nam, B. H., Seo, W. S., Kim, H. Y., Hwang, E. J, ... & Park, E. C. (2010). The current status of utilization of palliative care units in Korea: Six months results of 2009 Korean terminal cancer patient information system. *Korean J Hosp Palliat Care*, 13, 181-189.
- Shrank, W. H., Kutner, J. S., Richardson, T., Mularski, R. A., Fischer, S., & Kagawa-Singer, M. (2005). Focus group findings about the influence of culture on communication preferences in end-of-life care. *Journal of General Internal Medicine*, 20, 703–709.

- Silveira, M. J., DiPiero, A., Gerrity, M. S., Feudtner, C. (2000). Patients' knowledge of options at the end of life: ignorance in the face of death. *JAMA*, *284*(19), 2483-2488.
- Silveira, M., Kim, S., & Langa, K. (2010). Advance directives and outcomes of surrogate decision making before death. *The New England Journal of Medicine*, *362*(13), 1211-1218.
- Simons, K. K., & Park-Lee, E. E. (2009). Social work students' comfort with end-of-life care. *Journal of Social Work In End-of-Life & Palliative Care*, *5*(1-2), 34-48.
- Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association*, *281*, 163–168.
- Smith, A. K., Earle, C. C., & McCarthy, E. P. (2009). Racial and Ethnic Differences in End-of-Life Care in Fee-for-Service Medicare Beneficiaries with Advanced Cancer. *Journal of The American Geriatrics Society*, *57*(1), 153-158.
- Smith, A. K., Sudore, R. L., & Pe´rez-Stable, E. J. (2009). Palliative care for Latino patients and their families: Whenever we prayed, she wept. *JAMA*, *301*(10), 1047–1057.
- Smith, C., & Hung, L. (2012). The Influence of Eastern Philosophy on Elder Care by Chinese Americans: Attitudes Toward Long-Term Care. *Journal of Transcultural Nursing*, *23*(1), 100-105.
- Social Work Policy Institute (2011). Social work services in nursing homes: Toward quality of psychosocial care. Retrieved March 10, 2012, from <http://www.socialworkpolicy.org/research/social-work-services-in-nursing-homes-toward-quality-psychosocial-care.html>
- Sperber, A. D. (2004) Translation and validation of study instruments for cross-cultural research. *Gastroenterology*, *124*, S124-128.

- Statistics Korea (2011). *Death statistics in 2010*. Statistics Korea [in Korean], Daejeon
- Steinberg, S. M. (2011). Cultural and religious aspects of palliative care. *International Journal of Critical Illness and Injury Science, 1*(2), 154-156.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M. M., McIntyre, L. L., Tulsky, J. A., & ... Tulsky, J. A. (2000). End-of-Life Survey. *Journal of the American Medical Association, 284*, 2476-2482.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Grambow, S., Parker, J., & Tulsky, J. A. (2001). Preparing for the end of life: Preferences of patients, families, physicians, and other care providers. *Journal of Pain and Symptom Management, 22*(3), 727-737.
- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., et al. (2004). *Measuring quality of life at the end of life: validation of the QUAL-E, Palliative Support Care, 2*(1), 3-14.
- Sung, K. (1995). Measures and dimensions of filial piety in Korea. *Gerontologist, 35*, 240-247.
- Sung, K. T. (1998). An exploration of actions of filial piety. *Journal of Aging Studies, 12*, 369-386.
- Sung, K. T. (2001). Elder respect: Exploration of ideals and forms in East Asia, *Journal of Aging Studies, 15*, 13-27.
- Tang, S. T. (2003). When death is imminent, where terminally ill cancer patients prefer to die and why. *Cancer Nursing, 26*, 245-251.
- Tennstedt, S. L. (2002). Commentary on 'Research Design in End-of-Life Research: State of Science'. *Gerontologist, 42*99-103.
- Teno, J. M (1998). Looking beyond the "From" to complex interventions needed to improve end-of-life care. *Journal of the American Geriatrics Society, 46*(9), 1170-1171.

- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2010). *Family perspectives on end-of-life care at the last place of care*. In D. E. Meier, S. L. Isaacs, R. G. Hughes, D. E. Meier, S. L. Isaacs, R. G. Hughes (Eds.), *Palliative care: Transforming the care of serious illness* (pp. 235-245). San Francisco, CA US: Jossey-Bass.
- Tervalon, M. & Murray-García, J. (1998). Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved, May 9(2)*, 117-25.
- Trill, M. D., & Holland, J. (1993). Cross-cultural differences in the care of patients with cancer: a review. *Gen Hosp Psychiatry, 15*, 21-30
- Touhy, T. A., Brown, C., & Smith, C. J. (2005). Spiritual caring: End of life in a nursing home. *Journal of Gerontological Nursing, 31(9)*, 27–35.
- Twycross, R. G. (1995). *Introducing palliative care*. Oxford; New York: Radcliffe Medical Press.
- Twycross, R. G. (2002). Palliative Care: An International Necessity. *Journal of Pain & Palliative Care Pharmacotherapy, 16(1)*, 61.
- United Nations [UN]. (2005). *World population Prospects: The 2004 Revision*, New York: UN
- United Nations [UN]. (2009). *World Population Aging*. Retrieved, March 12, 2012 from, [http://www.un.org/esa/population/publications/WPA2009/WPA2009\\_WorkingPaper.pdf](http://www.un.org/esa/population/publications/WPA2009/WPA2009_WorkingPaper.pdf)
- U.S. General Accounting Office [GAO] (1979). *Hospice Care--A Growing Concept in the United States*. Retrieved from, <http://archive.gao.gov/f0302/108711.pdf>
- Van Ness, P. H., Towle, V. R., O'Leary, J. R., & Fried, T. R. (2008). Religion, Risk, and Medical Decision Making at the End of Life. *Journal of Aging and Health, 20(5)*, 545-559.

- Volker, D. L. (2005). Control and end-of-life care: Does ethnicity matter? *American Journal of Hospice & Palliative Medicine*, 22(6), 442–446.
- Waters, M. C. (1999). *Black Identities: West Indian Immigrant Dreams and American Realities*. Cambridge, MA: Harvard University Press.
- Werner, P., & Carmel, S. (2001a). End-of-life decision making: Practices, beliefs and knowledge of social workers in health care settings. *Educational Gerontology*, 27(5), 387-398.
- Werner, P., & Carmel, S. (2001b). Life-sustaining treatment decisions: Health care social workers' attitudes and their correlates. *Journal of Gerontological Social Work*, 34(4), 84-97.
- Whitaker, T., Weismiller, T., & Clark, E. (2006). *Assuring the sufficiency of a frontline workforce: A national study of licensed social workers*. Washington, DC: National Association of Social Workers.
- Worcester, A. (1945). *The care of the aged, the dying and the dead*. Springfield, Ill., Thomas.
- World Health Organization [WHO]. (2004). *Revised Global Burden of Disease Estimates 2002*. Geneva: WHO.
- WHO. (2007). Cancer Control: Knowledge into action; WHO guide for effective programmes; Module 5
- WHO. (2011). Palliative care for older people; better practices. Retrieved from, [http://www.euro.who.int/\\_data/assets/pdf\\_file/0017/143153/e95052.pdf](http://www.euro.who.int/_data/assets/pdf_file/0017/143153/e95052.pdf)
- World Population Ageing, 1950-2050 (2002). United Nations, New York, NY.  
Retrieved from, <http://www.un.org/esa/population/publications/worldageing19502050/>
- World Population Ageing (2007). *United Nations, Dept. of Economic and Social Affairs, Population Division*, New York, NY



- Wright, M., Wood, J., Lynch, T., & Clark, D. (2008). Mapping levels of palliative care development: a global view. *Journal of Pain & Symptom Management, 35*(5), 469-485.
- Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., & ... Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of the American Medical Association, 300*(14), 1665-1673.
- Xakellis, G., Brangman, S. A., Hinton, W., Jones, V. Y., Masterman, D., Pan, C. X., & ... Yeo, G. (2004). Curricular framework: core competencies in multicultural geriatric care. *Journal of the American Geriatrics Society, 52*(1), 137-142.
- Yoo, H. S. (2008). A Study on the Hospice Service in the elderly welfare facilities. Unpublished master's thesis, Samyook University, Seoul, South Korea.
- Yoo, K. (2010). National Cancer Control Program in Korea. Retrieved from, <http://www.pitt.edu/~super4/41011-42001/41041-41051.pdf>
- Yoon, Y. H., Lee, Y. S., Nam, S. Y., Cha, Y. M., Heo, D. S., Lee, S. W., Hong, Y. S., Kim, S. T., & Lee, K. S. (2004). Public attitude toward dying with dignity and hospice and palliative care. *Korean J Hosp Palliat Care, 7*(1), 17-28.
- Yun, Y. H., Choi, E. S., Lee, J. I., Rhee, Y. S., Lee, J. S., You, C. H., Kim, H. S., & Paek, Y. J. (2002). Survey on quality of hospice palliative program in Korea. *Korean J Hosp Palliat Care, 31*-42.

APPENDICES

## APPENDIX A

## QUESTIONNAIRE (ENGLISH)

## Section 1: Experience with Hospice Care

*Experiences with Hospice Care***1. Years of Experience at social welfare facility for aged individuals (Please circle one)**

- 1–2 years working
- 3–5 years working
- 5–10 years working
- More than 10 years working

**2. Have you heard of hospice care? (Please circle one)**

- I have never heard of hospice care.
- I have heard about hospice care.
- I have heard and know a lot about hospice care.

**3. If yes, how did you learn about the hospice services? (Please circle all that apply)**

- I know someone who used hospice services (Direct/ indirect experiences).
- I heard about hospice care from a class in social work school (Undergraduate or graduate level).
- I heard from training and experiences in the social work field.
- I heard about hospice from the radio, television, newspaper, or Web.
- I heard about hospice from other health-care professionals (i.e., doctor, nurse, other health-care professionals).
- I heard from others outside health care. (Please identify) \_\_\_\_\_

**4. Have you worked with clients who were terminally ill or who were near death? (Please circle one)**

- Yes**
- No**

If you say, “yes,” Please **specify** the service provided (Please circle all that apply)

- (1) Symptom management such as relaxation exercise
- (2) Ethical dilemmas such as withdrawing or withholding treatment
- (3) Financial stress such as navigating resources’ health coverage and medical costs
- (4) Advance care planning
- Grief and bereavement such as emotional support (Raymer, M., 2011)

5. Have you ever attended a class or formal training program including seminars related to end-of-life care? (Please circle one)

Yes ( )                      No ( )

If you indicate "Yes," please specify the name of the class \_\_\_\_\_  
Or the name of the formal training program \_\_\_\_\_

## Section 2: Knowledge and Attitudes regarding Hospice Care

The purpose of the survey is to measure an individual's attitude of hospice care among social workers who work with older adults.

**Hospice care is the active total care of patients whose disease no longer responds to curative treatment. It focuses on controlling pain and other symptoms and is concerned with the quality of life remaining, integrating the psychological and spiritual aspects of care.**

- For the set of statements about hospice, you should respond as follows depending on how much you agree or disagree with the statement. There is no right or wrong answer; **please circle one of a 5 point Likert scale.**

	Strongly Disagree			Strongly Agree	
<b>Knowledge of hospice and palliative care</b>					
<b>1. Hospice care is a service to aid individuals with a life-limiting illness and their family by providing medical, social, emotional, and spiritual support.</b>	1	2	3	4	5
<b>2. Hospice care helps people die with dignity and comfort.</b>	1	2	3	4	5
<b>3. Services are performed by the interdisciplinary team with a nurse, a doctor, a pastor, and a social worker.</b>	1	2	3	4	5
<b>4. Hospice is for those whose life expectancy is 6 months or less.</b>	1	2	3	4	5
<b>5. Hospice care is more focused on comfort throughout pain management rather than trying to cure.</b>	1	2	3	4	5
<b>6. Hospice serves patients and their family.</b>	1	2	3	4	5
<b>7. Services are extended to bereavement of the family after facing death.</b>					
<b>Attitude</b>					
	1	2	3	4	5
<b>1. Death is a normal part of living.</b>	1	2	3	4	5
<b>2. Patient should prepare mentally and spiritually for death.</b>	1	2	3	4	5
<b>3. Care in the home maximizes patient's dignity.</b>	1	2	3	4	5
<b>4. Death is the final stage.</b>	1	2	3	4	5
<b>5. Achieving a good death is goal.</b>					

	Strongly Disagree		Strongly Agree		
<b>6. An interdisciplinary team is best.</b>	1	2	3	4	5
<b>7. Death with dignity is central to hospice care.</b>	1	2	3	4	5
<b>8. One should live life as fully as possible while dying.</b>	1	2	3	4	5
<b>9. Hospice does not influence extending life or promote the dying process.</b>	1	2	3	4	5
<b>10. The patient/family must be partners in plan of care.</b>	1	2	3	4	5
<b>11. If I had a terminal illness, I would want hospice care.</b>	1	2	3	4	5
<b>12. If I had a serious illness (like cancer) that doctors could not cure, I would best cared for by friends or family.</b>	1	2	3	4	5
<b>13. With hospice care, you do not receive treatment to stay alive.</b>	1	2	3	4	5
<b>14. People who receive hospice care have given up all hope of living.</b>	1	2	3	4	5
<b>15. People receiving hospice care die before they should.</b>	1	2	3	4	5
<b>16. Hospice care is unpopular with the culture I belong in.</b>	1	2	3	4	5
<b>17. I want to use all opportunities to live as long as I can, even if it is painful.</b>	1	2	3	4	5
<b>18. It is not proper for patients' families to allow terminal cancer patients to receive hospice and</b>	1	2	3	4	5

palliative care as formal service.

19. Hospice care is not important to my family because I will take care of them if the need arises. 1 2 3 4 5

### Section 3: Level of Comfort

1. I feel comfortable discussing the topic of death and dying in general. 1 2 3 4 5

Strongly  
Disagree

Strongly  
Agree

2. I feel comfortable discussing death and dying with older adults who are in institutions. 1 2 3 4 5

3. I worry that my client feels unpleasant or upset when I start discussion on the topic death and dying. 1 2 3 4 5

### Section 4: Role of Social Work in End-of-Life Care

1. As a geriatric social worker, do you think you have a responsibility to provide psychosocial care for clients' end-of-life issues? (Please circle one of a 5 point Likert scale) 1 2 3 4 5

· If not, who should be engaged in the issue? 1 2 3 4 5

(Please circle all that apply)

1) Doctor 2) Nurse 3) Clergyman

4) Family membe 5) Other

2. I feel that I am ready to help dying clients and their families with psychosocial or psychological support. (Please circle one)      1      2      3      4      5

3. I am willing to provide end-of-life care (ex, education for a good death, or counseling regarding death, dying, end-of-life care) in the geriatric gerontology facilities if needed.      1      2      3      4      5

(Please circle one)

### Section 5: Professional Values on Self-Determination

1. What is your definition of “Self-determination”? (Please write down)

→

2. Let’s assume you are in a situation where terminally ill patient needs to have end-of-life decision. What do “you” think about “who” should be involved in the decision-making process? (There is no right or wrong answer; please circle one of the items.)

- **Clients alone**
- **Clients and family member, if you choose this**, which family member? (Please circle all that apply)
  - 1) Wife/husband or partner
  - 2) Adult son
  - 3) Adult daughter
  - 3) Close relatives
  - 4) Significant others such as friends, priest, etc.
- **Only family members and patient’s doctor (without informing the client)**
  - Please provide a reason not to inform patients (Please circle all that apply)
    - 1) Not to give feeling of abandonment to patients
    - 2) Not to give feeling of fear regarding a death
    - 3) Not to worsen the patient’s health condition after knowing he or she is terminally ill by increasing stress
    - 4) Other \_\_\_\_\_

3. If I were terminally ill patient, I want to know exactly information what to expect physically.

(Please circle one)



1=*strongly disagree*      2=*disagree*      3=*neutral*      4=*agree*      5=*strongly agree*

4. If I were terminally ill patient, I want **doctor** to antecedently tell me about the exact information.

(Please circle one)

1=*strongly disagree*      2=*disagree*      3=*neutral*      4=*agree*      5=*strongly agree*

5. If I were terminally ill patient, I want my family member to antecedently tell me about the exact information.

(Please circle one)

1=*strongly disagree*      2=*disagree*      3=*neutral*      4=*agree*      5=*strongly agree*

6. If my family member were terminally ill patient, I will let him. Her know the exact information what to expect physically.

(Please circle one)

1=*strongly disagree*      2=*disagree*      3=*neutral*      4=*agree*      5=*strongly agree*

**\* Self-determination in social work practice**

7 “**Self-determination**” is an important ethical principle in my social work practice.

(Please circle one)

1=*strongly disagree*      2=*disagree*      3=*neutral*      4=*agree*      5=*strongly agree*

8. If I were situated in a self-determination conflict such as involuntary decision making with end-of-life issues, I will feel troubled. (Please circle one)

1=*strongly disagree*      2=*disagree*      3=*neutral*      4=*agree*      5=*strongly agree*

## Section 6: Advance Care Planning and Advance Directives

### 1. Have you heard of advance directives? (Please circle one)

- (1) I have never heard of advance directives.  
 (2) I have heard about advance directives  
 (3) I have heard and know a lot about advance directives  
 If you choose number (2) or (3), please **write down** about where you heard

▪ \_\_\_\_\_

### 2. Here is example of medical technologies that may be used on dying people.

**Please check all if you know about**

- (    ) **Cardiopulmonary resuscitation (CPR):** Efforts to start breathing or heartbeat to a person in cardiac or respiratory arrest.  
 (    ) **Mechanical ventilation:** Use of an artificial breathing machine (respirator).  
 (    ) **Dialysis:** Removal of waste, salts, and extra liquid from blood by artificial means when the kidneys fail.  
 (    ) **Tube-feeding:** Liquid (Hydration) or food (fluid nutrients or nutrition) administered through a tube that is put into the person's body, tube-feeding can be used for either a short or long period of time.  
 (    ) **I do not know all that above**

Advance care planning (ACP) is a process of exploring treatment options, discussing or communicating medical treatment and documenting preference with a legal statement regarding end-of-life care.

- For the set of statements regarding advance care planning and advance directives, you should respond as follows depending on how much you agree or disagree with the statement. There is no right or wrong answer; please circle one of the 5 Likert scale.

	<b>Strongly</b>		<b>Strongly</b>		
	<b>Disagree</b>		<b>Agree</b>		
<b>1. Discussing death and dying bring misfortune.</b>	1	2	3	4	5
<b>2. It is the most important for me to make an end-of-life decision based on my wishes.</b>	1	2	3	4	5
<b>3. It is important to involve a friend or family member in end-of-life care decisions before a final decision is made.</b>	1	2	3	4	5

<b>4. If there are conflicts about the end-of-life decision, my wishes should be given priority.</b>	1	2	3	4	5
<b>5. I prefer to have someone close to me make important decisions for me.</b>	1	2	3	4	5
<b>6. It is important to plan for the future.</b>	1	2	3	4	5
<b>7. Planning or communication for death could make it happen sooner.</b>	1	2	3	4	5
<b>8. Completing an advance directive will help to ensure that my wishes are followed if I could no longer speak for myself.</b>	1	2	3	4	5
<b>9. Completing an advance directive will give doctors a reason to stop caring for me even if I needed the treatment.</b>	1	2	3	4	5
<b>10. If I do not write my end-of-life care wishes down, my family members may not do what's the best for me when the time comes.</b>	1	2	3	4	5
<b>11. There is no need to plan for end-of-life because God will take care of everything.</b>	1	2	3	4	5
<b>12. I am willing to complete advance directive for myself.</b>	1	2	3	4	5
<b>13. I am willing to provide or encourage advance directive planning for clients who I am working with.</b>	1	2	3	4	5

---

## Section 7: Participant's Characteristics

**1. Gender:** Male (    ) Female (    )

**2. Age** \_\_\_\_\_

### **3. Education Level**

(1) Highest level of education achieved related to social work **(Please circle one)**

- Some college or technical school
- College degree
- Graduate degree

(2) Social work license grade **(Please circle one)**

- First-grade social work license
- Second-grade social work license

**4. Are you currently living with an “elder parent” in the household? (Please check one)**

Yes (    )                      No (    )

**5. What is your current marital status? (Please circle one)**

- (1) Married
- (2) Unmarried (single, divorced)

**6. Please check religious affiliation (Please check one)**

- (    ) Christianity
- (    ) Catholic
- (    ) Buddhism
- (    ) Won Buddhism
- (    ) Agnostic
- (    ) Others \_\_\_\_\_

### **7. Job description**

(1) Type of facilities **(Please circle one)**

- Nursing and rehabilitation center or nursing home
- Hospital
- Old adult recreation / leisure facilities
- Other\_(please specify)\_\_\_\_\_

(2) Job Position (**Please circle one**)

- I directly interact with older adults
- I work indirectly with older adults as an administrator

(3) Job title (**Please write down**)

I work as a\_\_\_\_\_ at my facility

(Example: A senior social worker, clinical social worker, supervisor, case manager, counseling worker, director, etc.)

**Thank you for your participation! ☺**

## APPENDIX B

### INTRODUCTION LETTER OF STUDY (KOREAN)

안녕하십니까?

본 설문은 미국 University of Georgia 박사 논문 프로젝트로 미국 심의위원회(Institutional Review Board)의 연구승인을 받고 미국 University of Georgia, Dr. Stacey Kolomer, Dr. Anne Glass, and Dr. Edwin Risler 교수님 감수 하에 진행되고 있습니다.

전세계적인 고령화 현상과 함께 좋은 죽음(well-dying) 또는 성숙한 임종문화에 대한 개인적, 사회적, 국제적 관심과 요구가 증가하고 있습니다. 미국을 비롯한 여러 나라에서는 좋은 죽음을 행복한 삶의 완성으로 보며, 임종 케어와 그 계획에 대한 관심과 심리 사회적 지원을 노인 전문 사회복지사의 영역으로 확대하고, 그 역할을 강조하고 있습니다. 특히 한국사회는 세계 어느 나라 보다 빠르게 초고령화가 진행되고 있으며, 문화적 특수성을 감안한 성숙한 임종문화와 좋은 죽음(well-dying)에 대한 고찰과 노력, 또한 노인 전문 사회복지사의 역할과 임무의 중요성과 필요성이 점차 인식되어 가고 있습니다.

이 설문은 이러한 한국 사회변화와 요구에 대비하여 노인복지 기관 및 시설에서 일하는 사회복지사들을 대상으로 죽음, 또는 그와 관련된 서비스에 대해 어떤 개인적인 생각과 태도를 가지고 있는지 알아보고자 합니다. 각각의 질문에 대한 정답이나 오답은 없으며, 자신이 그 질문에 얼마나 동의하는지 또는 얼마나 동의하지 않는지에 대해 자신의 생각을 표시해 주시기 바랍니다.

일곱 개의 섹션으로 이루어진 설문지로 20분 정도의 시간을 할애할 것으로 예측됩니다. 설문 참여를 동의하시면 뒷장의 영문의 동의서에 귀하의 성명과 서명을 해주시기 바랍니다. 자발적인 동의에 의한 설문참여이므로 언제든지 중단하거나 거부할수 있습니다. 이 설문은 직위와 관계없이 현재 노인복지 기관 및 시설에서 근무하며, 1급 또는 2급에 해당하는 사회복지사 자격증을 소지하신 사회복지사를 대상으로 하고 있습니다. 초고령화 사회를 앞둔 한국사회의 성숙하고 적극적인 임종문화 이해와 발전을 도모하기 위한 내용임을 주지하시고 적극적으로 참여해 주시기를 부탁드립니다. 설문 중 다른 질문이 있으시면 언제든지 아래의 이메일 [sak398@uga.edu](mailto:sak398@uga.edu)이나 핸드폰 010-90x7-xxxx로 문의바랍니다. 감사합니다.



## APPENDIX D

### QUESTIONNAIRE (KOREAN)

#### 섹션1: 사회복지사의 경험 (Experiences with Hospice Care)

해당사항에 동그라미 (O) 표시해 주세요)

##### 1. 노인복지시설에서 귀하의 근무경력

- (1) 1-2 년 근무
- (2) 3-5 년 근무
- (3) 5-10 년 근무
- (4) 10 년 이상 근무

##### 2. 호스피스 케어에 대하여 들어본 적이 있습니까?

- (1) 들어본 적이 없다.
- (2) 들어본 적이 있다.
- (3) 잘 알고 있다.

##### 3. 들어본 적이 있다면, 어떤 경로를 통해서 알게 되었습니까? (해당 사항을 모두 선택하시오)

- (1) 직접/ 간접경험 (예: 호스피스 케어 서비스를 받았던 사람을 보았다).
- (2) 대학 또는 대학원 학교수업과정을 통해 알게 되었다
- (3) 사회복지 현장실습이나 실무교육 또는 경험을 통해 알게 되었다
- (4) 라디오, 텔레비전, 신문, 혹은 웹 사이트를 통해 알게 되었다
- (5) 병원 또는 의료 종사자들로부터 (예, 의사, 간호사, 기타 의료인)
- (6) 위에 제시되어 있지 않은 다른 경로를 통하여 알게 되었다. (어떤 경로인지 적어주세요→\_\_\_\_\_)

##### 4. 임종을 맞이하는 환자 또는 어르신 대상자에게 케어 서비스를 제공한 적이 있습니까?

(1) 예, 있습니다,

**“예”라고 대답하셨다면 제공한 서비스를 구체적으로 선택해 주십시오** (해당 사항을 모두 동그라미 치십시오)

- (5) 신체적인 증상관리를 위한 비의료적 서비스(예:이완 체조(relaxation exercise))
- (6) 연명치료 중지나 보류와 같은 윤리적인 딜레마에 관한 상담
- (7) 재정적인 지원, 탐색, 또는 정보수집에 대한 서비스 (건강 보험 적용 범위와 의료 비용 탐색)
- (8) 임종케어에 관한 계획 또는 사전 의료 진료서(Advance Directive) 작성 또는상담
- (9) 환자와 가족을 위한 심리, 정서적 지지 서비스 (사별에 대한 슬픔, 애도)

(2) 아니요, 없습니다.

\*연명치료 중단이란? 더이상 치료적 행위가 환자의 회복에 영향을 미치지 못하는 경우에 산소호흡기나, 심폐소생술 같은 생명유지 장치를 철회하거나 더 이상의 치료적 활동을 보류하는 것이다.

##### 5. 죽음, 호스피스, 임종케어와 관련된 세미나, 수업 또는, 교육 프로그램에 참가한 적이 있습니까? (해당사항에 동그라미 (O) 표시해주세요)

(1) 예

**“예”라고 대답하셨다면**



- 수업 또는 훈련 프로그램의 명칭을 적어주세요→ \_\_\_\_\_

(2) 아니요

## 섹션 2: 호스피스에 대한 지식과 태도

### (Knowledge and Attitudes regarding Hospice Care)

본 조사의 목적은 고령의 어르신들과 일하는 사회 복지사들의 호스피스 케어에 대한 개인의 지식과 태도를 측정하는 것입니다.

**호스피스는 치료가능성이 없는 상태의 말기질환이나 임종을 앞두고 있는 환자나 노인들에게 신체적, 정신적, 사회적, 존재적인 고통을 해결하고 환자의 남은 삶의 질과 죽음의 질을 높이기위한 총체적인 돌봄(Holistic Care)을 뜻하다.**

호스피스와 관련된 다음 진술들에 대해서, 자신이 얼마나 동의하고 동의하지 않는가를 다섯개의 항목 중 해당하는 번호에 동그라미 치십시오.

(1=매우동의하지 않는다(전혀 그렇지 않다), 2 동의하지 않는다(그렇지 않다), 3, 중간적 입장, 4 동의한다(그렇다), 5, 매우동의한다(매우 그렇다))

	전혀 그렇지 않다				매우 그렇다
<b>호스피스 케어 대한 지식</b>					
1. 호스피스는 임종을 앞두고 있는 말기환자들과 그의 가족들에게 신체적, 심리적, 사회적, 영적인 필요를 충족시키기 위한 서비스를 제공한다.	1	2	3	4	5
2. 호스피스는 남은 여생동안 가능한 한 편안하고, 의미있고, 가치있는 삶을 통한 품위있는 임종을 도와준다.	1	2	3	4	5
3. 호스피스 케어는 여러분야의 전문가로 이루어진 팀 (Interdisciplinary team), 즉 의사, 간호사, 성직자, 사회 복지사에 의해 제공된다.	1	2	3	4	5
4. 호스피스는 기대 수명이 6개월 또는 그 이하인 환자를 대상으로 한다	1	2	3	4	5
5. 호스피스는 병의 치료나 치유보다는 증상관리, 통증완화에 중점을 둔다.	1	2	3	4	5
6. 호스피스는 환자뿐만 아니라 그의 가족들도 돌봄의 대상이 된다.	1	2	3	4	5
7. 환자의 임종 후 호스피스 케어는 사별가족의 슬픔에 대한 서비스로 확대된다.	1	2	3	4	5
<b>자세/태도(Attitude)</b>					

1. 죽음은 자연스러운 삶의 한 과정이다.	1	2	3	4	5
2. 임종을 맞이하는 환자는 심리적, 영적인 준비가 필요하다.	1	2	3	4	5
3. 가정에서의 보살핌은 환자의 편안하고 품위 있는 죽음을 극대화(maximize) 한다.	1	2	3	4	5
4. 죽음은 삶의 마지막 단계이다.	1	2	3	4	5
5. 고통이 없고 편안한, 자연적이면서도 품위있는 임종을 맞이해야 한다.	1	2	3	4	5
	전혀 그렇지 않다			매우 그렇다	
6. 여러분야의 전문가들로 이루어진, 즉 학제적 팀 (Interdisciplinary Team)이 최상의 서비스를 제공한다.	1	2	3	4	5
7. 호스피스의 중심 철학은 환자의 편안하고, 의미 있고, 가치 있는 삶을 통한 환자의 품위 있는 죽음 실현이다.	1	2	3	4	5
8. 환자는 임종하는 순간까지 인간답게 살고 정신적으로 풍요로움과 존엄성을 가져야 한다.	1	2	3	4	5
9. 호스피스는 환자의 수명을 인위적으로 단축하거나 연장하지 않는다.	1	2	3	4	5
10. 환자와 그 가족은 호스피스 케어에 있어서 적극적 협력자가 되어야 한다.	1	2	3	4	5
11. 호스피스는 생명 유지, 연장을 위한 치료를 제공하지 않는다.	1	2	3	4	5
12. 호스피스 선택한다는 것은 삶에 대한 모든 희망을 포기하는 것이다.	1	2	3	4	5
13. 호스피스 대상자는 예상된 수명보다 더 빠르게 임종을 맞이한다.	1	2	3	4	5
14. 죽음의 과정에 있는 말기환자에게 호스피스 서비스를 받도록 허락하는 것은 가족으로서 적절하지 못한 행동이다.	1	2	3	4	5

15. 만일 내가 죽음의 과정에 있는 말기환자라면, 나는 호스피스 케어를 받을 것이다.	1	2	3	4	5
16. 보다 큰 고통이 따를지라도, 나는 가능한 모든 의학적 방법 (산소호흡기, 투석 등)을 통하여 생명을 연장할 것이다.	1	2	3	4	5
17. 만일 내가 죽음의 과정에 있는 말기환자라면, 가족이나 내가 원하는 가까운 사람들에 의해 보살핌을 받는 것이 가장 좋을 것이다.	1	2	3	4	5
18. 만일 내 가족이 죽음의 과정에 있는 말기환자라면, 내가 그들을 보살필 것이므로 호스피스 케어는 내 가족에게 필요하지 않다.	1	2	3	4	5
19. 호스피스는 한국문화에서 생소한 개념이다.					
	전혀 그렇지 않다			매우 그렇다	
<b>섹션 3: Level of Comfort</b>	1	2	3	4	5
1. 나는 일반적으로 죽음에 대해 이야기하는 것에 대해 편안함을 느낀다 (또는 불편함이 없다).	1	2	3	4	5
2. 나는 어르신들과 죽음에 대해 논의 또는 상담하는 것에 대해 편안함을 느낀다 (또는 불편함이 없다/ 없을 것이다).	1	2	3	4	5
3. 사회복지사로서 만일 내가 죽음 또는 임종케어에 관한 이야기를 먼저 꺼냈을때, 어르신들께서 이 주제에 대해 불쾌한 감정을 느낄까 걱정된다.					

(1=매우동의하지 않는다(전혀 그렇지 않다), 2 동의하지 않는다(그렇지 않다), 3, 중간적 입장, 4 동의한다(그렇다), 5, 매우 동의한다(매우 그렇다))

#### 섹션 4: 임종 간호에서 노인 전문 사회복지사의 역할

	전혀 그렇지 않다	매우 그렇다
--	--------------	-----------

1. 귀하는 노인복지 실무현장에서 임종교육 또는 임종 케어계획에 관한 서비스가 필요하다고 생각하십니까? (옆에 해당 번호에 표시해주세요)	1	2	3	4	5
2. 어르신을 케어하는 사회복지사로서, 어르신들의 다가올 임종과 그와 관련된 심리사회적 상담을 제공할 책임이 있다고 생각하십니까? (옆에 해당 번호에 표시해주세요)	1	2	3	4	5
3. 사회복지사의 일이 아니라면, "누가" 임종과 관련된 심리사회적 문제에 적극적으로 관여해야 한다고 생각하십니까? (해당사항에 모두 표시해주세요)	1	2	3	4	5
1) 의사 2) 간호사 3) 성직자 4) 가족 구성원 5) 기타 _____					
4. 나는 현재 어르신들과 그 가족들에게 임종과 관련된 심리사회적, 정서적 지원을 제공할 적절한 준비가 되어있다. (옆에 해당번호에 표시해주세요)	1	2	3	4	5
5. 필요하다면, 어르신들께 임종관련에 관한 서비스 (예:좋은 죽음에 관한 교육이나 정보지원, 심리사회적 지지등)를 제공할 의향이 있다. (옆에 해당번호에 표시해주세요)	1	2	3	4	5

### 섹션 5: 자기 결정권에 대한 가치(Values on Self-Determination)

1. “자기-결정권”의 정의는 무엇입니까? (귀하의 생각을 적어주세요)

---



---



---

2. 어르신 또는 말기질환자가 삶의 마지막 순간을 어떻게 맞이할 것인가에 대한 결정 (임종 의사결정)이 필요한 상황에 있다면, “당신”은 “누가” 그 결정 과정에 적극적으로 관여해야 한다고 생각하십니까?

(정답이나 오답은 없으며, 한 번호에 동그라미 (O) 표시해주세요)

- (1) 본인 스스로 결정해야 한다.

- (2) 본인과 가족구성원 모두가 상의해서 결정해야 한다-이 항목을 선택했다면, 어떤 가족 구성원이 참여해야 합니까?

(해당사항 모두 표시동그라미 (O) 표시해주세요)

- 1) 배우자(아내 또는 남편)
- 2) 성인 아들
- 3) 성인 딸
- 4) 가까운 친척

5) 친구나 사제 등과 같은 중요한 다른 사람들

(3) 가족과 의료진이 상의해서 결정해야 한다 1) 환자에게 알리고 ( )

2) 환자에게 알리지 않고 ( )-이 항목을 선택했다면, 환자에게

알리지 않는 이유를 선택해 주십시오 (해당 사항 모두 동그라미 (O) 표시해주세요)

- 5) 죽음에 대해 언급을 하고 싶지 않아서
- 6) 환자에게 삶에 대한 자포자기감을 주지 않기 위해
- 7) 환자에게 다가올 자신의 죽음에 대한 불안감 또는 두려움을 주지 않기 위해
- 8) 환자가 자신이 죽음이 가까워 왔다는 사실을 알게 된 후 현재의 건강 상태를 악화시키지 않기 위해
- 9) 기타이유(이유를 적어주십시오)

다음 질문들에 대해서, 자신이 얼마나 동의하고 동의하지 않는가를 다섯개의 항목 1 개만 (o) 표시해 주세요

(1=매우동의하지 않는다(전혀 그렇지 않다), 2 동의하지 않는다(그렇지 않다), 3, 중간적 입장, 4 동의한다(그렇다), 5, 매우 동의한다(매우 그렇다))

	전혀 그렇지 않다			매우 그렇다	
3. 만일 내가 죽음의 과정에 있는 말기환자라면, 나의 질병의 상태나 앞으로의 일어날 일들에 대해 정확하게 알고 싶다.	1	2	3	4	5
4. 만일 내가 죽음의 과정에 있는 말기환자라면, 나는 나의 질병의 상태와 진행에 대해 <u>의사</u> 를 통해 알기를 원한다.	1	2	3	4	5
5. 만일 내가 죽음의 과정에 있는 말기환자라면, 나는 나의 질병의 상태와 진행에 대해 <u>가족</u> 을 통해 알기를 원한다.	1	2	3	4	5
6. 만일 나의 <u>가족</u> 이 죽음의 과정에 있는 말기환자라면, 환자 본인의 질병의 상태와 진행에 대해 정확하게 말해 줄 것이다.	1	2	3	4	5
7. “자기결정권 (self-determination)”은 나의 사회 복지 현장에서 지켜져야 할 중요한 윤리적 원칙이다.	1	2	3	4	5
8. 만약 사회복지 현장에서 어르신들의 자기결정권이 존중되지 못하는 상황에 처해 진다면, 나는 사회복지사로서 난처 할 것이다.	1	2	3	4	5

섹션 6: 사전의료계획(Advance Care Planning)과

**사전의료 의향서 (지시서) (Advance Medical Directives)**

**1. 사전 의료 의향서에 대해 들어본 적이 있습니까? (해당번호에 동그라미 (O) 표시해주세요)**

- (1) 들어본 적이 없다.
- (2) 들어본 적이 있다.
- (3) 잘 알고 있다.
  - (2)(3)번을 선택하셨다면, 어떤 경로를 통해 알게 되었는지 적어주세요 \_\_\_\_\_

**2. 죽음의 과정에 있는 말기환자에게 사용할 수 있는 생명 유지를 위한 의료기술 (medical care for life prolongation) (예시) 입니다.**

**(알고 있는 모든 것에 표시(v) 해 주십시오)**

- (     ) **심폐 소생 장치** (심폐 소생술CPR): 심장이나 호흡이 정지 상태에 있는 사람에게 호흡과 심장 박동을 시작시키려는 노력.
- (     ) **기계 환기**: 인공 호흡기계 사용(인공 호흡기).
- (     ) **투석**: 신장 기능이 손상 (말기) 되었을 때 인공적인 수단에 의해 혈액에서 폐기물, 염분 및 불필요한 액체 제거
- (     ) **튜브-수유**: 액체나 (수분) 음식을(유동식 혹은 영양 공급) 사람의 신체에 삽입된 튜브를 통해 투여, 튜브 수유는 단기 혹은 장기 사용할 수 있다.
- (     ) **상기 사항들에 대한 사전지식이 없습니다.**

사전의료 의향서(Advance Medical Directives)는 자신이 죽음에 임박하여 스스로 자기자신에 대한 의료 결정을 내릴 수 없는 경우에 대비하여 삶의 마지막 순간을 어떻게 맞이 할 것인지를 본인의 의사를 밝히고 기록해 놓는 문서이다. 예를 들어 임종이 임박한 경우 심폐소생술이나 인공 호흡기등의 의학적인 방법을 이용해 생명을 연장할 것인지 아니면 이러한 의료행위 없이 자연스런 죽음을 받아들일지를 선택하는 절차입니다.

아래의 설문은 사전의료 계획에 관한 개인의 태도를 알아보기 위한 것입니다. 다섯개의 스케일중에 해당되는 번호에 동그라미(o) 해주세요.

	전혀 그렇지 않다			매우 그렇다	
1. 죽음에 대해 이야기 하면 불행이 찾아올 것이다	1	2	3	4	5
2.나의 마지막 순간을 어떻게 맞이할 것인가(임종케어)를 결정하는데 있어서 나의 의견이 가장 중요하다.	1	2	3	4	5
3. 최후의 의사 결정을 하는데 있어서, 가족구성원 또는 가까운 친척들과 함께 결정하는 것이 중요하다.	1	2	3	4	5
4. 나의 임종 케어 결정에 있어 나와 내 가족간에 의견차이가 있다면, 나의	1	2	3	4	5

의견이 우선시 되어야 한다.					
5. 나와 가까운 사람들이 (가족, 친척, 친구등) 나를 대신해 중요한 의사결정을 해주길 원한다.	1	2	3	4	5
6. 미래에 대해 계획하고 준비하는 것은 중요하다.	1	2	3	4	5
7. 죽음에 대하여 계획하고 이야기 하면 죽음을 더 빨리 경험할 것이다.	1	2	3	4	5
8. 나를 위한 사전 의료 지시서를 미리 작성해 놓는다면, 내가 말을 할 수 없고 의사결정 불가 상태가 되었다더라도 내가 원하는 치료를 받을 수 있을 것이라 확신한다.	1	2	3	4	5
9. 사전 의료 지시서를 작성함은 내가 의학적 치료가 필요한 상태임에도 불구하고 의사들이 나의 치료 중단할수 있는 이유를 줄 것이다.	1	2	3	4	5
	전혀 그렇지 않다			매우 그렇다	
10. 내가나의 마지막 순간에 대한 나의 바램을 먼저 기록해 놓지 않는다면, 내가 말을 할 수 없는 상태가 되었을때 나의 가족들은 내가 원하는 치료를 제공해 줄 수 없을 것이다.	1	2	3	4	5
11. 죽음에 있어서는 모든것이 신(God)의 뜻이므로 어떠한 계획도 필요하지 않다	1	2	3	4	5
12. 나를 위한 임종케어에 관한 사전 의료 지시서를 작성해 놓을 것이다.	1	2	3	4	5
13. 나는 어르신들에게 사전 의료 지시서에 대해 설명하거나 그들의 임종케어 바램을 작성해 놓는것을 장려하고 도와줄 것이다.	1	2	3	4	5

### 섹션 7: 조사 참여자 특성(Participant's Characteristics)

1. 성별: 남 (        ) 여 (        )

2. 연령 \_\_\_\_\_

### 3. 귀하의 학력과 자격사항

(1) 교육 (해당사항에 동그라미 (O) 표시해주세요)

- 전문대 졸업
- 4년제 대학 졸업
- 전문 대학원 졸업

(2) 사회 복지 자격증 (해당사항에 동그라미 (O) 표시해주세요)

- 1급 사회복지사 자격증
- 2급 사회복지사 자격증

### 4. 가정에서 현재 "고령의 부모"와 거주하고 있습니까? (해당사항에 (V) 표시해주세요)

예(        )                      아니요 (        )

### 5. 결혼 여부는? (해당번호에 동그라미 (O) 표시해주세요)

- (1) 기혼
- (2) 미혼 (독신, 이혼)

### 6. 당신의 종교는 무엇입니까? (해당번호에 동그라미 (O) 표시해주세요)

- (1) 기독교
- (2) 불교
- (3) 천주교
- (4) 무교
- (7) 기타 \_\_\_\_\_

### 7. 직업 사항

(1) 어떤 노인복지시설에서 근무하고 계십니까? (해당사항에 동그라미 (O) 표시해주세요)

- a) 노인 의료복지 시설 (요양원, 노인전문 병원)
- b) 재가 노인 복지 시설 (단기보호, 주야간 보호 기관, 방문요양, 가정봉사 파견센터등)
- c) 노인 여가 복지 시설(노인 복지관, 경로당, 노인교실, 노인 여가시설등)
- d) 일반 병원
- e) 기타\_(시설의 명칭을 적어주십시오\_\_\_\_\_)

(2) 어르신들께 어떤 서비스를 제공합니까? (해당사항에 동그라미 (O) 표시해주세요)

- (1) 어르신들에게 직접적 서비스를 제공합니다.
- (2) 관리자로 어르신들과 간접적 서비스를 제공합니다



(3) 직장 직위 (아래 밑줄에 적어주세요)

나는 노인복지 시설에서 \_\_\_\_\_ 로 근무하고 있습니다.

(예: 노인 복지사, 임상 사회 복지사, 사례 관리자, 상담사, 관장, 부장, 이사, 인턴 등.)

**참여해 주셔서 감사합니다! ☺**