

Chinese American's Readiness for Advance Care Planning

BY

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THESIS

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This thesis is dedicated to Jesus Christ.

To God be the glory and thank you Lord, for what you have done and what you are doing for me.

This work is also dedicated to all the people who never stop believing in me and who along with God,
have been my “footprints in the sand:”

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I. INTRODUCTION

A. Background

The development of resuscitation procedures and life-sustaining devices has brought significant changes to the treatment of terminally ill patients at the end of their lives (EOL). Typically used life-sustaining treatments, such as cardiopulmonary resuscitation (CPR), mechanical ventilators (MV), hemodialysis, and artificial nutrition and hydration, merely prolong the dying process as they neither reverse clinical course nor improve health (Teno & Lynn, 1996). In response to the Patient Self-Determination Act of 1990 (Fitten, Lusky, & Hamann, 1990; Madson, 1993), legal documents called "advance directives" have been developed as part of a national effort to facilitate EOL treatment decision making and to limit the use of futile life-sustaining treatment (Basile, 1998; Teno, Branco, & Mor, 1997; Wetle, 1994).

Evidence has shown that successful advance care planning has assisted patients in achieving their EOL care goals (Hammes & Rooney, 1998), increasing satisfaction (Tierney, Dexter, & Gramelspacher, 2001), reducing chances of over- or under-treatment at the EOL (Lynn & Goldstein, 2003), and minimizing conflicts between family members and health care providers during EOL discussions (Song, Kirchhoff, Douglas, Ward, & Hammes, 2005). Culture has been found to be an important factor influencing advance care planning (Kwak & Haley, 2005), and ethnic differences during EOL treatment decision making have been documented in the literature (Blackhall et al., 1999; Braun, 1998; Caralis, Davis, Wright, & Marcial, 1993; Murphy et al., 1996; N Wenger et al., 1997).

However, the primary focus of the literature related to Asian Americans' EOL decisions has been to discuss the value conflicts between non-Western and Western culture (Braun & Nicoles, 1997; Dinh, Kemp, & Rasbridge, 2000; Klessig, 1992; McLaughlin & Braun, 1998; Thomas, 2001; Yeo & Hikoyeda, 2000), rather than how advance care planning is utilized and tailored for Asian Americans. The majority of studies have emphasized how Asian cultures as a whole differ from the American mainstream culture of European and Christian traditions. These studies have addressed death and dying experiences (Braun & Nicoles, 1997; Koenig & Gates-Williams, 1995; McLaughlin & Braun, 1998; Muller & Desmond, 1992) and attitudes and preferences toward life-sustaining treatment (Blackhall, et al., 1999; Braun, 1998; Crain, 1997; Klessig, 1992; Matsumura et al., 2002), but have not discussed how Asian Americans are and can be engaged in advance care planning.

What can be learned from the literature is that Asian Americans are more collective in their decision making compared with their Euro-American counterparts. They also have reported greater discomfort and lower participation in making EOL decisions (Braun & Nicoles, 1997; Yeo & Hikoyeda, 2000). In general, they are reluctant to participate in advance care planning: they have reservations about completing advance directives (Braun, 1998; Der-McLeod, 1995; Karel, Zir, & Braun, 2003), trust the physician will make the best treatment decision for them (Crain, 1997; McLaughlin & Braun, 1998; Muller & Desmond, 1992), and are confused by the idea of designating a surrogate for future treatment decision (Nishimura & Yeo, 1992). On the whole, they do not have a

sufficient understanding about life-sustaining treatments and advance directives (Braun & Nicoles, 1997; McLaughlin & Braun, 1998; Yeo, 1995).

In addition, there are differences in views toward death and dying and preferences of life-sustaining treatment among the Asian American population, based on differences in acculturation to the American culture (Bito, Matsumura, Fukuhara, & Wenger, 1998; Blackhall et al., 1995; Braun & Nicoles, 1997; Crain, 1997; Matsumura, et al., 2002; Yeo, 1995).

B. Statement and Significance of the Problem

While some information is available regarding Asian Americans, few studies have investigated specifically Chinese Americans' use of and readiness for advance care planning. Although a considerable number of studies have claimed the benefits of advance care planning (mostly among Euro-American populations) (Morrison & Meier, 2004; R. A. Pearlman, Starks, Cain, & Cole, 2005; Schwartz et al., 2002), surprisingly little empirical research has been conducted for Chinese Americans. Despite the fact that the Chinese American group is the largest Asian American population (Barnes & Bennett, 2002; U.S. Census Bureau, 1993a, 2001), it is still unclear to what extent they, as a whole, understand and accept the idea of advance care planning. As far as we know, this study is the first attempt to describe the concept of motivational readiness for advance care planning in this cultural group. Chinese Americans consist of American-born Chinese and immigrants from the People's Republic of China, Taiwan, Hong Kong, Singapore, and some areas of Vietnam (Kemp & Bhungalia, 2002; U.S. Census Bureau, 2001). Currently, there are approximately 2.8 million Chinese Americans

in the U.S., constituting 1.02% of the total American population (U.S. Census Bureau, 2001). In the past two decades, the number of Chinese immigrants in the U.S. has increased dramatically.

The majority (72%) of Chinese Americans are foreign-born, and their countries of origin, immigration time, and acculturation to the American society differ widely (U.S. Census Bureau, 1993b, 2002). In fact, with continued immigration, the People's Republic of China (China) is now the second leading country from which U.S. immigrants originate (U.S. Census Bureau, 2002). In the coming years, it will be increasingly common for American healthcare providers to encounter diverse Chinese Americans faced with EOL decisions. According to the Census data (Huff & Kline, 1999; U.S. Census Bureau, 1993b, 2002), approximately 60% of those who immigrated before 1990 are now age 65 or above. In 2010, elderly Chinese Americans are projected to be 10% of the total Chinese American population, and among them more than 80% will be foreign-born.

When examining the existing literature in this area, there were only a few studies that discussed issues regarding life-sustaining treatment decisions. These studies, however, often did not limit their participants to those of Chinese ethnicity but included other cultural groups (Braun, 1998; Braun & Nichols, 1996; Crain, 1997; Karel, et al., 2003; Klessig, 1992; Koenig, 1997; Orona, Koenig, & Davis, 1994). Moreover, topics of these studies were not exclusively advance care planning, but varied enormously, ranging from preferences of death ritual, funeral arrangement, and organ donation, to comfort care at the EOL. In these studies, briefly mentioned are Chinese Americans' immigration history, a cultural reluctance to discuss death and dying, immigrants' language barriers, and a low

completion rate of advance directives, but not how Chinese Americans view the idea of advance care planning.

The existing literature reveals not only that advance care planning is rarely used by Chinese Americans, but also that some barriers hinder them from using it, such as English proficiency and knowledge needed for advance care planning (Braun & Nicoles, 1997; Crain, 1997; Karel, et al., 2003; McLaughlin & Braun, 1998). More importantly, the literature has indicated that Chinese Americans' major difficulties when dealing with EOL decisions are ethical dilemmas stemming from reconciling Chinese cultural beliefs and American expectations embedded in advance care planning (Braun, 1998; Braun & Nichols, 1996; Crain, 1997; Muller & Desmond, 1992; Orona, et al., 1994; Yeo, 1995). Chinese Americans demonstrate psychological reluctance for such discussions related to death and dying by claiming they are uncomfortable or do not need to plan for future life-sustaining treatment decisions (Braun, 1998). Also widely acknowledged in the literature is that Chinese Americans' preferences of family (group) decision making at the EOL are usually not accommodated (Der-McLeod, 1995; Haddad, 2001; Muller & Desmond, 1992) by surrogacy laws for advance care planning, which are based on American individualistic values. Another commonly seen concern is that full disclosure of terminal illness sometimes may be interpreted as harmful and thus undesirable for Chinese Americans (Kemp & Chang, 2002; Muller & Desmond, 1992; Orona, et al., 1994). Advance care planning, a process of reflecting and communicating personal values and beliefs with others, may be too personal in Chinese culture (Lassiter, 1995; McLaughlin & Braun, 1998).

Finally, communication about and decisions of advanced life-sustaining treatment preferences seem to be culturally unnecessary because Chinese Americans usually do not expect to have control over their own medical decisions (Kemp & Chang, 2002; Yeo & Hikoyeda, 2000); deferring EOL decisions to physicians or adult children is commonly practiced among elderly Chinese Americans (Der-McLeod, 1995; Muller & Desmond, 1992; Orona, et al., 1994). Taken together, the literature suggests that Chinese Americans' readiness for advance care planning is in a preliminary stage. In particular, the idea of making life-sustaining treatment decisions prior to medical crises may seem to be culturally insensitive to Chinese Americans. Before answering the question regarding when and how an advance care planning intervention will be developed and tailored for Chinese Americans, the issue of how receptive they will be to the advance care planning interventions needs to be addressed.

C. Purpose and Specific Aims of the Study

The purpose of this study is to describe the factors that influence Chinese Americans' readiness for advance care planning. Both quantitative and qualitative methods will be used to collect data from Chinese Americans from four Chinese community churches in the greater Chicago area. The following specific aims are proposed:

1. To describe Chinese Americans' readiness for advance care planning by using both in-depth interviews and quantitative measures.
2. To examine the effects of cultural factors, knowledge of advance care planning, spirituality, quality of life, and demographic characteristics on Chinese American' readiness for advance care planning.
3. To discover strategies that Chinese Americans would prefer to use in advance care planning interventions.

II. CONCEPTUAL FRAMEWORK AND RELATED LITERATURE

A. Conceptual Framework

The conceptual model developed to guide this study, *Chinese Americans' Readiness for Advance Care Planning* (Figure 1), was based on an extensive literature review of multiple health behavioral theories (Ajzen, 1991; Ajzen & Fishbein, 1980; Bandura, 1982; Fishbein & Middlestadt, 1987; J. O. Prochaska & DiClemente, 1983a; J. O. Prochaska, Redding, Harlow, Rossi, & Velicer, 1994; Rosenstock, 1990; Triandis, 1979) and previous studies related to advance care planning (Braun, 1998; Fischer, Tulskey, Rose, Siminoff, & Arnold, 1998; Gordon & Shade, 1999; High, 1993a; Hopp, 2000; Karel, et al., 2003; Kwak & Haley, 2005; Martin, Thiel, & Singer, 1999; McDonald et al., 2003; Morrison & Meier, 2004; Rosnick & Reynolds, 2003; Schwartz et al., 2003; Straton et al., 2004; Witte, Menon, Ruskin, Wiley, & Hebel, 2003). *Chinese Americans' motivational readiness (stage of change) for advance care planning* is the outcome element of the model. Although readiness can be conceptualized into different components (perceived barriers, perceived benefits, etc.), this study focuses primarily on motivational readiness in making a behavioral change for advance care planning. Factors of culture, knowledge, quality of life, spirituality and demographic characteristics are proposed in this study to be related to readiness for advance care planning.

The conceptual basis of this study is the Transtheoretical Model of Behavioral Change (TTM) (J. O. Prochaska & DiClemente, 1983b; J. O. Prochaska, et al., 1994), and the primary relationships of the model were drawn from assumptions of the TTM. The outcome element of this model, Chinese Americans' motivational readiness for advance care planning (a behavioral change), is conceptualized

in terms of six stages of change—precontemplation (non-believers), precontemplation (believers), contemplation, preparation, action, and maintenance.

According to Prochaska and DiClemente's Transtheoretical Model (1983b), two other core concepts, decisional balance (pros and cons) and self-efficacy (situational confidence) are incorporated as indicators of the dependent (outcome) variables. They are often measured to assess and predict an individual's stage of change, and by assessing these two components potential barriers are identified that need to be targeted to increase the readiness to behavioral change (J. O. Prochaska, et al., 1994). For this study, Chinese Americans' readiness for advance care planning is characterized as their stage of change for making life-sustaining treatment decision(s) and documenting advance directive document(s) prior to medical crises. Their decisional balance and self-efficacy are included in the conceptual model as the indicators of outcome variable in order to identify possible barriers and facilitators during the decision-making process.

In this model, five components were proposed that influence Chinese Americans' readiness for advance care planning: culture, knowledge, quality of life, spirituality and demographical characteristics. A one-way relationship exists between the five components and the outcome of readiness. The cultural component includes Chinese cultural beliefs related to advance care planning, Chinese Americans' acculturation, their individualistic and collective orientations, and their English proficiency for advance care planning. The knowledge component has two concepts: Chinese Americans' self-perceived knowledge for advance care planning.

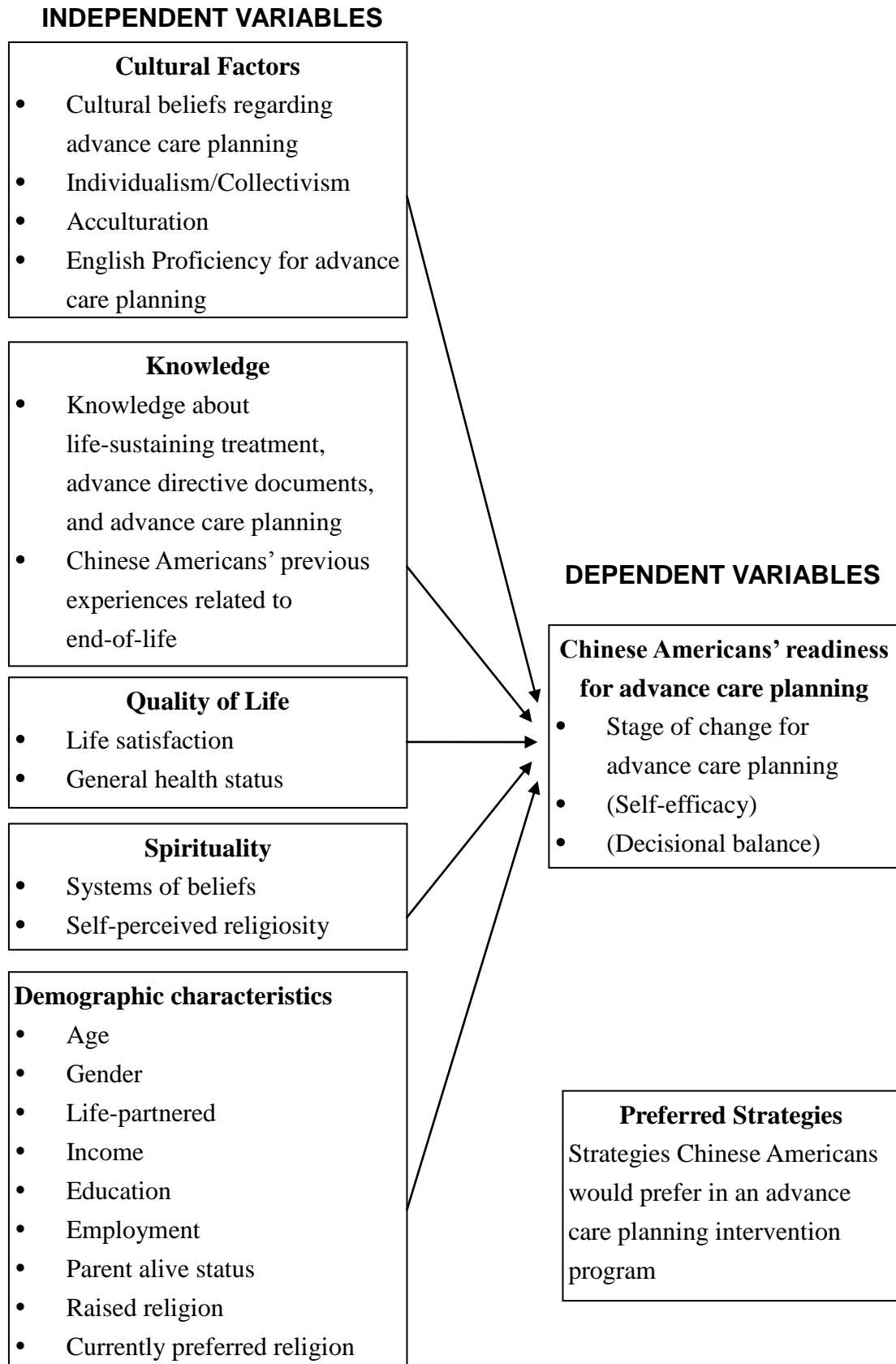


Figure 1. Conceptual Framework: *Chinese Americans' Readiness for Advance Care Planning*

For example, whether they believe their knowledge responsible for advance care planning is sufficient ("I don't think I understand advance care planning"). Their previous experience related to EOL is also conceptualized in the knowledge component. The quality of life (QOL) component includes both standard QOL concepts of life satisfaction and general health status (health-related quality of life). Spirituality is conceptualized in terms of their systems of beliefs (the presence and importance of religious beliefs and practice and value of support from the religious community) and their self-perceived religiosity. Lastly, the demographic characteristics include general socioeconomic statuses of age, gender, income, education, marital status, parent alive, employment, and the type of religions by which they were raised and currently prefer.

A separate component proposed in this model is the strategies Chinese Americans would prefer to use to participate in advance care planning. This is not linked to the other variables in the model but included in the study to gain understanding and obtain information for future intervention studies. All concepts in this conceptual model are operationalized and assessed (Table 1) using both quantitative and qualitative measures. Major constructs and theoretical stipulations of the Transtheoretical model and how the TTM can be applied in this study is discussed in more detail in the following section of related literature review.

B. Review of Related Literature

1. Overview of the Transtheoretical Model (TTM)

Emerging from a comparative analysis of more than 300 leading psychotherapy theories (J. O. Prochaska, Redding, & Evers, 2002), the Transtheoretical Model (TTM) primarily addresses

behavior change (J. O. Prochaska & DiClemente, 1983a) about how human beings modify a problem behavior or acquire a positive healthy behavior. In the past two decades, the TTM has been used extensively as a theoretical basis for developing effective health promotion interventions, such as smoking cessation, physical activity/exercise, weight control, and HIV prevention (J. O. Prochaska, et al., 1994). There are four major constructs in the conceptualization of TTM: stages of change (the core construct), processes of change, decisional balance (the pros and cons of change), and self-efficacy (the level of confidence in the ability to change) (J. O. Prochaska, et al., 2002). The following section gives an overview of the TTM constructs that are chosen in this study and discusses how TTM can be applied for this study.

a. **Stages of change: Chinese Americans' Readiness for Advance Care Planning**

The core construct of the TTM is the six stages of change (five ordered categories): precontemplation (non-believers), precontemplation (believers), contemplation, preparation, action, and maintenance. These stages represent a continuum of motivational readiness when people modify a problem behavior (e.g., smoking cessation) or acquire a health promotion behavior (safer sex) (J. O. Prochaska, et al., 1994). The TTM is all about motivational readiness (intentional change). According to the theorists (J. O. Prochaska, et al., 1994), "...people move from precontemplation, not intending to change, to contemplation, intending to change within 6 months, to preparation, actively planning change, to action, overtly making changes, and into maintenance, taking steps to sustain change (pp.473)."

The underlying assumption in this study is that advance care planning has a health-promoting nature, and Chinese Americans will benefit from making advanced life-sustaining treatment decisions prior to medical crises. Because Chinese Americans' intention about whether to acquire advance care planning varies, their motivational readiness for advance care planning can be conceptualized in six different stages.

1) **Precontemplation (non-believers and believers)**

In the previous section, the literature reveals that multiple barriers exist to prevent Chinese Americans from utilizing advance care planning, and their motivational readiness for this healthy behavior has never been systematically assessed. A majority of Chinese Americans, even those highly educated (Chinese American professionals) seem to be still in the *precontemplation* stage. Some have shown no interest and/or never believe in the benefits of making advanced treatment decisions (non-believers), and some were found to be unaware of advance care planning and not seriously considering making a change (believers).

According to the TTM, precontemplators are individuals who are uninformed or under-informed about the consequences of their current behavior. They may also be demoralized about their ability to change, or just not want to think about change due to various reasons (J. O. Prochaska, et al., 1994). These individuals are often characterized in other behavioral theories as resistant or unmotivated. Precontemplators are not the perfect candidates for interventions according to TTM. Therefore, if an advance care planning intervention is designed for Chinese Americans whose readiness is in general in the precontemplation stage, the intervention is likely to fail. It is extremely important to investigate the

distribution of stage of change among Chinese Americans so that they can be assisted to transition to the advanced stages.

2) **Contemplation**

Contemplators as defined in the TTM are those who seriously think about changing within the next 6 months (J. O. Prochaska, et al., 1994). Compared to precontemplators, contemplators are usually more open to feedback and interested in information about behavioral change. However, they are still quite ambivalent about the positive aspects (pros) and negative aspects (cons) about change (the concept of decisional balance will be introduced in the following section). Chinese Americans in the contemplation stage for advance care planning would be those individuals who may know some benefits about advance care planning but still consider the risks of making a change. These individuals have the potential to consider using interventions in the future 6 months.

3) **Preparation, Action, and Maintenance**

According to the TTM, individuals in the preparation stage are ready for action. To be more specific, they are seriously planning to make a behavioral change within the next month. Also in this stage, they have already taken some steps towards action. Chinese Americans in the preparation stage would be those information seekers who have already thought through the pros and cons of advance care planning and are going to make the life-sustaining treatment decisions within a month. In other words, they may be ready to have their advance directives signed in the next month.

The most advanced stages in the TTM are stages of action and maintenances. Action apparently involves the overt change of the behavior, and maintenance is defined as the period that begins after 6

months of continuous, successful behavioral change. Applying these TTM definitions in our study, Chinese Americans who are in the action stage are individuals who have given oral directives or made legal advance directives (within six months). In the action stage, their preferences of life-sustaining treatment decisions and care desired at the EOL have been made clear.

On the other hand, maintenance could be defined as consistent communication among families and healthcare providers for more than 6 months. Individuals in the maintenance stage make ongoing efforts to have conversation about EOL decisions in the family and healthcare context. For example, these Chinese American maintainers for advance care planning may continuously revise their advance directives with their families on a regular basis.

b. **Decisional balance**

Decisional balance and self-efficacy are two constructs that are often assessed as part of the readiness in the TTM. In this study, in order to represent the underlying socio-psychological factors that may predict Chinese Americans' readiness for advance care planning, decisional balance and self-efficacy for advance care planning are measured along with the outcome variable--stage of change. The pros and cons of change and an individual's confidence in the ability to change across difficult situations are important intervening variables for future intervention effectiveness as well. According to the TTM, these two concepts are assessed as indicators of the outcome variable.

The decisional balance construct is the individual's relative weighing of the positive aspects (pros) and the negative aspects (cons) of changing. As suggested by the TTM, measuring decisional balance is assessing respondents' weighted importance of pros and cons of behavioral change. Previous

longitudinal studies of smokers (J. O. Prochaska, et al., 1994) revealed that, in the stage of precontemplation, pros of smoking far outweigh the cons of smoking. However, in the stage of contemplation, pros and cons are more equal, suggesting cons begin to compete with the pros. In the advanced stages, cons of smoking were found outweigh the pros (J. O. Prochaska, et al., 1994). Because the pros and cons of making an advanced life-sustaining treatment decision are culturally determined, only when Chinese Americans' decisional balance is assessed can a comprehensive understanding of their motivational readiness for advance care planning be attained.

c. **Self-efficacy**

Similar to decisional balance, the self-efficacy construct is an outcome indicator. It represents individuals' "situation-specific confidence." Adapted from Bandura's self-efficacy theory (1982), self-efficacy in the TTM has been demonstrated to be an important mediator between knowledge and action. In other words, when sufficient knowledge has been obtained, people's situational confidence becomes the key to successful behavioral change. Evidence of this was provided from previous smoking cessation studies that showed that smokers' confidence in quitting increased almost linearly from precontemplation to maintenance (J. O. Prochaska, et al., 1994).

It is worth noting that in the precontemplation and contemplation stages, low self-efficacy can be interpreted as both perceived inability and/or unwillingness to change (J. O. Prochaska, et al., 1994). This may suggest that Chinese Americans whose situational confidence is low for advance care planning may not have sufficient knowledge, do not think they have the ability to make a change on their own, or are reluctant to the idea of advance care planning. Self-efficacy as situational confidence

needs to be assessed and compared with the other two outcome measures, stage of change and decisional balance.

d. **Other variables specific to the behavioral change**

The original TTM includes psychological, environmental, cultural, socioeconomic, physiological, biochemical, or even genetic variables specific to the behavior change (J. O. Prochaska, et al., 2002). Although not depicted in the original TTM, recognized are effects of these emotional, cognitional, and behavioral factors on an individual's readiness for change. In this study, factors of culture, knowledge, quality of life, spirituality, and demographics are described as independent variables contributing to the dependent variables: motivational readiness for advance care planning (Figure 1).

e. **Summary**

Chinese Americans' motivational readiness for advance care planning can be appropriately characterized by the TTM. Despite the individual focus of the TTM, social influences on behavioral change are evidently recognized. This is conceptually important as Chinese culture is a collective culture where subjective norms are highly valued. In addition, the TTM makes no assumption that people are ready for interventions, which makes it appropriate for our study. Lastly, because the theoretical postulations of the TTM have been extensively verified and defined in previous research, we hope that based on these valid relationships, the outcome variable measures will have the sensitivity to identify Chinese Americans in various readiness stages.

2. **Cultural factors related to Chinese Americans' advance care planning**

As culture fundamentally shapes how individuals comprehend health, illness, and death, there is no doubt about the importance of culture in EOL decision making. Ethnically diverse groups in America have been found making life-sustaining treatment decisions based on their original culture (Blackhall, et al., 1999; Bonner, 1996; Kagawa-Singer & Blackhall, 2001; Klessig, 1992). Ethnicity was found to have stronger influence on people's attitudes toward advance care planning than other demographic characteristics (Caralis, et al., 1993).

Although Chinese culture indisputably plays a fundamental role in shaping Chinese Americans' attitude toward death and dying, the literature does not clearly show to what extent traditional Chinese beliefs influence Chinese Americans' stage of change, decisional balance, and self-efficacy for executing advance directives. In this study, the term "Chinese Americans" refers to people of Chinese ancestry who are residing in the U.S. regardless of their American citizenship and countries of origin. Shaped by the shared traditional Chinese culture, their collective attitudes toward advance care planning have been showed different from those of Euro-Americans (Crain, 1997). However, within-group differences might exist because the strength with which these cultural beliefs influence attitudes toward EOL decisions may vary depending on the individual's level of acculturation. Cultural elements of traditional Chinese ethical and religious beliefs and their anticipated influences on Chinese Americans' readiness, decisional balance, and self-efficacy for advance care planning are summarized in the following sections.

a. **Confucian ethics**

Confucianism, the teaching of Confucius about 500 B.C., has long been the backbone of the Chinese value system. It is not a religion but rather is a set of guidelines for living that provide an overarching foundation for Chinese Americans' values and beliefs. Confucianism strongly emphasizes mercy, social order, and fulfillment of responsibilities. In particular, the central ethical principle of Chinese culture is *Ren* (love, mercy, and humanity) (Eliot, 2001; Guo, 1995). Considered the golden rule of Chinese decision making, *Ren* as promoted throughout all of Chinese history is best explicated by a Confucian saying, "Do not do to others what you do not want done to yourself" (Eliot, 2001). This ethical principle is further strengthened by the Buddhist tradition, which holds that merit is accumulated by doing merciful acts and leads to a better next life through reincarnation (Kemp & Bhungalia, 2002).

Stemming from *Ren*, ethics of compassion and avoidance of undue suffering are embedded in Chinese culture and in Chinese Americans' decisional balance for advance care planning. Chinese elderly patients may choose to discuss the possibility of forgoing future life-sustaining treatment for the reason of not burdening their families (Bowman & Singer, 2001). On the other hand, families may also be willing to participate in advance care planning in order to prevent the terminally ill patient from suffering at the EOL.

b. **Collectivism**

In Confucianism, a person is defined as a relational identity (F. Tsai, 2001). A study revealed that even among other collectivistic Asian cultures the Chinese culture is the most

collectivistic and the least individualistic (Oyserman, Coon, & Kemmelmeier, 2002). This cultural expectation has encouraged Chinese people to feel more duty to their families and society than to themselves. Family harmony is also considered more important than individual independence in Chinese culture.

Collectivism directly affects how health care decisions are made and who makes them. In a collectivistic culture, an interdependent relationship takes precedence over values of self-reliance and independence (S. Shih, Shih, Chen, & KaoLo, 2000; Yick & Gupta, 2002). Because patient autonomy is not highly valued in collectivistic culture, patients generally do not expect to have control over decision making. Many Chinese American patients feel a need to consult with other family members before making any treatment decisions (Braun, 1998). Health care providers in Chinese countries have reported experiencing ethical dilemmas when required by their institutions to incorporate patient autonomy in patient care ((Fielding, Ko, & Wong, 1995; Holroyd, 2003; Triandis et al., 1986).

In comparison to Euro-Americans, elderly Chinese immigrants were found to have a significantly lower belief in personal control over events in their lives. In this New York study of medical decision making (Crain, 1997), Chinese immigrants were significantly oriented toward external-control beliefs, including the power of others, luck, and fate. A majority of these Chinese immigrants stated that the value of independence was not important to them; they preferred to leave all decisions to their physicians rather than to be personally involved. This finding indicates that Chinese Americans' self-efficacy for advance care planning may be affected by Chinese collectivistic ideals of family, responsibility, and social harmony, as well as their relatively low sense of control and independence.

c. **Familialism**

Familialism refers to a cultural value of one's strong identification with and attachment to his/her nuclear and extended families (Triandis, et al., 1986). Considered as the most important and fundamental collectivist value (D. T. Tsai & Lopez, 1997), familialism is embedded in almost all Chinese people's value systems. In Confucian teaching, family is always to be considered before the individual, and a person's most important social responsibility is to take care of his/her family members. Not only that, family members identify closely with each other, even to the extent of sharing the shame, guilt, and humiliation of other family members. Among Chinese Americans, family and kin members also form the center of the care network (Wellish et al., 1999) and are perceived as the most satisfying sources of support (Lan, 2002).

The literature indicates that people's main reason for initiating advance care planning or completing advance directives is mostly so as not to burden their families (Bonner & Miles, 1997). A study found that the primary reason Chinese Americans decided to have advance care planning was because they wanted their families to know their wishes (Braun & Nichols, 1996). Elderly people in particular prefer that their families participate in advance care planning; only those who do not have families would appoint others to take charge of their advance directives (Rosnick & Reynolds, 2003). This cultural value of familialism remains quite resilient even in highly acculturated families. In studies of EOL decisions in other collectivistic cultures (Mexican and Japanese Americans), regardless of the levels of acculturation, family decision making is preferred, and the family head is usually the primary decision maker (Blackhall, et al., 1999; Blackhall, et al., 1995; Matsumura, et al., 2002).

Although the idea of family being involved in advance care planning seems universal (Mold, Looney, Viviani, & Quiggins, 1994), for Chinese Americans family is in general the unit that makes the most important treatment decisions. Chinese-ethnic patients prefer that their life-sustaining treatment decisions be made by families (Muller & Desmond, 1992; Orona, et al., 1994), and family members also expect to be involved in such important discussions (Orona, et al., 1994; F.-J. Shih et al., 2001). When Chinese Americans are contemplating whether to make decisions about life-sustaining treatments, familialism is expected to strongly influence their self-efficacy for making the decision about advance care planning.

d. **Filial Piety**

Along with familialism comes the traditional Chinese belief of “filial piety” that may also play a role in Chinese Americans’ readiness for advance care planning. In Confucianism, filial piety is defined as the ideal father-son relationship (Eliot, 2001), which means children, especially the oldest sons, have a great obligation to protect, care for, and respect their parents (Kemp & Chang, 2002). A recent Chinese American immigrant study (Lan, 2002) discovered that filial duty rooted in Chinese Americans’ value system continues to be popularly practiced among adult children.

Although taking care of the elderly also seems universal to all cultural groups, among Chinese Americans, fulfilling filial duty has unique cultural meanings that may interfere with EOL decision making, in particular the self-efficacy for advance care planning. For example, the sick parent in Chinese culture is often considered incompetent to make important medical decisions. Adult children, in order to fulfill filial obligations, may override the parent’s wishes for executing advance directives.

It is possible that adult children of a terminal Chinese American patient may wish health care providers to conceal emotionally disturbing information in order to protect the sick parent from stress (Kemp & Chang, 2002; Muller & Desmond, 1992; Orona, et al., 1994), even though the patient may be ready for advance care planning. In this case, advance care planning becomes difficult when full disclosure of the terminal illness contradicts to filial piety.

On the other hand, the belief of filial piety may conversely facilitate advance care planning. Der-McLeod (1995) reported that Chinese American adult children believed their parents' autonomous advance directive decisions should be respected, and it was their filial duty to obey their elderly parents. Adult children reported being relieved by the fact that this difficult decision had been made by parents themselves. In this case, when advance care planning was conducted among relatively healthy, functioning Chinese American patients, full disclosure of terminal illness was not a concern.

e. **Male paternalism**

In contrast to Euro-Americans' egalitarian model, individuals in a Confucian society are considered "unequal" based on their social characteristics, such as gender, age, occupation, and income (Guo, 1995; Ip, Gilligan, Koenig, & Raffin, 1998; Wellish, et al., 1999). People who possess higher status in society command more respect and also hold more power in decision making (Bowman & Singer, 2001). In Confucian teaching, males (the grandfather, father, or the eldest son) in the family have absolute authority and are the primary decision makers (Tai & Tsai, 2003; Yick & Gupta, 2002).

In contrast to the American cultural expectation, because the father-son relationship outweighs that of husband-wife in importance in Chinese culture, male paternalism implies that Chinese adult sons

may be given a higher priority than the wife to act as the legal surrogate for EOL treatment decisions. Among traditional Chinese American families, it is the eldest son who most commonly serves as the spokesperson for the family. He also holds the power to screen medical information, disclose terminal illnesses, and make final treatment decisions for his dying parents (Muller & Desmond, 1992). By the same token, wives, daughters, or daughter-in-laws usually do not assume the role of medical decision makers (Lan, 2002) even though they generally provide physical care to the patients (Der-McLeod, 1995). A recent study found that while the head of the Chinese family may discuss issues with other family members, he is the one who makes the final life-sustaining treatment decision (Tai & Tsai, 2003). This cultural expectation of males making the final decision may influence Chinese Americans' readiness for advance care planning, in particular female Chinese Americans' self-efficacy (situational confidence) in making advanced EOL decisions.

f. **Physician Paternalism**

Physician paternalism also comes into play in Chinese Americans' advance care planning (Berling, 1982; Guo, 1995; Ip, et al., 1998). Physician paternalism can conflict with patient autonomy in EOL treatment decision making in that physicians who feel obliged to intervene (Casaret, Stocking, & Siegler, 1999) may unilaterally override patients' advance directives such as DNR orders (Karnik, 2002).

Stemming from two traditional Chinese beliefs, a Confucian ideal of propriety, *Li*, and the Taoist belief of *Tao* (the way of life), physician paternalism is phenomenal in Chinese culture. *Li* as a cultural expectation is to be polite, appropriate, and conforming to the social hierarchy. Intended for a long and

healthy life (Chen, 1996; Lassiter, 1995), practicing *Taoism* is to practice discipline and emotional control in all circumstances (Wellish, et al., 1999). Therefore, Chinese people have long negatively regarded behaviors of personal openness, challenging authority, and standing out from the group as culturally impolite and offensive. Those who hold these traditional values may be culturally accustomed to conform to social authorities (e.g., physicians) with obedience, agreement, and acceptance. In the medical decision making context, these traditional Chinese Americans may think it would be inappropriate for them to reveal what they truly think about their health and treatment preference (Ip, et al., 1998; Kemp & Chang, 2002; Lassiter, 1995). Chinese American patients were found to not fully communicate their preferences and wishes (Crain, 1997) and habitually deferred EOL treatment decisions to their primary physicians, believing that physicians were equipped to make the best decisions (Der-McLeod, 1995; Kayashima & Braun, 1997). Recent studies conducted in Taiwan also showed that physicians were often given the authority to make medical decisions with little consultation with patients and families (S. Shih, et al., 2000; Tai & Tsai, 2003). As physician and Chinese American patient are rarely equal collaborators (Crain, 1997; Der-McLeod, 1995; Haddad, 2001; Ip, et al., 1998), Chinese Americans' self-efficacy in advance care planning is strongly influenced by physician paternalism. Some Chinese Americans may believe that the physician can make the best decisions and advance care planning would not be necessary.

g. **Discussion of death as a cultural taboo**

It is well known that many Chinese Americans are reluctant to discuss issues related to death and dying (Braun & Nichols, 1996; Crain, 1997; Yeo, 1995; Yick & Gupta, 2002) making

advance care planning difficult in this cultural group. Even among Caucasians, a hesitance to discuss death and dying is one of the reasons why people are not ready for advance care planning (Molloy et al., 2000; Rosnick & Reynolds, 2003).

A rich literature shows that, because of the Buddhist belief of Karma in Chinese culture, discussing things related to death is believed to be inauspicious—this brings bad luck and hastens death) (Braun & Nicles, 1997; Crain, 1997; Der-McLeod, 1995; Kemp & Chang, 2002; Orona, et al., 1994). An open discussion of death in the presence of an elderly Chinese patient is considered extremely rude and disrespectful in Chinese culture; this is almost indirectly casting a curse of an early, unexpected death. A study investigating community attitudes toward EOL care options (Braun, 1998) reported that three-fourths of the Chinese American seniors declined to participate in this project because they believed that being part of such studies would bring bad luck. Crain (1997). Some reported that they were not reticent in discussing issues related to death and dying, but they commented advance care planning is difficult for Chinese Americans because the topic is culturally sensitive.

h. **Fatalism**

Discussing death is culturally unnecessary for many Chinese Americans because they may believe that the time of death cannot be controlled. Confucian and Taoist influences on Chinese culture have created a belief that death and life have their determined appointments (Char, Tom, Young, Murakami, Ames, 1996; Eliot, 2001; Hsin, 2003); many Chinese believe there is no need to plan for or even discuss death. Evidence of this was provided by a community survey in Hawaii, in which almost half of the Chinese participants agreed, “If it is your time to die, you will,” and “Life is in God’s hands”(Braun, 1998).

This cultural belief of there being no need to discuss death and dying has an important role in Chinese Americans' readiness for advance care planning for it directly influences decisional balance and stage of change.

i. **Chinese view of a prepared good death and preclusion of hope**

Like Christians, Buddhists and Taoists both believe in the preservation of life and human dignity (Ip, et al., 1998). The traditional ideal of a good death for Chinese is a natural, peaceful death without life-sustaining treatment. Specifically, the desired characteristics of a death are to die at home (Kemp & Chang, 2002), peacefully leave the world without regret, after family duties are fulfilled, with burial clothes well-prepared, and being surrounded by offspring (Der-McLeod, 1995; Hsin, 2003; Kayashima & Braun, 1997). It can be concluded that a well-prepared and natural death is preferred in Chinese view (Anonymous, 2004; Hsin, 2003). Some Chinese Americans reported in favor of a well-prepared death and believed that the best time to complete advance directives was when a person was young and healthy (Braun & Nichols, 1996). Although advance care planning has the potential to achieve and fulfill the cultural expectation of a good death, few had executed advance directives. The reason given was that they worried advance care planning would take away their hope, and life-sustaining treatment decisions that preclude the possibility of a miracle from either God or the American medical system were better not made in advance.

The fear of taking away hope may be a barrier to Chinese Americans' readiness for advance care planning. Because longevity is the Chinese cultural desire, a case study mentioned that there is no need to complete advance directives because life-sustaining treatment will be used anyway (Hern, Koenig,

Moore, & Marshall, 1998). An earlier study (Klessig, 1992) reported that Chinese Americans were much more likely to favor initiating life-sustaining treatment and were less likely to withdraw it. Similar findings were found in the nursing home setting that Chinese American patients were more likely to initiate cardiopulmonary resuscitation (CPR) for cardiac arrest than their Japanese counterparts (Vaughn, Kiyasu, & McCormick, 2000).

j. **Chinese Americans' acculturation in relation to EOL decision making**

As mentioned in the previous section, the term Chinese Americans refers to people of Chinese ancestry who are residing in the United States regardless of their American citizenship. The majority of them have as countries of origin the People's Republic of China (China), Taiwan, Hong Kong, or Vietnam (D. T. Tsai & Lopez, 1997). Despite continuous westernization and modernization in these Chinese overseas countries, Chinese American immigrants remain very traditional in their cultural dimensions of death, dying, and bereavement (Yick & Gupta, 2002).

Speaking in broad generalizations, Chinese Americans can be categorized into four groups according to their level of acculturation: (1) the most traditional and least acculturated elderly immigrants; (2) less acculturated immigrants of working class; (3) bi-accultured professionals; and (4) American-born Chinese, who are the most acculturated. Their diverse levels of acculturation are influenced by a complex set of variables, such as the age at which they came to the United States, the length of time they have spent in the U.S., and their desire to assimilate with the dominant American culture (Triandis, et al., 1986). This level of acculturation is also highly associated with socioeconomic status (Crain, 1997; Lieber, Chin, Nihira, & Mink, 2001) and the historical period during which

Chinese Americans emigrated to the U.S. (i.e., which immigrant waves).

Elderly Chinese immigrants shared that they had not completely replaced their traditional Chinese beliefs with American values; they reported traditional Chinese beliefs that they valued were kept, some beliefs that were inappropriate in the American environment were abandoned (Chen, 1996). In general, the longer Chinese immigrants stay in the United States, the more Westernized they become (J. L. Tsai, Ying, & Lee, 2000), and at the same time they become less traditional and less interpersonal (Lin & Church, 2004). American-born Chinese's cultural identification and values, on the other hand, were closer to that of Euro-Americans than Chinese immigrants; they were found to be neither "Chinese" nor "Americans" (J. L. Tsai, et al., 2000). Lassiter (1995) explained that this was because American-born Chinese still retained a fair number of traditional Chinese values.

Being aware of immigrants' levels of acculturation is critically important in EOL decision making. Studies among Japanese Americans support this idea that acculturation strongly influences immigrants' views toward advance care planning in the aspects of a preference for disclosure of terminal illnesses and willingness to forgo life-sustaining treatment (Bito, et al., 1998; Matsumura, et al., 2002; N. Wenger et al., 1997). They found that the most acculturated Japanese Americans desired full disclosure and patient autonomy, but overseas Japanese did not endorse executing advance directives at all. It is worth mentioning that regardless of the level of acculturation, all participants preferred to involve the family in EOL decision making (Bito, et al., 1998).

Acculturation is found strongly correlated with demographical characteristics, such as age, income, English proficiency, and education (Berry, 2001). Chinese Americans' level of acculturation is

expected to influence their readiness for advance care planning, but up to now the relationship between these two variables has not been clearly established in the literature. Only one focus-group study reported that those more open to advance care planning were younger American-born Chinese, Chinese immigrants who have been in the U.S. longer, and those who were more westernized (Kayashima & Braun, 1997). Since advance care planning is not promoted in China, Hong Kong or Taiwan, Chinese American immigrants tend to consider it a foreign idea and their readiness is questionable.

k. **English proficiency in relation to EOL decision making**

If the healthcare is not provided in a familiar language, a lack of English proficiency may hinder Chinese Americans' readiness for advance care planning. The degree of Chinese immigrants' English proficiency varies and it is associated with levels of acculturation. Highly acculturated Chinese immigrants usually have a better command of English and may socialize with other cultural groups. A considerable number of elderly Chinese immigrants were found to be unable to communicate in English and thus are information-isolated. English proficiency has not been thoroughly assessed in the Census among Chinese Americans. According to an early survey in Chicago's Chinatown, 23% of respondents could read "a little" or "none" even in their native language (Yu, Huber, Wong, Tseng, & Liu, 1990). Crain (1997) in a relatively recent study also reported that many of her Chinese immigrant participants in New York's Chinatown were illiterate in both languages and could not communicate in English.

A lack of English proficiency may also influence elderly Chinese Americans' healthcare utilization. Social interaction of these immigrants who speak no English depends only on limited

Chinese-language media, their utilization of American health care services is found hindered by their language deficiency (Jang, Lee, & Woo, 1998; D. T. Tsai & Lopez, 1997). Tsai and Lopez (1997) in a California study revealed that among 93 elderly Chinese immigrants, the two main barriers to use of health care services were related to English proficiency: 53.8% of the immigrants did not know about the services offered, and 36.6% of the health care providers did not speak Chinese.

Until now, advance care planning has not been widely available in Chinese. Because of the lack of English proficiency, it is common for elderly Chinese immigrants to rely on their adult children to translate and interpret medical information (Muller & Desmond, 1992). However, these adult children are usually fairly young, of the opposite gender, and/or may not understand their parents' preferences, which makes advance care planning difficult in Chinese Americans' family context. The importance of English proficiency needed for advance care planning is not only for the illiterates. Braun (1997) reported that many elderly Chinese immigrants in Honolulu, who were comparatively highly acculturated, still had requested translation assistance in completing advance directives.

3. Knowledge factors related to Chinese Americans' advance care planning

a. Knowledge regarding life-sustaining treatment, advance directives, and advance care planning

Sufficient knowledge has been shown to be predictive of completing advance directives (Ejaz, 2000). Advance care planning is a deliberative process to help people to formulate life-sustaining treatment preferences, and as such a difficult task it requires substantial cognitive abilities (Huberman & Miles, 1995). There are complex questions to be contemplated, such as why one

needs advance directives, which type of advance directives best suits an individual's needs, which life-sustaining treatment should be used in what state of health, and so on. From a healthcare provider's perspective, one important goal of advance care planning is to increase patients and families' knowledge about advantages and disadvantages in completing advance directives. Therefore, patients' knowledge regarding advance care planning itself and the end point of advance directives are prerequisites for successful advance care planning.

According to Prochaska's Transtheoretical Model of Behavioral Change, knowledge coupled with self-efficacy moves people to advanced stages for behavioral change (J. O. Prochaska, et al., 1994). Based on this model, self-efficacy for advance care planning is influenced by the perception of having sufficient knowledge. For example, a patient who does not have enough knowledge will not be able to think through the difficult questions of advance care planning, and will not be confident about completing the advance directives.

However, the effect of people's knowledge (about advance directives and the advance care planning process) on their readiness for advance care planning has not been fully understood. One reason could be that the term "knowledge" is loosely defined. An examination of the literature in this area shows that measures of knowledge regarding advance directives and life-sustaining treatment are varied, including choices of "I am aware of," "I know," "I think I know," "I am comfortable with," "I am familiar," and so on (Braun, 1998; Caralis, et al., 1993; Crain, 1997). In addition, a standardized test of clinical understanding of advance directives is difficult to develop because of the progressive nature of disease, variations in legal documents, and complexity of life-sustaining treatments.

Based on a review of the literature, Miles and colleagues (1995) concluded that most people are aware of the possibility of advance care planning and do not object to the idea of executing advance directives. Unfortunately, this is not the case among most ethnically diverse populations in America, in particular among Chinese Americans. In fact, studies have shown that most people were unaware of advance care planning, and their knowledge about advanced directives and life-sustaining treatment was insufficient (Karnik, 2002; Rosnick & Reynolds, 2003). For example, the definition of advance directives, which includes both the living will and the durable power of attorney for health care, is still a relatively new concept for a majority of the general population (Hallenbeck & Goldstein, 1999). Patients' understanding of advance directives was found to be poor among elderly nursing home residents (Fitten, et al., 1990). Moreover, a majority of people still believe erroneously that advance care planning is only for the old and the sick (Gordon & Shade, 1999; High, 1993a).

The lack of knowledge stems from the lack of information related to life-sustaining treatment, advance directives, and advance care planning in healthcare settings. Butterworth (2003) in a review article concluded that physicians in their patient care often did not initiate a dialogue related to life-sustaining treatment and EOL care. For example, despite the public awareness of CPR, CPR-related education and people's knowledge were not parallel to their level of awareness. Overestimation of CPR efficacy was found to be rarely addressed in most advance care planning interventions (Bonner & Miles, 1997). In a study of 19 hemodialysis patients (Weisbord et al., 2000), knowledge about life-sustaining treatment was insufficient, and a majority of them (68%) paid no attention to advance care planning despite their considerable mortality, devastating symptoms, and

deteriorating health.

There also is evidence that people are confused about what advance directives and life-sustaining treatments actually are. One classic study (Caralis, et al., 1993) showed that 56% of participants claimed to know about advance directives, but only 45% of them correctly defined the term and 23% confused them with financial wills. Similarly, in the researcher's previous work, all seven Chinese immigrant participants in an informal focus group confused living wills with financial wills.

The literature has shown that even those who are equipped with some knowledge usually do not complete advance directives. Hopp (2000) reported among 520 community-dwelling respondents that, while some of them had the knowledge, they did not necessarily have advance directives completed. Of the total, only 37% had some form of advance directives and the reasons varied. Janofsky and Rovner (1993) surveyed 191 nursing home residents and their families and also found that the majority of the participants had some knowledge of advance directives (81.6% reported being familiar with durable power of attorney and 86.8% being familiar with living wills), but 80% of them did not have their advance directive decisions made. These studies, mostly conducted among Euro-Americans, have shown that knowledge about advance directives is limited in chronically ill elderly patients as well as in the general population. People are either unaware of or do not clearly understand what information is needed for advance care planning, which directly influences their self-efficacy and stage of change. People's knowledge of advance directives does not directly relate to the completion rate or preferences of life-sustaining treatment (Caralis, et al., 1993). The relationship among knowledge, self-efficacy, and stage of behavioral change has not been studied before and needs to be scientifically addressed.

b. **Chinese American immigrants' knowledge about advance care planning**

The knowledge needed for advance care planning includes adequate information about advance care planning itself, the advance directive documents, and the efficacy of several typically used life-sustaining treatments. However, for Chinese Americans, knowledge of advance directives and advance care planning is still in its infancy and is complicated by various influences of cultural beliefs and the lack of English proficiency. As mentioned above, language barriers prevent most Chinese Americans from gaining a basic awareness of advance care planning (Braun, 1998). In addition, the rationale of limiting futile treatment seems to be a fundamentally different philosophy for immigrants (Muller & Desmond, 1992). Braun and Nicols (1996) reported that many Chinese immigrants regarded advance care planning to be a foreign idea, since it is not promoted overseas in Chinese countries such as China, Hong Kong, and Taiwan. Although most Chinese Americans desire a peaceful EOL (Der-McLeod, 1995), patients and families may not have sufficient knowledge to judge when and how to forgo treatment. In a narrative case (Hern, et al., 1998), a Chinese female patient with terminal cancer replied she would “try every chance” for recovery and was confused and irritated by the idea of limiting treatment. Another unfortunate case was described by Muller and Desmond (1992) in which, because neither the terminal patient nor the family understood the type and extent of life-sustaining treatment, family did not agree to a do-not-resuscitate (DNR) order. Since there was no advance directive from the patient, the physician, convinced of the futility of possible resuscitation, executed a DNR order without the family's consent. These cases reflect the complexity of Chinese Americans obtaining culturally appropriate knowledge for advance care planning.

Existing studies about Chinese Americans have not specified how participants' knowledge was tested. There is also no standard translation of the terms "advance care planning" and "advance directives." Most of the studies gave the participants' self-reports of how much they knew about advance directives and life-sustaining treatments (Braun, 1998; Crain, 1997). As discussed above, because participants may not have an accurate understanding of the terms, self-report knowledge can be misleading. A Hawaii-based study (Braun, 1998) investigated 393 community-dwelling participants (55% Asians including Chinese Americans) and solicited how much the participants knew about advance directives. Eighty-three percent and 88% responded "knowing" about living wills and durable power of attorneys, respectively. This knowledge did not reflect on their practice, since more than 50% had not completed advance directives. Crain (1997) in a New York study asked the study question "Have you heard of advance directives?," and reported a significantly lower understanding among Chinese immigrants than among Euro-Americans. Only three (5%) participants had heard of a living will and six (10%) participants had heard of a health care proxy. Der-McLeod (1995) similarly in a qualitative report stated that elderly Chinese immigrants in a San Francisco-based nursing home claimed they understood questions regarding preferences regarding life-sustaining treatment. During informal advance care planning, after explaining the need to understand their health wishes and obtain advance directives, elderly Chinese immigrants, however, deferred EOL discussion and their decisions to adult children. It was unknown to what degree they understood the efficacies of the different types of life-sustaining treatment and various forms of advance directives.

To conclude, discussing life-sustaining treatment and advance directives with families is not a cultural norm among Chinese Americans. For this cultural group, knowledge regarding advance care planning needs to be clearly defined so that levels of understanding can be identified. Public awareness needs to be raised, standard translations developed, and information of advance directives and life-sustaining treatment options tailored to fit Chinese culture. Only when Chinese Americans are provided with all information needed for advance care planning can they decide on their treatment preferences and other personal considerations, such as family, religion, finances, and the like. This lack of knowledge needed for advance care planning has not been extensively addressed by the current American health care system. Culturally appropriate information needs to be collected to fill in this knowledge gap.

c. **Chinese Americans' previous end-of-life-related experiences**

As discussed previously, Chinese Americans' death and dying experiences are often perceived negatively for they are culturally associated with bad luck and fear of corpses (Yick & Gupta, 2002). In the researcher's previous work, although elderly Chinese American did not refuse to participate in discussing about death and dying, they considered death experiences "mysterious, often negative, and uncomfortable." Some recalled that their previous EOL experiences (a close family member or a significant other's death) were full of sufferings and sad memories. Funeral homes and Buddhist/Taoist temples, where funeral ceremonies were usually held, often triggered their negative feelings and thus discussions of previous experiences of death and dying could become emotional and possibly uncomfortable. Previous experiences related to death and dying may influence Chinese Americans' readiness for advance care planning for they may naturally avoid talking about this topic.

However, although experiences related to "death and dying" are usually thought to have a negative effect, they do sometimes increase people's knowledge and readiness for advance care planning. In a secondary data analysis study in which the participants were mainly Euro-Americans (Rosnick & Reynolds, 2003), negative life events were significantly associated with advance directives. In particular, the use of durable power of attorney for health care increased if people had experienced negative life events, such as a family member's or a close friend's death. In a multiethnic interview study (Braun & Nichols, 1996), one Chinese participant also recalled that as a result of her grandfather's existing in a coma for four years, both her parents decided to initiate living wills. These studies indicate that negative experiences trigger re-examination of one's health care planning that the

experience of a family member's death may lead people to think about their own deaths and EOL treatment decision-making.

One would think previous experience of life-sustaining treatment may increase their knowledge about life-sustaining treatment, but the effect of this experience on readiness for advance care planning is still unclear. Cohen-Mesfield and colleagues (1991) in their study of nursing home residents stated that people who have had some experience with life-sustaining treatments tend to initiate advance care planning. This experience of having life-sustaining treatment, similar to experiences of significant others' deaths, increased one's readiness for advance care planning. However, this experience itself has not shown to predict specific treatment preferences at the EOL. Caralis and colleagues (1993) on the other hand operationalized and evaluated the effect of treatment experience on patients' attitudes toward advance directives. They reported that neither the experienced nor the inexperienced patients had appointed a durable power of attorney for health care. Therefore, having previously been in the ICU or receiving life-sustaining treatment alone was not predictive of readiness for making advanced EOL decisions. Interestingly, Caralis also reported that this life-sustaining treatment experience did not increase patients' knowledge about advance directives—compared with participants who did not have the experience, they were no more likely to know (be able to clearly define) what a living will is.

In a cross-cultural study that includes Chinese Americans, Kayashima & Braun (1997) operationalized and expanded personal medical experience into experience with life-threatening conditions (self and significant others), experience with ICU (significant others), experience with caregiving (self), and experience of using hospice (significant others). The results showed that more

elderly people than adult children had experienced a life-threatening illness themselves, but no significant differences were found between generations regarding all other experiences. Approximately 56% of Chinese Americans had had a family member or close friend in the ICU for more than 30 days. Despite the fact that personal experience was the second common reason why Chinese American participants decided to draw up a living will (25%) or have durable power of attorney for health care (31%), influences of medical experience on Chinese Americans' readiness for advance care planning was not specifically addressed in this study.

Previous experiences of EOL discussions may have an effect on advance care planning, but this relationship also has not yet been established in the literature. While the experience of participating in family's advance care planning is expected to have a major effect on people's knowledge about advance care planning, how physician-patient EOL discussion influences Chinese Americans executing advance directives and their motivational readiness has not been reported. Finally, other than patients' EOL-related experiences, a separate concept worth discussing is a person's personality trait regarding "openness to new experience." It has been reported that that a person's openness to new experiences was the only personality trait related to advance directives completion (Rosnick & Reynolds, 2003). This finding suggested that the more the individual was open to new experience, the better his or her readiness was for advance care planning. For Chinese Americans, those who are more open to new ideas and experiences may be more ready for advance care planning. To conclude, patients' previous experience with a family member's (or significant others) death and dying, their own experience with ICU and life-sustaining treatment, and previous physician-initiated EOL discussion form a complex

construct. The net effect of these experiences on people's readiness for advance care planning needs to be further explored.

4. **Quality of Life**

a. **Conceptualization of Quality of Life and life-satisfaction**

The understanding of the relationship between quality of life (QOL) and advance care planning is still limited, not to mention how people's QOL influences their readiness for advance care planning. QOL is a complex construct and the conceptualization of QOL should acknowledge its subjective, multidimensional nature (Ferrans, 1996). It is universally agreed now life satisfaction in multiple domains is the most appropriate QOL definition, and this should not be erroneously equated with the conditions of life (Campbell, Converse, & Rodgers, 1976) or functional status (Gill & Feinstein, 1994).

In fact, life-satisfaction should be paid more attention when conceptualizing QOL in the context of EOL decision-making. It is because preserving dignity at the EOL is a fundamental desire that underlies all advance care planning (Huberman & Miles, 1995). The conceptualization of QOL in this case, often weighed against longevity, is obvious an evaluation of overall life satisfaction. The term "quality of death" often used by Chinese elderly people which refers to a peaceful death without life-sustaining treatment (Der-McLeod, 1995) is also an evaluation of life satisfaction instead of physical, functional status. Functional status or physical health are problematic conceptualizations of QOL for they only limits QOL in one physical domain (Gill & Feinstein, 1994) and is clearly insufficiency when considering the role of QOL in advance care planning. Advance care planning

which aims to prevent future unbearable, worse-than-death situations is a consideration of life satisfaction.

Life satisfaction as a QOL variable for advance care planning has not commonly been included in recent studies of advance care planning. However, health status measures have often been measured in EOL studies as indicators of severity of illness. Some studies despite their intention to include QOL as a variable often did not include or wrongfully defined life satisfaction. For example, Teno (2000) recommended palliation of symptoms (palliation of cancer pain) be included as a QOL measure in one randomized advance care planning intervention study (Molloy, et al., 2000). However, palliation of symptoms is a physical health measure and does not capture the concept of life satisfaction. Crain (1997) in her EOL decision making study concluded that there was no difference between Chinese Americans' life satisfaction and attitudes toward death, but the measure "value history questions" used in her study is neither a life satisfaction measure nor captures the multidimensional construct of QOL.

The only study found to compare life satisfaction and advance care planning was Rosnick and Reynolds' secondary data analysis (2003). They reported that among respondents (mostly White) who indicated being more satisfied with their lives, the chance of executing advance directives increased 228%. Life satisfaction seems to influence the likelihood of initiating advance care planning.

Since the effect of Chinese Americans' QOL on their readiness for advance care planning has not been examined in the literature, it is important to choose a life-satisfaction measure that correctly conceptualizes QOL. Ferrans' QOL definition (Ferrans & Powers, 1992) as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to

him/her (p.29),” manifested in her Quality of Life Index (QLI), represents an appropriate conceptualization of QOL for EOL decision making.

b. **General health status and advance care planning**

It appears that underlying disease and its prognosis motivate people to plan for future life-sustaining treatment. Advance care planning, therefore, is found often considered and used predominantly among patients who are in poor health. For example, the rate of those using advance care planning was found to be generally higher in hospitalized patients than in the general population and also higher than in people with terminal illnesses, such as AIDS and cancer (Huberman & Miles, 1995). As expected, physicians usually initiate EOL discussions and suggested advance care planning among older and sicker patients (Morrison, Morrison, & Glickman, 1994).

While a worsening health status may precipitate advance care planning, healthy people usually procrastinate and rarely complete advance directives (Butterworth, 2003) because they believe they are not sick enough. In two studies, use of advance directives was studied among participants who were community-dwelling, generally in good health, fairly educated, highly functioning, and somewhat affluent. Gordon (1999) found that although self-rated health status alone was not predictive, people who were older and in poor health tended to execute advance directives. Similarly, in Rosnick’s study (2003), the number of prescription medications, selected as a variable to represent health status, was an important predictor for advance directives.

Although it is anticipated that self-rated health status would be positively related to readiness for advance care planning among Chinese Americans, there has been no study examining this relationship.

In Crain's study (1997) Chinese immigrant respondents were asked to rate their overall health, but this information of health status was not compared with participants' knowledge and readiness for advance care planning. Another study (Braun, 1998) revealed that Chinese Americans perceived their health to be generally "good" (three on a four-point Likert scale), but again participants' health status in relation to their EOL decisions was not reported, even though questions regarding advance care planning questions were asked.

5. **Spirituality**

a. **Conceptualization and measurement of spirituality and religiosity**

Patients in general believe that spirituality plays an important role in their lives and religious commitment has been found to correlate positively to health outcomes (Anandarajah & Hight, 2001). Spirituality is a complex, multidimensional part of the human experience; it encompasses both religious and nonreligious perspectives (Puchalski, 2006). In order to understand the relationship between spirituality and advance care planning, a clarification of the difference between spirituality and religiosity is necessary. According to Highfield and Cason (1983), spirituality is "the need for finding satisfactory answers to...ultimate questions about the meaning of life, illness and death (p. 187)." Among the many aspects of spirituality are: (a) the search for meaning and the purpose or truth in life; (b) feelings of hope, love, connection, inner peace, comfort, and support; (c) the ability to give and receive love; (d) relationships within self, community, nature, and the transcendent; and (e) the way a person may manifests his/her spiritual beliefs and inner state externally (Anandarajah & Hight, 2001).

One's spirituality can be assessed according to the above conceptualization, but it should be made clear that although spirituality is often found through religion or a personal relationship with the divine, it should not be limited to or equated exclusively with religiosity. Assessment of spirituality should be broader than religious beliefs and practices because people who consider themselves quite spiritual may not adhere to any particular religion. In the instrument System of Beliefs Index (Holland et al., 1998) used in this study, spirituality is conceptualized in four domains: existential perspective on life and death, religious beliefs and practices, social support received from religious and spiritual community members, and relationship to a superior being. Spirituality can be measured by examining the person's existential perspective on life and death and relationship to a superior being, which may or not may be related to their religious beliefs (Holland, et al., 1998).

b. **Religiosity and advance care planning**

The construct of religiosity is also multidimensional, and often includes an intrinsic aspect of a system of religious beliefs and an extrinsic social aspect involving religious traditions, social interactions, and rituals (Cristian J. Nelson, Barry Rosenfeld, William Breitbart, & Michele Galietta, 2002). A simplistic religiosity instrument usually measures a faith belief and the frequency of attending religious services (Cristian J. Nelson, et al., 2002). For example, in a study soliciting African American caregivers' EOL decisions (Bonner et al., 1999) religiosity was measured in terms of formal religious inner beliefs and overt participation.

Religious beliefs and participation in church and worship have long been associated with improved health, but religiosity has not often been included as a variable in intervention studies of

advance care planning. In addition, most of the studies about religiosity related to EOL decision making have been conducted within the African American population (Mouton, 2000), because more African Americans than Caucasians believed that religious beliefs have strongly influenced how they face death. Prayer was noted to be the way in which many of African Americans practiced their religion (Kalish & Reynolds, 1976).

Religiosity appears to have a minor effect on the completion of advance directives (Huberman & Miles, 1995). In other words, stage of change for advance care planning could be influenced by self-rated religiosity. One common reason that people do not have advance directives is that they believe fate or God should make these decisions (Butterworth, 2003). Bonner and her colleagues (Bonner, et al., 1999) in their interviews with 100 African American family caregivers, reported that all participants who claimed to be quite religious viewed life-sustaining treatment as pointless for God would be the ultimate decision maker. In contrast, in a study of mostly elderly White patients, Mold and colleagues (1994) in a retrospective chart review of 178 patients reported that patients with higher levels of religious involvement were actually more likely than others to express a desire to start planning for EOL decisions. The relationships among spirituality, religiosity, and readiness for advance care planning need to be further assessed.

c. **Chinese Americans' religiosity**

The relationship between religiosity and their readiness for advance care planning has not been established among Chinese Americans. While Chinese immigrants become Westernized and many of them convert to Christian beliefs, their spirituality becomes a complex combination of

religious and cultural beliefs. Chinese American Christians, in particular elderly Chinese immigrants, may practice Protestant or Catholic religions but remain greatly influenced by a cultural mix of superstition, folklore, Taoism, Buddhism, and Confucianism (Yick & Gupta, 2002). In addition, because the community church is often the source of social interaction opportunities for Chinese immigrants, some may consider social support from the religious community members more important than their religious beliefs or relationship to God.

Braun and Nicoles (1997) found that Chinese immigrants' beliefs about advance care planning differed among people who were third- or fourth-generation American-born Chinese; differences were found between new immigrants who were younger Christians and older Buddhists (or Confucianist). Those more open to advance care planning were younger American-born Chinese, Chinese immigrants who have been in the U.S. longer, and those Christians who were more westernized. But exactly how religiosity and a change of religion preference influence Chinese Americans' advance care planning was not reported in this study.

Chinese Americans' religiosity is anticipated to influence their readiness for advance care planning. To understand religiosity among Chinese Americans, additional questions should be asked; for example, in which religion were they raised, what is their current religion preference, how do their religious beliefs acculturate to the Protestant culture, and how do their cultural beliefs influenced by Chinese religions still play an role. Chinese American Christians, following Calvinist beliefs as most African Americans (Mold, et al., 1994), may believe that because life was in God's hands, one should only follow God's plan and not plan these things oneself. This belief of following the laws of nature is

also grounded in many Chinese Americans regardless their religions (Yick & Gupta, 2002). This outlook may also be influenced by traditional Taoist beliefs in Chinese culture. For Chinese American immigrants, the Protestant beliefs seem to play a role in their readiness for advance care planning; it is important to note that not all Chinese Americans are Christian believers and not all these believers view death and dying from a purely Christian perspective.

To conclude, spirituality and religiosity are highly correlated constructs but should not be used synonymously. As terminal patients proceed toward the EOL, the complex construct of spirituality and religiosity may have a direct effect on people's readiness for advance care planning. Since there has not been as much research into the effect of spirituality on advance care planning as there has been into physical health effects, more studies are needed in this area in particular among Chinese Americans.

6. **Demographical characteristics**

a. **Age**

Socio-demographic factors as predictors of advance care planning have been studied primarily in White populations (Gordon & Shade, 1999; Huberman & Miles, 1995; Mold, et al., 1994; Rosnick & Reynolds, 2003). Age, along with physical health status, was often considered together in studies of advance care planning. In general, studies have found that age is a factor of advance care planning; the older the people, the more likely they were to begin advance care planning. Evidence was provided in a recent Florida study among 451 relatively healthy and affluent community-dwelling elderly people. Age was the only significant predictor for the completion of any type of advance directives (Rosnick & Reynolds, 2003). In fact, each additional year of age suggested an 11% greater

chance of having advance directives executed. Miles and colleagues (1995) cautioned that since age is highly related with other factors (such as the factor of an underlying, unexamined severity of illness), a simple bivariate analysis between age and advance directives may not yield appropriate results.

Evidence for this was found in a random-sample survey among elderly HMO consumers (Gordon & Shade, 1999) in which age was reported to be the only predictor for the use of advance directives and other demographic factors including gender, ethnicity, marital status, or self-rated health status did not play a role. It was obvious that age was highly associated with EOL discussions—the older the people, the more likely that a clinician would initiate EOL discussions. This indicated that age was confounded with other demographic factors and should not be considered as a sole predictor.

It is anticipated that age will play a role in Chinese Americans' readiness for advance care planning. A cross-cultural survey found that elderly people were more likely to have advance directives than their adult children; however, this sample included all Asian Americans, not only Chinese Americans (Braun, 1998). This was the only study found the literature examining this relationship. For centuries, longevity has been a cultural desire (Braun & Nichols, 1996; Muller & Desmond, 1992) and respect for the elderly is a social norm in Chinese culture (McLaughlin & Braun, 1998). Age alone or associating with other factors might contribute to Chinese Americans' readiness for advance care planning.

b. **Gender**

In the literature, gender was not a predictor of executing advance directives, but gender differences were found in patients' attitudes toward life-sustaining treatment. In general, females were

less likely than males to have a positive attitude toward life support (Blackhall, et al., 1999), and female African American caregivers of elderly patients with cognitive diseases were found less likely than the male caregivers to prefer a particular life-sustaining treatment, mechanical ventilation (Bonner, et al., 1999).

The gender effect on Chinese Americans' readiness for advance care planning has not been clearly reported. However, as mentioned in the previous section, due to a cultural norm of male paternalism, Chinese American women are generally powerless and do not have control over their own health care. When making advanced decisions about life-sustaining treatment, males and females are expected to be different in their locus of control and self-efficacy. Therefore, it is hypothesized that Chinese American females' readiness for advance care planning would be lower than that of Chinese American males.

c. **Income**

It has been reported that advance care planning is more common among people who are of higher socioeconomic status (Silverman, Tuma, Schaeffer, & Singh, 1995; Sugarman, Weinberger, & Samsa, 1992), but these studies were mostly conducted among Caucasians. Rosnick and Reynolds (2003) reported that income, as an approximation of socioeconomic status, was predictive of advance care planning. Specifically, they found if participants' income was in the top tertiary level, their chance of having an advance directive (a durable power of attorney for health care) increased 131%. If participants' income was in the bottom tertiary level, their chance of having advance directives (living wills) decreased by 66%. These findings indicate that income has directly impacted people's stage of

change for advance care planning. On the contrary, in a Miami multiethnic study of 139 community-dwelling healthy outpatients, socioeconomic status (education level coupled with income) was reported to be not predictive of patients' preferences regarding life-sustaining treatment (Caralis, et al., 1993).

The effect of income alone on Chinese Americans' readiness for advance care planning has not been explored. There is great economic diversity among Chinese Americans, and income is anticipated to rise along with participants' education and acculturation. According to the last U.S. Census (U.S. Census Bureau, 1997), American-born Chinese and Taiwanese American families tended to have better incomes than other Chinese American subgroups, but such income comparison has not been reported in the Census 2000. In addition, elderly Chinese American immigrants residing in big cities often have a low socioeconomic status. Crain (1997) reported that compared with their Euro-American counterparts (41%), 93% of her Chinese American participants were living in poverty and had Medicaid. But the overall percentage of families below the poverty level for all Chinese Americans (about 11%) was reportedly similar to that of the general American population (10%) (McBride, Morioka-Douglas, & Yeo, 1996). Chinese Americans are not wealthier or poorer than their counterparts. As far as we know, no recent data are available of Chinese Americans' income in the 2000s.

d. **Education**

From the existing literature, the relationship between education and readiness for advance care planning has been generally established: people who are better educated and who come from a relatively higher socioeconomic class tend to start advance care planning and complete advance

directives (High, 1993b; Schonwetter, Teasdale, Taffet, Robinson, & Luchi, 1991; Stelter, Elliott, & Bruno, 1992). Only one study, in contrast to this finding, found that college graduates were significantly less likely to have advance directives than other less-educated people, even controlling for age and gender (Gordon & Shade, 1999). However, this finding can be explained by the effect of age that younger people are less likely to think about EOL treatment decisions and have advance directives.

Better education may be related to greater trust in the health care system, better ability to understand and complete advance directives (Huberman & Miles, 1995), and a greater desire to be involved in medical decision making (Caralis, et al., 1993). Low education, on the other hand, was associated with low knowledge level about advance directives (Caralis, et al., 1993). For example, in a multiethnic study (Caralis, et al., 1993), 61% of patients who were less educated did not know what an advance directive was, and their preferences in advance directives were less stable and more likely to change over time.

Education is anticipated to be associated with other socioeconomic factors among Chinese Americans. Braun and Nichols (1996) have conducted a series of focus group interviews soliciting Asian American immigrants' attitudes toward death, dying, and advance directives. As expected, they found that Chinese Americans who were better educated and acculturated tended to have already thought about advance care planning (planned to have living wills). However, their actual use of advance directives and readiness for advance care planning was not reported in this study. Crain (1997) reported that the knowledge of advance care planning was significantly lower in her Chinese American participants than their Euro-American counterparts, because most of the participants were monolingual

and often illiterate in both Chinese and English. The average number of years of education of her Chinese American participants was five, much fewer than in other elderly Euro-Americans.

7. **Strategies used in advance care planning interventions**

a. **Advance care planning in the general public and other populations**

Initiating advance care planning discussions is generally difficult and may be uncomfortable for both patients and health care providers (Hammes & Briggs, 2004). There is a growing interest in implementing advance care planning in special patient populations. This section summarizes various strategies in recent advance care planning interventions with the attempt to search for an appropriate approach for Chinese Americans.

The literature has shown that most advance care planning has targeted special-patient populations rather than the general public, but studies supported by the Agency for Healthcare Research and Quality (Kass-Bartelmes & Huges, 2003) still concluded a lack of advance care planning among chronically ill patients. Advance care planning interventions have mainly focused on individuals with end-stage chronic illnesses, such as heart failure, renal disease, and AIDS. Among these patients, the advance care planning needs are beyond the typical decisions of life-sustaining treatment that the general population makes. Intervention strategies conducted for terminally ill populations are complex and include components of disease, prognosis, caregiving, and possible life-sustaining treatment. For example, the advance care planning intervention developed by a palliative multidisciplinary team at a University medical center setting focused on severely ill hemodialysis patients' specific needs (Weisbord, et al., 2000): the process of advance care planning consisted of recommendations for

symptom management, functional capability restoration, completion of advance directives, and a review session by both patients and nephrologists. Another advance care planning intervention supported by the Heart Failure Society of America has incorporated education materials of heart failure, emergency care, and information regarding commonly used life-sustaining treatment (Heart Failure Society of America, 2005). The “Let Me Decide” intervention (Molloy, et al., 2000) that addresses nursing home residents’ needs for advance care planning has instructional and proxy components to educate both staff in local health care institutions and potential proxies for mentally incompetent residents.

Disease-oriented intervention strategies are suggested unsuitable for the general public. Experiences from the successful “La Crosse advance care planning program” may be illuminating for health care providers who wish to implement advance care planning among relatively healthy individuals or those with well-managed chronic illnesses. Brigg (2003) concluded that the process of advance care planning for the general population can involve a fairly standardized procedure. The goals for this type of advance care planning are usually to introduce the purpose of advance care planning; plan for the unexpected situations; discuss personal preferences with families or loved ones; select a proxy; and learn how to complete, distribute, and maintain directives.

b. **Teaching strategies in advance care planning interventions**

In the literature, various interventions have been designed to effectively increase the general population’s completion of advance directives, including community-based education, outpatient education among the frail elderly, and discussions initiated during follow-up visits after

hospitalization (Huberman & Miles, 1995). Teaching strategies included in these multimodal education programs usually combine face-to-face education with written material, classes, or multiple media (tapes and videotapes). In addition, a combination of didactic education to both healthcare providers and administrative staffs has successfully increase completion rates of advance directives in that healthcare providers were encouraged to spend extra time with patients and families to discuss advance care planning (Markson, Fanale, Steel, Kern, & Annas, 1994).

In addition to educational sources such as written materials of brochures or multimedia, a teaching strategy recommended in almost all interventions was a structured, patient-centered advance care planning interview (Linda Briggs, 2003; Kass-Bartelmes & Huges, 2003; R. A. Pearlman, Cain, Cole, Uhlmann, & Patrick, 2000; Robert A. Pearlman, William G. Cole, Donald L. Patrick, Helene E. Starks, & Kevin C. Cain, 1995). Using semi-structured interviews in a discussion format, patients and proxy families were encouraged to start advance care planning and/or complete advance directives. Medical jargon was to be avoided in the discussions, and credible information was to be provided to replace misconceptions. Health care facilitators would be able to explore patients' and families' understanding about patients' current health status and various forms of advance directives, clarify their values for future care and treatment options, and help patients and families fine-tune personal values and treatment preferences.

This interview strategy has been used in a randomized trial among patients undergoing cardiac surgery and their surrogates (Song, et al., 2005). The results showed that the intervention significantly improved patient-surrogate congruence and reduced patient decisional conflict. However, it was

interesting that no difference was found in patients' knowledge of advance planning between the interview intervention group and the control group. This result was explained by the authors that this strategy was mainly designed to explore values rather than increase knowledge. A slightly different discussion format was suggested by Gillick (2003) that its focus was on helping patients to prioritize their personal goals rather than decide on specific treatment preferences. This type of advance care planning strategy was successful in assisting patients and their proxies to set their priorities for care goals, and it also helped physicians to narrow possible interventions in medical crises. Other useful teaching strategies included using a patient-centered workbook (Robert A. Pearlman, et al., 1995) or a check list (Voltz, Akabayashi, Reese, Ohi, & Sass, 1998) during the interview. This type of teaching strategy was interactive and designed to accommodate patients' different needs in learning. Bonner's advance care planning intervention provided an example of interactive teaching strategies (Personal Communication, May 12, 2006). Based on Bandura's self-efficacy framework (1982), Bonner's intervention, proposed to assist African American caregivers to make advanced EOL decisions, adopted Kolb's experiential model "Teaching around the Circle" in designing learning objectives, teaching techniques, methods, and specific learning activities. Included in her interactive intervention were teaching strategies of a concrete experience, a reflective observation, an abstract conceptualization, and an active experimentation. Participants from an adult day-care center were to discuss advance care planning topics in a group format led by a nurse facilitator. During the discussions, education about advance directives and the risks and benefits of life-sustaining treatments related to dementia would be offered with the aim of increasing self-efficacy and knowledge for advance care planning.

The religious community approach is recommended as a useful teaching strategy. A Hawaii-based EOL project offered an example of advance care planning intervention in religious community that educational activities and resources are included in a free handbook for people who wish to discuss EOL issues at churches and temples (Kayashima & Braun, 1997). Their goal was to provide sources of information and general outlines to promote education and stimulate conversations on issues of advance care planning in the religious community. In this handbook, specific discussions and activities, suggestions for speakers from the congregations, facts and resource materials, and agency directories were included. Lectures, workshops, and special-emphasis months were conducted to evaluate participants' advance care planning. Reportedly, this intervention has successfully conducted many focus groups in faith communities. Although the general public has used the training in care for the dying and bereaved (Braun, 2002), no detailed data of participants' acceptance of this program have been reported.

Finally, an advanced-level strategy was reported in the literature for health care organizations/communities to evaluate their current EOL services and advance care planning interventions. Because the "Respecting Choice" program in Wisconsin has received national attention for developing a system of advance care planning practices, policies, and education, a quality-improvement toolkit based on their experiences was developed. The strategy suggests organizations and communities addressing advance care planning components of community engagement, professional education, and organization/community standards of practice. For the purpose of quality control, specific outcomes of interventions should be defined and measured. In

general, a variety of system changes are recommended to be integrated into the quality improvement plan in order to achieve optimal and sustainable outcomes (Hammes & Briggs, 2004).

To summary, although intervention strategies have differed widely, they always included two basic components: (a) education programs for both health care providers and the patients (sometimes family proxies), and (b) facilitated discussions regarding values, goals, advance directives, and life-sustaining treatment preferences. In general, the intervention strategies intended to assist people realize that it is necessary to complete advance directives, understand the information needed for their health status, and translate their beliefs and values into specific treatment preferences. Caralis and colleagues (1993) suggested intervention strategies be designed specifically for cultural groups, and early and ongoing dialogues should be encouraged between patients and health care providers.

c. **Useful strategies for Chinese Americans' advance care planning**

To date, no advance care planning interventions have been developed exclusively for Chinese Americans. In one article (Nicoll, 2002), the author mentioned a Taiwanese American nurse who has personally conducted workshops for Chinese Americans on how to complete advance directives and use this documentation to initiate EOL care conversations with families and health care providers. However, no details about the workshop content were reported and no information has been published regarding this workshop.

This researcher has conducted a group conversation soliciting Chinese American Christians' (n = 7) preferences for future advance care planning interventions. Interview questions included: how they expected the intervention program to help them to deal with feelings about death topics; what type of

activities they would like to have in the intervention program; what group format would be most comfortable to them in terms of age, gender, family, friend composition, and so forth; and what activities, media, frequency, and location they might want to participate in. The preliminary findings provided an interesting insight into Chinese Americans' readiness for advance care planning, their preferences for such interventions, and the appropriate teaching strategies suitable for their needs.

First of all, American-held education sessions were not attractive to Chinese American participants; some participants stated that "these were not things for us." They reported they would shy away from sessions held in health care facilities, such as hospitals and nursing homes for the setting made them somewhat uncomfortable. Preferred are church-based, education-oriented, Chinese-language, free seminars or workshops. They would be interested in programs that their close friends have had highly recommended, and preferably led by someone they knew, medical professionals, or well-known figures in the community. Multimedia lecture was favored, but most elderly participants clearly mentioned that they would not want to use computers. Also, individual activity was more desired for many elderly Chinese Americans were afraid that they would be made fun of and/or embarrassed in public. A group discussion format not longer than 2 hours was preferred because an individual one-on-one program seemed too intensive for the participants. They would prefer groups of individuals with backgrounds similar to theirs (i.e., age, health condition, and church fellowships). The most outstanding result was probably that they were horrified by the idea of having family members get together as a group to discuss and make EOL decisions. Most elderly Chinese

immigrants regarded this as unnecessary and uncomfortable, and would not reveal more about their attitude.

Five out of the seven participants specifically indicated that the sessions should never force them into making any commitments or decisions. They stated, “If I liked this program, I would go for another two or three times.” “Once a week is enough. Why would I need more?” “Is there that much to learn?” They expressed that their concentration span was approximately two hours for each session, and it was a cultural expectation to have snacks or meal breaks provided in between. When asking about what other information they would like at this point in time, most elderly Chinese immigrants were interested in knowing about the relationship between cost and life-sustaining treatments. In addition, topics of insurance and chronic illness related to EOL were popular during the focus group sessions; however, they also agreed these were not their urgent needs at this point in time.

To conclude, the education materials that may be useful for Chinese Americans include educational materials such as brochures and videos, vivid descriptions and explanations of common chronic diseases among Chinese Americans, information about typically used life-sustaining treatments translated into Chinese layman terms, and a worksheet or checklist documenting the advance care planning discussions. Health care providers trained to be culturally appropriate and capable of reflecting Chinese Americans’ values are also crucial to deliver this health service. A theoretical-based, religious community-targeted, Chinese-language, and culturally friendly intervention may increase Chinese Americans’ readiness for advance care planning. However, it is noteworthy that not all advance directives are completed with the assistance of health care providers (Huberman &

Miles, 1995). An early study found that married, female, elderly, poor, less-educated Chinese immigrants tended to use informal social networks for information rather than the official services that Caucasians usually used (Endo, 1984). This may indicate that, to increase Chinese Americans' readiness to complete advance directives, training non-health professional facilitators for informal advance care planning may be effective. Lastly, Briggs (2003) commented that sometimes listening itself is the best advance care planning intervention. Because Chinese Americans are usually uninformed, the best advance care planning strategy for Chinese Americans might be health care providers explain Western values that might conflict with their cultural beliefs, facilitate the dialogue, further explore their preference of life-sustaining treatment, and listen to any of their concerns.

C. **Summary**

This chapter is a review of research literature concerning Chinese Americans' readiness for and current practice of advance care planning. The conceptual model for this study is developed from an extensive review of the literature and the conceptual basis of this study is the Transtheoretical Model of Behavioral Change (TTM) (J. O. Prochaska & DiClemente, 1983b; J. O. Prochaska, et al., 1994). This study focuses primarily on motivational readiness in making a behavioral change for advance care planning. It is apparent from this review that Chinese Americans' readiness for advance care planning is associated with factors of culture, knowledge, quality of life, spirituality and demographic characteristics. The literature review indicates that Chinese Americans' readiness for advance care planning has not been well recognized and the relationships among these factors and readiness for advance care planning have not been clearly understood. Some of these factors contributing to readiness have been investigated in Western cultures, but almost no such information exists among Asian cultures, particularly in elderly Chinese Americans. Understanding these factors will aid healthcare providers in designing appropriate and culturally competent interventions to enhance the quality of care for Chinese Americans and prepare them for a better EOL.

III. METHODOLOGY

A. Study Design

This study has a non-experimental, descriptive cross-sectional design, using both quantitative and qualitative methodologies, to describe and identify factors influencing Chinese Americans' motivational readiness for advance care planning. A convenience sample of 211 adult Chinese Americans aged 45 years and older from four community churches in the greater Chicago area were recruited and asked to complete a self-administered questionnaire. In addition, a subsample of 28 elderly Chinese Americans aged 65 and older was asked to participate in in-depth qualitative interviews. The qualitative interviews, guided by the conceptual model (Figure 1), were to validate the questionnaire data and provide additional insights of Chinese Americans' readiness for advance care planning. Interview participants were selected based on their willingness to participate, physical ability to complete the interview, and various statuses of readiness for advance care planning.

The technique of combining quantitative and qualitative methods is known as *mixed method* (Tashakkori & Teddlie, 2003). This mixed method approach is sometimes referred to as *triangulation* (Breitmayer, Ayres, & Knafl, 1993) or a design of *concurrent triangulation*, where two methodological approaches are used to confirm, cross-validate, or corroborate findings within a single study (Creswell, 2003). In this present study, both quantitative and qualitative data were collected independently at the same time and analyzed to answer a single type of research question, and the final inferences were made on the basis of both quantitative and qualitative findings. A particular methodological framework was followed to meaningfully integrate and analyze both types of data (see more information in the latter section of data analysis) (V. J. Caracelli & J. C. Greene, 1993; Greene & Caracelli, 1997; Greene, Caracelli, & Graham, 1989).

Employing a mixed method design for this study is not only desirable but also essential because the understanding of Chinese Americans' readiness for advance care planning is still in its infancy.

This design offers a unique opportunity to support quantitative instruments with narrative data in several important components of this study, such as motivational readiness, cultural and knowledge factors, and spirituality related to Chinese Americans' advance care planning. The *quantitative component* of this study assumes an underlying statistical association among variables. Aims of quantitative analysis are to describe and understand what factors contribute and influence the outcome variable and indicators of the dependent variable. This descriptive cross-sectional design in the survey component employs 13 self-report instruments and demographical questions to describe physical, spiritual, and socio-cultural factors that influence Chinese Americans' readiness for advance care planning. On the other hand, the *qualitative component* of this study, from a purposive, non-random sample, attempts to understand the complexity of Chinese Americans' concerns and motivational readiness for advance care planning. Semi-structured interviews were conducted among elderly Chinese Americans in order to identify meaningful themes (Lincoln & Guba, 1986) and to enhance the interpretation and understanding of quantitative data (V. W. Caracelli & J. C. Greene, 1993).

B. Sample

1. Sample design and recruitment settings

The Chinese American sample in this study consists of self-identified Chinese American participants from four Chinese community churches in greater Chicago area. The rationale for using a convenient church sample is twofold. First, local churches are important for adult Chinese Americans' socialization; it has been observed that most adult Chinese Americans, in particular elderly immigrants, choose to go to non-English, Chinese/Taiwanese-speaking churches, which relatively young Chinese Americans usually prefer English-speaking worships and services. According to an unofficial report (Taipei Economic and Cultural Office in Chicago, 2004), 80% of the Chinese American immigrants in greater Chicago area have been contacted at least once by a community Chinese church or have been invited to church activities during Chinese cultural holidays.

Second, a recent trend of educating advance care planning in public is encouraged to be faith community related. In particular, this type of intervention is better to involve ministry or religious caregivers with the purpose to reach the dying and the bereaved (Kayashima & Braun, 1997). Education within faith communities was found to be successful among multiethnic populations as well. According to the Hawaii's Coalition to Improve End-of-life Care (Braun, 2002), after completing ministry education of advance care planning, advance directive completion rates increased from 29% to 32% in the general public and from 62% to 68% in residents aged 65 and above. Conducting research in the Chinese American faith community is desirable especially in the aspect of understanding how readiness for advance care planning is influenced by spirituality issues and religious beliefs. Findings of this study will provide insights when developing future intervention in the context of Chinese American faith communities.

This sampling strategy, however, excludes many adult Chinese Americans who are physically inaccessible to churches and those who do not identify themselves with Christian beliefs. It also excludes those Chinese American church-goers who participate in English-speaking services. Since this study is the first initiative to understand motivational readiness for advance care planning among Chinese Americans, this convenient church sample is not ideal but an acceptable technique to study multiple factors' effects on readiness. It is acknowledged that the selected participants do not represent the non-churchgoing Chinese American population, and results from this study cannot be over-generalized..

There are reportedly 26 Chinese/Taiwanese/Cantonese (non English-speaking) community churches within the Chicago metropolitan area (Chinese Christian Herald Crusades, 2006) together serving more than 2,500 Chinese American Christians immigrating from China, Taiwan and Hong Kong. Only one church is located in the Chinatown, and 25 other churches are located in middle- to upper-class, suburban areas in greater Chicago. Among these churches, selected are four churches with

congregations larger than 100 and whose locations are geographically close to the largest Chinese communities.

2. **Considerations of sample size**

a. **Sample size for the survey**

It is necessary to determine the appropriate number of subjects for the quantitative component of the study. Required sample size depends on several parameters, such as desired power, alpha level, expected effect size, and a number of predictors. Normally a power analysis is performed and effect size (f^2) would be estimated to achieve this goal (Cohen, 1988). However, information needed for a power analysis and the effect size is not available from previous studies that have examined similar phenomena. Many instruments developed for this study have not been used before as well. Pedhazur and Schmelkin's (1991) recommendation of approximately 10 subjects per predictor for a reliable regression equation is then employed in this study. Because 19 predictors will be used to examine their influences on the dependent variable, a minimum number of 190 subjects for the quantitative survey will be adequate. This study has successfully recruited 211 subjects for the quantitative questionnaire.

b. **Sample size for in-depth interviews**

Additional consideration is also needed in determining a sample size sufficient for the qualitative interviews. A common understanding of the qualitative sampling logic is that generalizability and representativeness are not strictly defined as with quantitative sampling—whether the sample size is sufficient for qualitative interviews depends on the purpose of the study and the judgment and experience of the investigator. However, these common beliefs may lead to inadequate sampling and sample size may be either too small to present a new and richly textured understanding of experience, or too large to provide a deep, case-oriented analysis (Sandelowski, 1995). Tashakkori and Teddie (2003) has recommended a “manifest effect size” for qualitative sampling, and the goal is to

reach *data saturation*, the point at which no new insights are likely to be obtained. After discussing with two qualitative investigator experts, a minimum of 20 elderly Chinese American subjects (10 males and 10 females) was recommended to be recruited for participation in the in-depth interviews. However, it is possible that because these 20 interviews may not provide saturation, the final qualitative sample size may be as large as 30. A total of 28 subjects (16 females and 12 males) have successfully completed their in-depth interviews, and because gender differences were noted during data analysis, saturation of data was determined for each gender separately so more females were recruited for this study.

3. **Inclusion criteria**

a. **Inclusion criteria for the total sample (quantitative sample)**

For the quantitative survey, a convenience sample of a minimum of 190 Chinese Americans was necessary and a total of 211 subjects have been successfully recruited from four Chinese churches. The inclusion criteria for these subjects were: a) self-identified Chinese-ethnic Americans who are aged 45 and older, b) Chinese Americans who can read (traditional) Chinese, and c) Chinese Americans who attend Sunday service in the target church settings during the data collection period (one of three consecutive Sundays).

Because of the culturally-sensitive nature of the study question, participants are limited to self-identified Chinese Americans; however, no subjects will be excluded based upon gender, economical and marital status, sexual orientation, or religion preferences. Both male and female have equal opportunity to participate in this study.

b. **Inclusion criteria for the interview subsample (qualitative sample)**

A purposive, non-random sample of 28 elderly Chinese Americans were recruited for and have successfully completed in-depth interviews. Because it is critically important to explore how much elderly Chinese Americans, in the trajectory of EOL, understand or are receptive to advance care

planning, semi-structured interviews are best conducted among those who are very traditional in their cultural view and may use advance care planning in the near future. Specific inclusion criteria for the interview subset include self-identified elderly Chinese Americans: a) who are aged 65 or older, b) who understand and speak fluent Chinese, and c) who are willing to discuss their experiences related to cultural beliefs, past EOL experience, and advance care planning motivations in an in-depth interview format.

In this study, an effort was made based on the investigator's judgment to recruit an interview sample varying in terms of their age, level of acculturation, socioeconomic status, and their readiness for advance care planning. Their questionnaire answers provide a basic understanding of the above information and the investigator could use their answers in the survey to select potential interview subjects. This purposive sampling strategy, based on informational needs rather than statistical representativeness (Sandelowski, 1995), has yielded a rich set of data from the total sample (N.K. Denzin & Lincoln, 2000). This sampling of "maximum variation cases" (Patton, 1990) is particularly desirable for this study, because our purpose is to depict various factors influencing the dependent variables.

C. **Data Collection**

1. **Preparation prior to data collection**

Before the study began, the investigator has made initial contacts with four senior pastors at the targeted churches. Purpose, data collection procedures, and protection of human subjects of the study have been explained to the church congregations, and permission to collect data has been granted by the deacon board of the four churches. The church social halls of the four targeted churches were reserved in advance for data collection.

2. **Procedure for recruiting subjects from the church settings**

Each data collection session was designed to take place after Sunday service at the target churches on three consecutive Sundays during July 2007 to October 2007, after the protocol of this study was approved by the Institutional Review Board (IRB) of University of Illinois at Chicago. During each session, the investigator was physically present at the church settings to recruit potential subjects by verbally explaining the purpose and inclusion criteria of the study (Appendix A). Chinese American church attendees who met the eligibility criteria (determined by the investigator) and were interested in this study were approached and invited to the reserved social halls. In the church social halls, the investigator again explained and repeated the data collection procedures of this study. A survey packet was distributed to each eligible adult Chinese American (Appendix B).

3. **Quantitative survey data collection**

Enclosed in the survey packet are a cover letter, a booklet about advance care planning written in both English and Chinese languages, a referral list of Chinese counseling service, a questionnaire containing 13 self-administered instruments and demographic data (Table 1), and an informed consent of the survey (Appendix C). The cover letter signed by the investigator and two faculty advisors included a description of the purpose and procedure of the study, the categories of information that will be collected, and an acknowledgement of the investigator's appreciation for their participation. The

enclosed advance care planning booklet: “Medical Decisions near the End of Life—Mrs. Lee’s Story” is produced by Sacramento Healthcare Decisions, which has played a leadership role in Chinese Americans’ EOL care and developed educational materials for use in community and healthcare settings. This booklet follows a story of Mrs. Lee, a Chinese immigrant, and her family as they face Mrs. Lee’s terminal illness. It also introduces advance directives, pain management at the EOL, hospice care, and EOL resources for elderly Chinese Americans. Furthermore, the investigator has prepared a referral list containing appropriate Chinese counseling services in order to provide information about bereavement care and religious support suitable for Chinese Americans. The list includes contact information of seven Chinese community church pastors, six mental health and grief counseling services in greater Chicago area, and 13 nation-wide grief counseling services and ethical consultation available in Chinese languages.

TABLE I
CONSTRUCTS/COMPONENTS, VARIABLES, AND MEASURES

Constructs/Components	Variables	Quantitative Measures	Qualitative Interviews
Chinese Americans' Readiness for Advance Care Planning	• (outcome variable) Stage of change for Chinese Americans' advance care planning	• * Stage of change for Chinese Americans' advance care planning (based on a 6-item algorithm)	Interview questions developed to describe elderly Chinese Americans' readiness for advance care planning
	• (outcome indicator 1) Self-efficacy for Chinese Americans' advance care planning	• * (outcome indicator 1) Self-efficacy for Chinese Americans' advance care planning (3 items)	
	• (outcome indicator 2) Decisional balance for Chinese Americans' advance care planning	• * (outcome indicator 2) Decisional balance for Chinese Americans' advance care planning (15 items)	
Cultural factors related to Chinese Americans' advance care planning	• Cultural beliefs regarding advance care planning	• * Chinese cultural beliefs related to advance care planning (13 items)	Interview questions developed to understand how Chinese culture may contribute to Chinese Americans' readiness for advance care planning
	• Chinese Americans' individualistic and collectivistic orientations	• Triandis and Gelfands' Individualism and Collectivism Scale (16 items)(Triandis & Gelfand, 1998)	
	• Chinese Americans' Acculturation	• Suinn-Lew Asian Self-Identity Acculturation Scale (21 items)(Suinn, Richard-Figueoraa, Lew, & Vigil, 1987)	
	• English proficiency for advance care planning	• * Chinese Americans' English proficiency for advance care planning (2 items)	

* Quantitative measures included in the survey questionnaire were developed by Hsiung and Ferrans based on the Transtheoretical Model of Health Behavioral Change (J. O. Prochaska & DiClemente, 1983b) and previous advance care planning studies

TABLE I (Cont.)
CONSTRUCTS/COMPONENTS, VARIABLES, AND MEASURES

Constructs/Components	Variables	Quantitative Measures	Qualitative Interviews
Knowledge factors related to Chinese Americans' advance care planning	<ul style="list-style-type: none"> Knowledge about life-sustaining treatment, advance directive documents (including living wills), and advance care planning Chinese Americans' previous experiences related to end-of-life 	<ul style="list-style-type: none"> * Chinese Americans' knowledge for advance care planning scale (10 items) * Chinese Americans' previous end-of-life experiences scale (6 items) 	Interview questions developed to understand how much elderly Chinese Americans know about advance care planning
Quality of life factors	<ul style="list-style-type: none"> Life satisfaction General health status 	<ul style="list-style-type: none"> Life-satisfaction subscale (33 items) of Quality of Life Index—Part I of Generic Version III (Ferrans & Powers, 1985) SF-12v2™ Health Surveys Taiwan (Chinese) – Standard Recall (12 items) (J. E. Ware, Kosinski, & Keller, 1996) 	
Spirituality factors	<ul style="list-style-type: none"> System of Beliefs Self-perceived religiosity 	<ul style="list-style-type: none"> Systems of Beliefs Inventory (15 items) (Holland, et al., 1998) * Chinese Americans' self-rated religiosity (2 items) 	Interview questions developed to explore how spirituality influence advance care planning
Demographics	<ul style="list-style-type: none"> Age Gender Life-partnered Income Education Employment Parent alive status Raised religion Currently preferred religion 	<ul style="list-style-type: none"> Age Gender Current marital status Income Education Current work status Alive parent number Raised religion Currently preferred religion 	

* Quantitative measures included in the survey questionnaire were developed by Hsiung and Ferrans based on the Transtheoretical Model of Health Behavioral Change (J. O. Prochaska & DiClemente, 1983b) and previous advance care planning studies

TABLE I (Cont.)
CONSTRUCTS/COMPONENTS, VARIABLES, AND MEASURES

Constructs/Components	Variables	Quantitative Measures	Qualitative Interviews
Strategies Chinese Americans would prefer in an advance care planning intervention program (not included in the conceptual model)	Preferred advance care planning program contents, settings, frequencies, learning methods, possible facilitators and barriers.	Questions developed for soliciting subjects' preferred strategies, including intervention contents, settings, frequencies, learning methods, possible facilitators and barriers.	Interview questions developed to explore elderly Chinese Americans' preferred strategies for advance care planning intervention

All survey participants needed to fill out an informed consent in their survey packet. Participants were encouraged to complete the survey at the church settings during sessions of data collection since the investigator was physically present to answer any question they might have. Some Chinese Americans who needed more time to complete the questionnaire were allowed to complete their surveys at home, but they must return or mail their surveys directly to the investigator anonymously.

Since an open invitation was given to all church members who attended Sunday services during the data collection period (July to October 2007) and some potential subjects who met the criteria have chosen to return their surveys later, it was difficult to control the number to be enrolled in this study. Not all participants who first were interested in the study and took the questionnaire home completed the survey; their consents were never returned. Twenty-two participants have approached the investigator and explained why they would prefer not to return their questionnaires. The reasons included: feel bad luck to participate in such a study (2), uncomfortable to continue (11), too complicated (3), too old, too busy, or too tired to read that much information in the survey (1), or simply they just regretted to participate in this study (1). Because they did not provide any data and voluntarily dropped out of the study, they were not officially enrolled in this study even though they have brought a questionnaire home.

The original sample approved by the IRB (June 2007) was a total of 200. During the data collection session, a total of 250 questionnaires were distributed to participants who met the inclusion criteria, considering a possible return rate of 80%. However, after the final distribution, a total of 211 completed questionnaires had been returned to the investigator. The over-accrual of questionnaires occurred on October 27, 2007. Once it was realized that the accrual goal had been reached, recruitment was stopped immediately. This unexpected problem regarding the over-enrollment of the 11 subjects was reported to and approved by the IRB of University of Illinois at Chicago in November 2007.

Among the 211 returned and completed questionnaires, only 205 informed consents were attached. Six participants returned their completed questionnaires without signing their consent forms. Because the survey consent form was designed to be distributed with the questionnaire and the investigator has instructed the participants to sign their consents before filling out the questionnaires, this problem was not unexpected until they directly returned the completed questionnaires to the investigator. When requesting them to fill out their consents, they demonstrated a hesitance to do so and felt uncomfortable putting their names on the consent form. Although these six participants have expressed an interest in the study, completed more than 90% of the questionnaire, and said they were glad to participate in the study, they still preferred not to leave their names on a research consent form. A request of permission to include these six completed questionnaires in the study was reported to the IRB of University of Illinois at Chicago. The IRB has approved and acknowledged this problem in November 2007. The overall number of enrolled subjects was 211, a response rate of 84.4% from four church settings. After examining the returned questionnaires, five participants had a tremendous amount of missing data, but all other participants have answered at least 83% (144 items) of the survey questions. Therefore, the total sample for this study consisted of 206 subjects ($n=206$) (Table 2).

4. Qualitative interviews sample recruitment and data collection

During survey recruitment, the inclusion criteria for in-depth interviews were announced to all survey participants in the church social hall. Eligible survey participants were encouraged to participate in the qualitative interviews. It was clearly stated that interview volunteers later would need to complete written consent forms in person with the interviewer (the investigator), and their completed questionnaires needed to be returned to the investigator directly. They were also told that their questionnaires would be kept confidential and identified by a study number accessible only to the investigator. Interview volunteers were contacted within one week by the investigator to screen for eligibility and a face-to-face appointment for the interview was arranged either over the phone or in person.

TABLE II
NUMBER OF RECRUITMENT, ENROLLED SUBJECTS, AND TOTAL SAMPLE

	Number	%
Questionnaires distributed to participants (who met the inclusion criteria):	250	100%
Lost contact	17	6.8%
Empty questionnaires returned (preferred to drop out of the study)	22	8.8%
Subjects enrolled in the study (respondents):	211	84.4%
Questionnaires completed but no informed consents were returned (IRB approved to use their data)	6	2.4%
Questionnaires completed and returned with signed informed consents	205	82%
Total sample:	n = 206	82.4%
Subjects who have completed their questionnaires	211	84.4%
Too much missing data	5	2%

Because of the sensitive nature of the research, an atmosphere of openness was maintained throughout the entire interview. The investigator/interviewer is commonly known as the “instrument” with qualitative research (Lincoln & Guba, 1986; Rew, Betchel, & Sapp, 1993), so in this study the investigator was the only interviewer conducted all interviews (n=28). Strategies to minimize harm were enacted during the interview (Kavanaugh & Ayres, 1998; Kavanaugh, Moro, Savage, Mehendale, in press). For example, during the interview the investigator cautiously preceded noting subject

cues that might indicate potential distress. The investigator also paid close attention to interaction style with the subject and displayed characteristics of genuineness and authenticity. The duration of each interview took approximately one and half hours. Each interview subject only needed to be interviewed one time. All 28 interview participants have successfully completed their in-depth interviews in one appointment within two hours.

This face-to-face interview was conducted in a mutually agreeable location with protection of participants' privacy. During each interview, the investigator repeated and explained the purpose of this study, and the interview informed consent (Appendix C) was first reviewed by both the investigator and the participant. All interviews were conducted by the investigator without any assistants and digitally recorded. Interview participants were given the opportunity to stop or ask questions at any time, but during the 28 interviews no participants have requested to discontinue or stop the interview. Both survey and interview subjects have been given the investigator's contact information so that they could contact the investigator by phone or email if they have questions about the study.

D. Measures

1. Development of new measures for readiness

One critical task in this study involved developing short, reliable, and valid measures for Chinese Americans' EOL decision-making. Because self-report has shown high accuracy in previous survey studies that applied the TTM (Velicer, Prochaska, Rossi, & Snow 1992), all new measures developed for this study were created in the self-report form. During instrument development, the investigator has discussed with the academic advisor, who is an internationally renowned instrument developer, in order to design reliable and valid self-report questions that reflect Chinese American participants' best knowledge. Questions in the new measures were particularly designed with a principle to minimize ambiguity so that even low-educated, elderly Chinese American participants could accurately respond to the survey questions without any possible distortion.

However, from the investigator's previous research, Chinese Americans in general did not show a sufficient understanding of life-sustaining treatment decisions and advance directives. It would be quite precarious to determine Chinese Americans' genuine knowledge and readiness for advance care planning if we completely rely on participants' self-report. In order to properly increase the accuracy of self-report without misleading them by providing too much educational information during data collection, careful considerations have been placed on wording, meanings, and sequences of self-report questions. Medical jargons have been intentionally avoided, and text boxes of simple, standard explanations about EOL decisions and advance care planning were inserted in the survey. Open-ended questions comparable to survey items were designed to be included in the questionnaire. Respondents' qualitative responses would be helpful in determining the trustworthiness of survey responses.

2. **Quantitative measures**

Each variable in this study was guided by the conceptual framework (Figure 1) and measured by a self-report (self-administrative) instrument. Quantitative measures in this study consisted of: three scales assessing Chinese Americans' readiness for advance care planning (one dependent variable and two dependent variable indicators), four measures related to Chinese cultural beliefs and Chinese Americans' acculturation, two measures about knowledge for advance care planning, two instruments of quality of life, two scales regarding self-perceived religiosity and spirituality, and a demographic form about the participants' personal characteristics (Table 1).

Five instruments chosen for this study were designed in the form of self-report survey and have showed satisfactory psychometric properties in previous studies, including: Triandis and Gelfands' Individualism and Collectivism Scale (16 items) (Triandis & Gelfand, 1998), Suinn-Lew Asian Self-Identity Acculturation Scale (21 items) (Suinn, Richard-Figueorosa, Lew, & Vigil, 1987), Life-satisfaction scale (33 items) of Quality of Life Index—Part I of Generic Version III (Ferrans & Powers, 1985), SF-12v2™ Health Surveys (Standard Recall 12 items)—Taiwan (Chinese) (Ware,

Kosinski, & Keller, 1996), and Systems of Beliefs Inventory (15 items) (Holland et al., 1998).

In this work, since no valid instruments have been developed for some variables, (including the outcome variable), eight measures were created for the quantitative survey: a) Stage of change for Chinese Americans' advance care planning (a 7-item algorithm), b) Self-efficacy for Chinese Americans' advance care planning (3 items), c) Decisional balance for Chinese Americans' advance care planning (16 items), d) Chinese cultural beliefs related to advance care planning (13 items), e) Chinese Americans' English proficiency for advance care planning scale (2 items), f) Chinese Americans' knowledge for advance care planning scale (10 items), g) Chinese Americans' previous end-of-life experiences scale (6 items), h) Chinese Americans' self-rated religiosity (2 items). A demographical form was developed containing questions about the participants' age, gender, current marital status, household income, highest education, current work status, the number of parents who were alive, the religion in their original family, and their current religion preference (Table 1).

It is worth noting that in the last section of the survey a variety of questions were developed in order to solicit Chinese Americans' preferred learning strategies if participating in an advance care planning intervention program (Appendix B). These questions about program content, setting, frequency, and media preferences were not conceptually linked to other variables, and thus not listed one of the factors that influence Chinese Americans' readiness for advance care planning. However, they formed an important tool to understand what strategies Chinese Americans would prefer in an advance care planning intervention.

a. **Stage of change for Chinese Americans' advance care planning**

This was the only outcome measure developed for this study to assess respondents' readiness for advance care planning. Based on an extensive literature review and suggestions of the TTM, the construct of Chinese Americans' readiness for advance care planning was conceptualized by their "stage of readiness for a behavioral change" being involved with the ongoing

decision-making process of advance care planning. A detailed literature review of the TTM was presented in chapter II.

Individuals in each “stage of readiness (for change)” for advance care planning were operationally defined in this study. For example, precontemplators have no intention of considering or starting advance care planning in the next six months, and among precontemplators were two subgroups of believers and non-believers. Contemplation group included those who were not actively involving in advance care planning, but were seriously considering doing so in the next six months. Those in the preparation stage were not only willing to start advance care planning but also have taken small steps and prepared to start. The action group has successfully made an advance directive decision not too long ago (less than six months), or they have made a decision longer than six months but have not shared with others their EOL preferences. People in the maintenance stage have made their advance directive decisions at least six months ago and were continuously communicating their wishes with others. Therefore, according to the above conceptual and operational definitions, the stage of change measure should be properly worded to have an ability to a) identify Chinese Americans’ motivations and intentions to a new behavior—advance care planning, b) assess both respondents’ advance directive status and their willingness or expected time to make a behavioral change, and c) reflect issues of respondents’ self-efficacy when making EOL decisions.

A 7-item measure was designed (Appendix B) in that the first two questions were about how much willing the respondents were to start advance care planning and how much interested they were in knowing more about it. Response choices of these two questions were rated on a 5-point Likert scale (0=“no, I don’t want,” 4= “yes, soon within six months.” The third question asked if the respondents felt necessary to start planning for their EOL treatments and care on 3-point Likert scale (0= “no, no need,” 2= “yes, necessary.” Their usage of advance directives/living wills was checked on a 3-point Likert scale (0= “no, never signed one,” 1= “yes, signed less than 6 months,” and 2= “yes, signed more

than 6 months ago.” In addition, for those who have signed their advance directive documents, the fifth question asked if they have told others about this decision on a dichotomous scale (0= “no,” 1= “yes”); and the sixth question asked if they still continued to communicate their EOL decisions and preferences with others (0= “no” and 1= “yes.” On the contrary, for those respondents who have not signed any advance directive documents, the last question in this measure asked if they were able to execute advance directives on the day they filled out the questionnaire. Response choices were rated on a 3-point Likert scale (0= “no,” 1= “I don’t know if I can decide today,” and 2= “yes”).

In order to precisely identify each respondent’s stage of change, the scoring of this measure adopted an algorithm (Table 3) rather than a summation score. For example, if one has an advance directive legally signed more than six months ago and still continued to communicate his/her EOL treatment and care preferences with family members, he/she would be placed in the most advanced stage of change, maintenance. On the contrary, if there existed a lack of awareness (i.e. they have never heard of advance care planning), an avoidance (i.e. they have no interest to know more about advance care planning), and a disbelief of such healthcare planning, they would be placed in the pre-contemplation (non-believer) stage. The final score of the stage of change measure ranged from “Precontemplation (non-believers= 1 and believers= 2)” to “maintenance (6).” The higher the score, the more ready the respondent is for advance care planning. A detailed description of scoring is attached in Appendix D.

During the pilot testing of this measure, Chinese American respondents could easily answer these questions without any confusion. This measure also has served well in distinguishing each respondent’s readiness in one of the six stages for advance care planning.

Although the algorithm was useful to position each respondent’s stage, items in this measure were useful to form two subscales to further describe Chinese Americans’ readiness for advance care planning. Scores of the “Stage of change intention” subscale were produced by combining those three

questions related to Chinese Americans' care planning motivations. The subscale score represented respondents' current motivation and internal intention for such a healthcare planning ranging from zero to ten, with high scores indicating a higher intention to start advance care planning. In addition, for those who have completed their advance directives, scores of "stage of change communication" subscale were produced by summing the scores of two questions related to continuous communication after executing advance directives. Response choices of the communication questions were on a dichotomous scale and the total score ranged from zero to two. Higher scores indicated a better communication with others about advance directives and EOL preferences.

TABLE III
THE STAGE OF CHANGE ALGORITHM

Survey Questions	Precontemplation (Non-believer)	Precontemplation (Believer)		Contemplation	Preparation	Action	Maintenance
38. Are you willing to start planning for your future life-sustaining treatment and possible care at the EOL?	No, I don't need to plan	I don't know if I am willing to plan Yes, but I don't know what time is better Yes, but later after 6 months		Yes, soon within the next 6 months	Yes, soon within the next 30 days		
39. Do you want to know more about "Advance care planning?"	No, I don't need to know more	I don't know if I need to know more Yes, but I don't know what time is better Yes, but later after 6 months		Yes, soon within the next 6 months	Yes, soon within the next 30 days		
40. In your opinion, do you think it is necessary now to plan for your future life-sustaining treatment?	No, not necessary.	I don't know if it is necessary		Yes, I think it is necessary	Yes, I think it is necessary		
58. Have you signed any advance directive?	No	No		No	No	Yes, less than 6 months	Yes, longer than 6 months
59. If you have signed an advance directive, have you told people that you have done so?						Yes or No	Yes
60. If you have signed an advance directive, do you still talk to people about your decisions in your advance directive?						Yes or No	Yes
61. If you have not signed an advance directive, are you able to sign on today?		Yes I don't know No	Yes I don't know No	No I Don't know	Yes		

There was a need to validate this new measure developed for this study. First, content validity of this measure was evaluated. All items of the new measures were developed based both on an extensive literature review of advance care planning and on the studies of Chinese Americans regarding life-sustaining treatment decisions.

Reliability assessment was determined after data were collected and adjusted for testing (the 1% missing data was handled by replacing the series mean). The internal consistency was supported (Cronbach's $\alpha = .86$) in this Chinese American sample. Although internal consistency would increase to .89 after deleting question #40 "In your opinion, do you think it is necessary now to plan for your future life-sustaining treatment," this was an important intention question in the stage of change algorithm and thus remained in the measure. Mean of inter-item correlation was at .66 (.58-.80, $p < .001$).

b. **Self-efficacy for Chinese Americans' advance care planning**

According to the TTM, self-efficacy is a reference variable of stage of change. A self-efficacy measure was developed as an outcome indicator for this study to gain an understanding of Chinese Americans' readiness for advance care planning. According to the TTM, the main interest of this measure should be in respondents' confidence in executing advance directives when other things got in the way. Particularly among those Chinese Americans who have not signed any advance directive documents, their self-perceived confidence about an advance care planning behavioral change needed to be assessed and compared with the outcome variable, stage of change.

Because Chinese people usually prefer not to reveal or report family issues, when developing items in this measure considerations were taken to avoid asking sensitive questions that seemed to interfere with family business or create conflicts in the family. Questions were carefully worded to focus only on respondents' self-perceived confidence in EOL decision-making, and they were not elicited to provide detailed information about any barriers or difficulties from significant others. This

approach, instead of asking how their EOL decisions were influenced or who in fact discouraged them to initiate advance care planning, has been confirmed very useful in the pilot testing. Chinese Americans reported questions in the self-efficacy measure were neutral and not “noisy.”

Another issue of self-report audacity and Chinese related humbleness were noticed when developing items in this measure. At first, self-efficacy questions were designed, as suggested by the TTM and other behavioral studies, to include difficult situations or provide hypothetical scenarios that might influence respondents’ self-efficacy for advance care planning. However, during the pilot testing Chinese participants seemed to have a tendency to accommodate primary physicians or family members’ suggestions. Not only they recognized this tendency but also commented that humbleness was a virtue in Chinese culture. One would not be appreciated if he boasted his own capability or insisted his opinions irrespective of other’s suggestions. This tendency was also revealed during the consequent interviews in that most interviewees would humbly agree with medical professionals and family members’ opinions. In this case, the real effect of self-efficacy became difficult to obtain. As a result, this measure omitted such questions to prevent confidence level being underreported in self-efficacy challenging circumstances.

Three simple questions were therefore created in this measure: “Are you able to sign an advance directive today (0= “no,” 1= “I don’t know,” and 2= “yes”),” “do you need other’s approval before signing your advance directive,” and “do you need to discuss with others before signing your advance directive?” (0= “yes,” 1= “I don’t know,” and 2= “no”). Response choices were designed on a 3-point Likert scale including an option of uncertainty and possible self-efficacy scores ranged from zero to six; higher scores indicated more self-efficacy the respondents have for advance care planning.

Content validity was first verified, and items in this new measure were judged by a panel of three cultural and clinical experts—all of whom were doctoral-prepared medical professionals who have expertise in measurement and cross-cultural research. The conceptual definition and the instrument

objective were provided to them. At first they suggested more questions to be included, but after explaining the concerns above, they agreed no question needed to be added or modified in this measure.

Reliability assessment was determined after data were collected for testing. It is worth mentioning that because this measure only assessed those respondents who have not signed any advance directives, 36 subjects were excluded from the total sample and thus 17.5% were valid missing data. Although among these three items, the internal consistency was moderately supported (Cronbach's $\alpha = .58$), results was shown in the item-item correlation matrix that one question "are you able to sign an advance directive today?" only weakly correlated with the other two questions ($r = .26$ and $.18$, $p < .001$). After deleting this question the Cronbach's α increased to $.65$. A moderate inter-item correlation ($.487$, $p < .001$) was between the questions "Do you need to get someone's approval to sign an advance directive document?" and "Do you prefer to discuss with others before signing an advance directive document." Therefore, the final measure consisted of only two items. Item-total statistics of the self-efficacy measure is presented in Table 4.

TABLE IV
ITEM AND ITEM-TOTAL STATISTICS OF THE SELF-EFFICACY MEASURE

	N ^a	Mean	Std. Deviation	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
1. If you have not signed an advance directive, are you able to sign one today?	170	1.40	.718	2.32	2.20	0.256	0.074	0.652
2. Do you need to get someone's approval to sign an advance directive document?	170	1.44	.806	2.28	1.58	0.505	0.270	0.298
3. Do you prefer to discuss with others before signing an advance directive document about your future life-sustaining treatment?	170	.88	.916	2.84	1.47	0.431	0.240	0.418

^a. Listwise deletion based on all variables in the procedure (36 subjects were excluded from the total sample)

c. **Decisional balance for Chinese Americans' advance care planning**

Similar to self-efficacy this was a measure of outcome indicator and a reference variable of the stage of change (Appendix B). The interest of this measure was in respondents' relative weighing of the positive aspects (pros) and the negative aspects (cons) of advance care planning. Two subscales were designed in this measure as suggested by the TTM: Chinese Americans' endorsement for advance care planning (6 pro statements) and Chinese Americans' concerns for advance care planning (8 con statements). To ensure the clarity of questions, there was no reverse scoring (opposite statement) within the same subscale. On a 4-point Likert scale, respondents decided how much these pros and cons statements were true or false to them (1= "never true," 4= "always true"). The subscale score was produced by the summation of corresponding statements in the subscale: the pros scores ranged from six to 24 and the cons scores ranged from eight to 32.

One evaluation question, separated from the pros and cons statements, was designed in this measure so that respondents had an opportunity to directly express whether they, in general, considered advance care planning a good idea or a bad idea. This straightforward question was rated on a 3-Likert scale, ranging from "a good idea" (1), "I don't know" (2), and "a bad idea" (3). The respondents were requested to provide the reasons to support their answer. The final score of the total scale was the summation of the two subscales and the single evaluation question. After a necessary score inversion, the total decisional balance score had a range from 15 to 59. Higher scores indicated the respondents had more concerns (less favor) for advance care planning.

Content validity was first verified and items in this new measure were judged by a panel of three cultural and clinical experts (all doctoral prepared). The conceptual definition and the instrument objective were provided to them. Minor changes were made about wording after discussing with the panel to make these statements more clear. For example, "Advance care planning helps others to know my EOL preferences in advance" was split into two statements in order to further define "others" in terms of "family members" and "doctors." Some statements in the cons subscale were modified to sound neutral in Chinese language, in particular to avoid negative cultural interpretations.

It is worth noting that during the instrument development one statement “advance care planning may possibly shorten my life” was deleted from this measure. The final measure therefore consisted of a total of 15 items. This statement originally included in the measure was found problematic during the pilot testing. Participants reported they were confused by this item because most believed the length of life was uncontrollable. This item was first revised in Chinese and an addendum “if I have advance care planning, I might not live as long” was supplemented in the parenthesis. However, this modification was still confusing to some interview subjects and they complained not understanding the true meaning of this statement. This item also has the lowest corrected item-total correlation (.18, $p < .001$). After deleting this item, the Cronbach’s alpha increased to .77 and .81 for the cons subscale and the total scale, respectively.

Reliability assessment was therefore determined among the final 15 items after data were collected for testing; and the 2.9% and 8.3% missing data in the pros and cons subscale were handled and replaced by the series mean. The internal consistency was well supported in the total scale (Cronbach’s alpha = .81). Even excluding the overall evaluation item, the summation of the two subscales provided strong support for internal consistency (Cronbach’s alpha = .80) as well.

In the pros subscale there was a strong support for internal consistency (Cronbach’s alpha = .94, $p < .001$) and an inter-item correlation mean of .72 (.62-.90, $p < .001$). The highest inter-item correlation was expected between two statements originally split from one statement. The cons subscale had an adequate internal consistency (Cronbach’s alpha = .76, $p < .001$) with an inter-item correlation of .30 (.03-.60, $p < .001$). The highest inter-item correlation was between statements of “bad luck” and “uncomfortable to think about my own death” which showed Chinese Americans’ major concerns about a cultural taboo when considering advance care planning.

d. Chinese cultural beliefs related to advance care planning

The existing literature reveals that the more traditional Chinese Americans become, the less willing they are for advance care planning. This measure was developed with an internationally renowned instrument developer who has rich experience in designing cross-cultural instruments and

cultural belief scales. Statements were created based on an extensive literature review and the investigator's cultural experience in EOL research. Cultural concepts of Confucian ethics, Chinese Americans' collectivistic nature, Chinese familialism, filial piety, male and physician paternalism, fatalism, death taboo, preclusion of hope, and the Chinese view of a prepared good death were chosen to be related to Chinese Americans' advance care planning. In addition, this measure was developed to include a variety of statements about Chinese religious views, life-sustaining treatment and EOL care options explicated in the Chinese social norm. An open-ended question "Please tell us in your own words what a good death means to you?" was created after the 13 statements to solicit Chinese respondents' qualitative response.

Although an individual's cultural orientation was viewed as a continuum in this measure, this scale has no intention to measure Chinese Americans' acculturation to the American mainstream society and contains only Chinese belief questions related to EOL decision-making and advance care planning in the American healthcare system. The interest was in how much Chinese Americans valued Chinese traditional beliefs when making EOL decisions in Western healthcare environment.

The response choices of this measure were designed on a 4-point Likert scale (1= "never true," 4=always true), on which Chinese American participants responded to belief statements based on their value system. To ensure the clarity, each statement was worded as a declaration of a specific Chinese normative belief, and there was no reverse scoring (opposite statement) in this scale. A summation of the 13 statement scores produced a total score ranging from 13 to 52. Chinese American respondents were rated on a continuum related to advance care planning. The higher the scores, the less traditional the respondents were to the traditional Chinese culture.

Content validity was first verified and items of this new measure were judged by a panel of three cultural and clinical experts (all of them were doctoral prepared medical professionals). The conceptual definition and the instrument objective were provided to them. After discussing with the panel and the other instrument developer, minor changes were made in Chinese wording to make these statements clearer and culturally more appropriate. For example, a Chinese cultural meaning of "losing face" was

added in the parenthesis in order to strengthen a Chinese concept of family shame. Fathers (or the eldest brothers) were added as examples of the family head in the statement to remind the respondents how their family's EOL decisions were possibly made by males in previous EOL experience. During the pilot testing, no Chinese respondents reported these statements confusing, troublesome, nor they misinterpreted or questioned the final 13 statements.

Reliability assessment was determined among 13 items after data were collected for testing. There was 4.9% missing data and they were handled by replacing the series mean. The internal consistency was adequately supported (Cronbach's $\alpha = .79$) with an inter-item correlation of .27 ($p < .001$). Although a higher Cronbach's α (.81) could be obtained by deleting one statement "Filial piety is to respect parents' wish to die," this statement was identified in the following in-depth interviews as an important cultural belief so should not be removed from the measure. A total of 13 items remained in the scale.

e. **Triandis and Gelfands' Individualism and Collectivism Scale**

Individualistic and collectivistic orientations were often used to explain cross-cultural differences (Darwish & Huber, 2003; Singelis, Triandis, Bhawuk, & Gelfand, 1995; Triandis, 1996). In particular in collectivist cultures, norms were usually given more weight than individuals' attitudes. The existing literature showed that differences exist within the same individualistic or collectivistic cultures, and in cross-cultural research there was a long history searching for the best conceptualization of individualism and collectivism (IC). A plethora of IC measurements have been developed to explain across-group and in-group differences in the past three decades (Hofstede, 1980; Hui, 1988; Singelis, 1994; Triandis, Chen, & Chan, 1998; Triandis, McClusker, & Hui, 1990).

It is now well-accepted that IC are both polythetic constructs which are horizontal (emphasizing equality) or vertical (emphasizing hierarchy) (Singelis, et al., 1995; Triandis, 1995). This vertical-horizontal (V-H) dimension was further proved to be a defining attribute of IC. One's relative emphases on self and social relationships can be described by four distinct IC patterns: a) horizontal individualism (HI) is people want to be unique and self-reliant, but they are not especially interested in

becoming distinguished or having high status, b) vertical individualism (VI) is people try to compete with others for distinction and status, c) horizontal collectivism (HC) is people perceive themselves as an aspect of in-group and emphasize common goals with others, and, d) vertical collectivism (VC) is people sacrifice their personal goals for the sake of in-group goals, but the members of the in-group are different from each other, some having more status than others. The viability of a V-H dimension and the validity of four IC constructs have been supported by many empirical studies (Chiou, 2001; Ghosh, 2004; Singelis, et al., 1995; Soh & Leong, 2002; Triandis, et al., 1998; Triandis & Gelfand, 1998; Wang, Shi, & Huang, 2003).

In this study, Triandis and Gelfand's (1998) comparatively short IC measurement was selected (Appendix B) to assess Chinese Americans' individualistic and collectivistic orientations, as one of the cultural factors. On the basis of Singelis' 32-item IC instrument (Singelis, et al., 1995), Triandis and Gelfand's (1998) modified 27 items that had high factor loadings on the four constructs and reduced the original 32 items to 16 items (four items for each IC construct). In Singelis' original version, the participants rated the extent to which they agreed with the statements on a 9-point Likert scale (1=strongly disagree, 9= strongly agree). This shortened 16-item measure has been later revised to be either on a 7-point (Chiou, 2001) or 5-point scale (Wang, et al., 2003). Chosen in this study was the most recent Chinese version (Chiou, 2001; Wang, et al., 2003) on a 5-point Likert scale (1=strongly disagree, 5= strongly agree). Four subscale scores were produced by summing the corresponding items in each subscale with a possible score ranging from 4 to 20. The higher the scores, the more horizontal/vertical individualistic or collectivistic the subject oriented.

In Singelis' original version (Singelis, et al., 1995), internal consistencies (Cronbach's alphas) ranged from .69 to .75. Two studies using this reduced version reported Cronbach's alphas ranged from .60 to .84 ($p < .05$) among Singapore (Chinese) undergraduates (Soh & Leong, 2002) and Taiwanese college students (Chiou, 2001). A study among 240 Asian Indians across various occupational groups also reported similar coefficient alphas ranging from .67 to .74. VC and HC were found significantly correlated ($r = .39$, $p < .05$) whereas HI and VI were not.

Construct validity of this 16-item measure has been supported among Asian undergraduates in the United States and Hawaii (46.8% were Asians), South Korean students, Chinese college students in Singapore and China, Taiwan, and Asian Indian occupational groups (Chiou, 2001; Ghosh, 2004; Singelis, et al., 1995; Soh & Leong, 2002; Triandis, et al., 1998; Triandis & Gelfand, 1998; Wang, et al., 2003). Findings showed that within the United States and across collectivistic cultural groups in Asia (Triandis & Gelfand, 1998; Wang, et al., 2003), this 16-item measure demonstrated good structural differentiation in four IC constructs (Goodness of Fit Index=.91, Adjusted Goodness of Fit Index =.75, and Root Mean Square Residual=.089)(Chiou, 2001). Convergent, discriminant, and criterion-related validity of this measure have been confirmed cross-culturally by various research designs, including a multi-trait/multi-method analysis (Triandis & Gelfand, 1998), an analysis exemplifying the relationships of the four constructs with interest types (Soh & Leong, 2002), a scenario-based measure (Triandis & Gelfand, 1998), and a 3-group confirmatory factor analysis (Chiou, 2001). In other words, cross-cultural validity of this measure has been confirmed at the individual level within the United States, across multiple collectivistic cultural groups, and various Chinese samples in at least three Asian countries. However, this measure has never been used among terminally ill populations or elderly groups in Chinese culture backgrounds.

Although this short measure has demonstrated sound reliability and validity, previous findings suggested further refinement and testing of the items to enhance the operationalization of IC constructs. Compared with the original 32-item scale, this shorten measure was considered less precise (Soh & Leong, 2002). In a China sample four items were found having higher factor loadings on two factors, which suggested the needs for modifications in Chinese culture (Wang, et al., 2003). When this measure was used in a Taiwanese sample, the author also reported the reduction of the items has caused the reliability and validity of the four constructs to be at the marginal level (Chiou, 2001).

In this study, reliability assessment among 16 items was determined after data were collected for testing; 5.3% and 3.9% data were missing in the horizontal individualism and vertical collectivism subscale, respectively. Missing data was handled by replacing the series mean as the instrument

developer suggested (n=206). The internal consistency of each subscale was at least above .688 (p<.001). Detailed reliability estimates in both four constructs and two IC constructs are presented in Table 5.

TABLE V
ITEM SCORES AND RELIABILITY ESTIMATES OF THE INDIVIDUALISM AND COLLECTIVISM SCALE

Scale	Number of Items	Cronbach's Alphas	Inter-item Correlations
Horizontal Individualism	4	.781	.472 (.389-.653)
Vertical Individualism	4	.688	.341 (.117-.605)
Horizontal Collectivism	4	.765	.448 (.289-.674)
Vertical Collectivism	4	.762	.441 (.320-.584)

f. **The Suinn-Lew Self-identity Acculturation Scale (SL-ASIA)** (Suinn, et al., 1987)

Acculturation has been concluded as an important factor to influence readiness for advance care planning, and many Chinese Americans are believed to be bi-cultural (Berry, 2001) in their acculturation orientation after immigrating to the States. SL-ASIA was chosen in this study to assess Chinese American respondents' behaviors and ideals (preferences) for a behavioral change in a different cultural setting (Appendix B). Modeled after the well-established acculturation scale: Acculturation Rating Scale for Mexican Americans (ARSMA), the SL-ASIA was composed of 21 multiple-choice questions which covered domains of: language, identity, friendship choice, behaviors, generation/geographic history, and attitudes. Because Chinese American respondents' acculturation dimensions (whether they are unidimensional or orthogonal) was not of the interest in this study, the expanded version of the SL-ASIA (26-item scale) was not necessary.

Response choices were rated on a 5-Likert scale (1= "only Chinese," 5= "very much Americanized"). Answers for the 21 items were summed to produce a total value and a final acculturation score was calculated by dividing the total value by 21. Ranging from 1.00 (low acculturation) to 5.00 (high acculturation), the final acculturation score was a reflection of Chinese identification, with high scores reflecting high western identification/lifestyle and low Chinese identification/lifestyle.

This instrument has been predominantly used among Asian American cultures. The earliest reliability estimates were among 82 Asian American undergraduates (Suinn, et al., 1987) and 324 Asian American university students (Suinn, Ahuna, & Khoo, 1992). These students were a healthy but much younger group different from the subjects in this study. Overall, the coefficient alpha for the 21-item scale was reported at .88 ($p < .05$). The concurrent validity has been supported that the SL-ASIA total score was significantly correlated with demographic information predicted to reflect levels of Asian American identity. For example, having attended school in the U.S. over a longer period of time was found associated with high SL-ASIA scores, in that Asian identity reduced over time in the U.S. Factorial validity was supported by comparing factors obtained for the SL-ASIA with factors reported for the ARSMA. Of the four interpretable factors reported for the ARSMA, three were identified for the SL-ASIA.

SL-ASIA also has demonstrated sound reliability and validity among overseas Asians. In two samples of 284 Asian American university students and 118 Singapore Asian individuals (mostly Chinese), the Cronbach's alpha was .79, and factor analysis was able to identify five factors to predict acculturation (Suinn, Khoo, & Ahuna, 1995).

In this study, reliability assessment among 21 items was determined after data were collected for testing; 7.3% data were missing and handled by replacing the series mean as the instrument developer suggested ($n=206$). It is noteworthy that one question (item 14) "What contact have you had with Asia (China, Taiwan, or other Chinese countries)?" was removed from the reliability test because no variance was found in this item. All respondents reported they have had "at least one year in Asia." The internal consistency for the total scale was at .81 ($p < .001$), and the inter-item correlations mean was at .17 ($-.19-.93$, $p < .001$). The highest correlation was anticipated between respondents' spoken ability and writing ability.

g. **Chinese Americans' English proficiency for advance care planning**

This was the last cultural measure developed for this study (Appendix B). A lack of English proficiency was found important to healthcare access; in particular, elderly immigrants might

be health information isolated due to their English insufficiency. Two short statements were designed in this measure to understand how much Chinese American participants, living in the States, perceived a language (English) barrier in daily life and during the process of seeking healthcare.

To ensure the clarity, both statements were worded as a declaration of English insufficiency, and there was no reverse scoring (opposite statement) in this scale. On a 4-point Likert scale (1= “always true,” 4= “never true”), respondents rated based on their self-perception how much they sensed English a problem in everyday life or needed a translator when seeing a doctor who does not speak their language. The total score was produced by summing the two statement scores; a possible score ranged from two to eight, with high scores indicating a better self-perceived English proficiency (they rated themselves having less problems with English).

Content validity was verified and items were then judged by a panel of three cultural and clinical experts (all of them were doctoral prepared medical professionals). Conceptual definitions and instrument objectives were provided to them. After discussing with the panel and the other instrument developer, one statement originally included in the measure “I preferred seeing a Chinese doctor” was removed. Many respondents mistook a Chinese doctor “a traditional Chinese herb doctor,” instead of “a Chinese/Mandarin-speaking doctor.” This item was reworded and explanation of “a Chinese doctor” was added in the questionnaire. However, during the pilot testing, many respondents still reported this item problematic and there are a number of points worth noting. Some reported they did not need to visit a Chinese/Mandarin-speaking doctor. Some even said they only knew doctors practiced in Chinatown and throughout their life they have never visited western medicine doctors. In addition, many reported they particularly went to bilingual services visiting a non-Chinese speaking doctor simply because there was Chinese healthcare information available. We have finally decided to remove this problematic item and an open-ended question “In which language do you prefer when receiving healthcare information and why?” was added after pilot testing to solicit qualitative feedback from the respondents. At this point, none reported the remaining two statements confusing, so the final measure contained only two items. Reliability of this measure was assessed after data were collected, and the

instrument developers decided to handle the 1% missing data by replacing the series mean. The internal consistency was well supported (Cronbach's $\alpha = .81$) with a .66 correlation ($p < .001$) between these two items.

h. **Chinese Americans' knowledge for advance care planning scale**

This was the first knowledge-related measure developed for this study (Appendix B). In the existing literature Chinese Americans were found in general unfamiliar with the idea of advance care planning and many were unequipped with knowledge needed to make advanced life-sustaining treatment decisions. From the investigator's previous EOL research, many elderly Chinese Americans reported they have never heard about advance care planning and its related concepts. This lack of knowledge might be a factor to influence their readiness for advance care planning.

It was challenging to developing a knowledge measure for such a group whose understanding seemed to be at a preliminary stage. While their knowledge in this area could be extremely insufficient or erroneous, the accuracy and validity of their self-reported knowledge became questionable. Commonly used advance care planning questions might be too advanced for them, such as what treatment options were defined as life-sustaining treatments, which types of advance directive documents were legal in Chicago (Illinois), or what responsibility the durable power of attorney held in making EOL decisions, etc. Also these questions did not reflect how this level of knowledge would be related to the readiness for advance care planning. Therefore, the knowledge measure designed for this study had no intention to evaluate or test the respondents' knowledge in advance care planning details. We decided that this measure should contain only basic questions of whether the respondents have been exposed to this idea.

A total of ten questions were finally designed in three simple sets, representing respondents' knowledge in the categories of life-sustaining treatment, advance directive documents, and the process of advance care planning, respectively. Each set consisted of two types of questions: a) whether respondents have heard of this particular concept (both English and Chinese terms were listed), and b) how much they felt they truly understood this concept. Response choices of the first type of question

were on a dichotomous (0= “no” and 1= “yes”) scale, and the second type of question (self-perceived knowledge sufficiency) were rated on a 4-point Likert scale (0= “not at all,” 3= “very much”).

In each subscale, scores of the above two types of questions were summed. The life-sustaining treatment subscale (three items) had a total score ranging from zero to five, the advance directive subscale (four items) had a total score ranging from zero to six, and the last subscale related to advance care planning (three items) had a total score from zero to five. A total score of this measure was the summation of the three subscale scores, ranging from zero to 16. High scores of this measure indicated a better self-perceived knowledge related to life-sustaining treatment, advance directive documents and the process of advance care planning.

In the early phase of instrument development, content validity was verified and item content was reviewed by a panel of three cultural and clinical experts (all of them were doctoral prepared medical professionals). Conceptual definition and instrument objectives were provided to them. After a thorough discussion among the panelists, one question assessing respondents’ knowledge about “Chinese advance directives” was removed. It was because until now, no universally agreed Chinese translation was available representing the idea of advance directives. Instead of providing various Chinese translations to represent the multiple concepts of advance directives, living wills, or durable power of attorneys, we have decided not to include items of Chinese terms in this measure. Later in the pilot testing, respondents reported the final ten items clear and easy-to-answer.

During instrument development, a concern of whether to include the score of the third subscale in the final total score was raised between the investigator and the other instrument developer. It was because in the consequent in-depth interviews, some respondents’ understanding of advance care planning was found entirely incorrect. Irrespective of the item clarity, they either misunderstood the survey questions or regarded advance care planning a completely different idea (such as healthcare options, nursing home, or a financial planning). These respondents were also found often overconfident or overestimated what they have known about advance care planning, causing their self-reported knowledge inaccurate.

Removing three items (of the third subscale) from the measure was proposed. However, after re-examining the data, a majority of these items were found appropriately reported. Nearly 75% and 82% Chinese American respondents have not heard about this term in English or in Chinese respectively. Only 10% of the respondents reported they knew a little or some about advance care planning, with approximately 62% reported knowing nothing about it. Only 1.5% of the respondents rated they knew very much about this planning, which these might be the candidates who misunderstood advance care planning. Therefore, items in the subscale of advance care planning were still correctly interpreted by the majority of the respondents. The advance care planning subscale was therefore included in this measure, so Chinese Americans' advance care planning knowledge was still represented in three domains.

To further address the above concerns, an open-ended questions, "Please tell us in your own words what life-sustaining treatment (advance directives or advance care planning) is?" was added in each knowledge subscale. Respondents were asked to provide examples to show their genuine understanding of this concept, and their qualitative answers were later compared with the in-depth interview findings to examine how many Chinese Americans have the correct knowledge related to advance care planning. A second open-ended question was later added as well for the respondents to check or write where they first learned about this concept. This was because many Chinese Americans reported they first learned EOL decision-making during family crises, and some have shared they had no access to English healthcare information. This question had an attempt to understand how and where those knowledgeable participants obtained correct information.

Reliability assessment among ten knowledge items was determined after data were collected for testing; 1%, 2.9%, and 1.5% data were missing in the life-sustaining treatment, advance directive, and advance care planning subscale, respectively. The total 4.9% missing data were handled by replacing the series mean ($n=206$). The internal consistency in the total scale was well supported (Cronbach's $\alpha = .85$), and each subscale had at least an internal consistency above .6 ($p<.001$). Reliability estimates of the total scale and each subscale are summarized in Table 6.

TABLE VI
RELIABILITY ESTIMATES OF CHINESE AMERICANS' KNOWLEDGE FOR ADVNACE CARE PLANNING

Scale	Number of Items	Cronbach's Alphas	Inter-item Correlations
Overall knowledge	10	.85	.33 (.10-.65)
Life-sustaining treatment knowledge	3	.76	.54 (.43-.63)
Advance directives knowledge	4	.64	.31 (.18-.36)
Advance care planning knowledge	3	.80	.57 (.51-.65)

i. **Chinese Americans' previous end-of-life experiences scale**

This was the second knowledge related measure newly developed for this study to assess Chinese Americans' previous experience related to EOL circumstances (Appendix B). The existing literature revealed that experience related to EOL circumstances might be a factor to influence readiness for advance care planning. For example, a family member's terminal illness or death might motivate people to initiate advance care planning, with a hope to prevent sufferings and prepare for better care at the EOL. But these circumstances might be negatively interpreted so adversely increased fear of death. In this case, advance care planning might be intentionally avoided to protect feelings or minimize discomfort.

A measure needed for this study was to understand whether rich EOL experience would have an impact on readiness for advance care planning. This study has no intention to quantify how many deaths in the past one has encountered nor how many EOL decisions one might have been involved in the family; also off the interest was how a specific death event in the family was interpreted. Sensitive questions that might bring one's sad memories were intentionally avoided, such as how critical life-sustaining treatment decisions were previously consented among family members.

A total of six statements were designed about one's personal experience with life-threatening illness, hospitalization in the intensive care unit (ICU), and EOL discussions regarding life-sustaining treatment. Each category contained experience of one's own and experience for a very close family member. The response choices were designed on a dichotomous scale (0="no" and 1="yes"), on which Chinese Americans responded statements based on their recalled experience. To ensure clarity, each statement was worded as a declaration of an EOL circumstance with no reverse scoring (opposite

statement) in this scale. A summation of the six statement scores produced a total score ranging from zero to six. Higher scores indicated a rich EOL experience the respondent had.

Content validity was first verified and items of this new measure were judged by a panel of three cultural and clinical experts (all of them were doctoral prepared medical professionals). Conceptual definitions and instrument objectives were provided to them. After multiple discussions, minor changes were made to increase clarity and comprehensiveness. For example, the concept of a “life-threatening accident” was supplemented in the statements with a life-threatening illness. The word “a family member” was changed to “one of my very close family members” to avoid a possible situation when Chinese respondents overly identify extended relatives as family members in their culture. In the consequent pilot testing, none reported the final six statements confusing, difficult, or troublesome.

Reliability assessment was performed after data were collected. There was a total 1.5% missing data and they were handled by replacing the series mean. The internal consistency of the total scale was adequately supported (Cronbach’s alpha = .67) with an inter-item correlation of .25 (.08-.61, $p < .001$). Significant correlations (.523, .605, and .558) were found between two items in these three subscales respectively, and the least correlation was between the item of self-EOL experience and the family caring experience.

j. **Quality of Life Index (QLI) (Generic Version III, Part I)** (Ferrans & Powers, 1985)

The Quality of Life Index (QLI), developed by Ferrans and Powers (1985), was chosen for this study to measure QOL (Appendix B). Over the past 20 years, QLI has been determined as a culturally sensitive instrument with sound psychometric properties and a number of versions have been developed for use with healthy populations and patients with terminal illnesses (i.e., cancer patients and survivors) reported in more than 200 published studies.

The most recent generic version of QLI consisted of two parts: the first part measured satisfaction with various aspects of life, and the second measured the importance of those life aspects. Written at a fourth-grade reading level, all 66 items could be completed in approximately 10 minutes. The full version scores were determined by weighting satisfaction responses with importance responses in each

of the 33 life aspects, and ranging from 0 to 30, higher scores indicated a better quality of life. After discussing with the instrument developer, Part I of the QLI was comprehensive and at an appropriate length, and using both parts of the QLI was unnecessary. Therefore, in this study only Part I of the QLI was chosen to measure Chinese Americans' QOL in terms of an overall life-satisfaction and the life-satisfaction in four domains: health and physical functioning, social and economic, psychological/spiritual, and family.

Specific steps were followed to calculate QLI scores for the satisfaction section only. First, the number 1 was subtracted from the response for each satisfaction item, and then each item was multiplied by the number 6. Second, appropriate items in each subscale were summed according to the scoring manual. Third, the subscale sum was divided by the number of items answered. In this way a mean score for each individual person was calculated and any missing value of the item would not affect his/her final score. The final scores of the life-satisfaction section, the same as in the original scale, ranged from zero to 30, with high scores indicating a better life-satisfaction (QOL).

The instrument developer has summarized detailed reliability and validity coefficients from studies over the last two decades (Quality of Life Index: Reliability and Validity <http://www.uic.edu/orgs/qli/reliability/reliabilityhome.htm>). Across 26 studies, internal consistency for the total scale was well supported (Cronbach's alphas = .84-.98) in various patient populations of cancer, cardiac diseases, end-stage renal diseases, HIV-positive/AIDS, and the general population. In addition, Cronbach's alphas of the four subscales ranged from .63 to .93 (mostly above .80) across 15 studies. Test-retest correlations for the total scale ($r=.78-.87$, $p<.05$) has shown a sound stability (temporal reliability) within a two-week interval (.87), a one-month interval (.81) (Ferrans & Powers, 1985) and a three- to four-week interval (Rustoen, Moum, Wiklund, & Hanestad, 1999).

All QLI items were created based on an extensive literature review, and content validity was demonstrated by a high Content Validity Index (Oleson, 1990). Evidence for convergent validity was supported by strong correlations between the overall QLI score and other valid quality of life measures ($r=.61-.93$, $p<.05$) (Anderson & Ferrans, 1997; Ferrans & Powers, 1985; Ferrans & Powers, 1992).

Factorial validation revealed four primary factors and a higher order factor representing the overall QOL (Ferrans & Powers, 1992). Studies using contrasted-groups approaches among cancer patients have demonstrated sound construct validity; those who had higher incomes and coped better with stress had significantly higher QOL scores (Ferrans, 1990; Ferrans & Powers, 1992). In addition, from 18 intervention studies, the QLI was sensitive in detecting a change of QOL before and after interventions.

The official (traditional) Chinese version of QLI (Generic Version III) was translated by the investigator in 2003. The original QLI developer, Dr. Carol Ferrans, has carefully guided the translation process. First, in order to properly translate this well-established instrument, the most important concern was selecting an adequate translation technique which took informativeness, source language transparency, security, and practicality into consideration. Recently, a committee-based approach (Harkness, Vijver, & Mohler, 2003) that involved a series of complicated procedures was recommended to outweigh the standard translation/back-translation (Brislin, 1970) with a strength to include optimal output from difference perspectives of the committee members.

However, recognizing the impracticability of a committee-based approach, Harkness' recommendation was combined with Brislin's traditional back-translation method (1970). First, a translation committee of three Chinese cultural and language experts who were familiar with the study population was constructed. They followed the same translation guideline and forward-translated the source language (English) into the target language (traditional Chinese). Second, multiple consensus meetings were held among these three forward translators and the investigator obtained an agree-on forward version. Third, back translation of the "agree-on forward version" was performed by another independent translator who was a bilingual Chinese American also familiar with the study population. The original English version and the backward translation version then were reviewed and compared by the investigator and the original instrument developer. Modifications were made between these two to obtain a suitable Chinese version. This Chinese version then was pilot tested among a group of bilingual Chinese Americans who were not familiar with the instruments ($n=7$). They were asked to take both instruments and report inconsistent, confusing, or troublesome items between the two

languages. The original instrument developer and the investigator again discussed suggestions from this pilot testing of the two groups in order to officially approve the Chinese version.

Reliability assessment was determined according to the scoring manual, item 21 and 22 were first combined to create one variable for testing (because respondents checked only one of them). Satisfactions about sex (item 11), chances to live as long as they would like (item 7), and spouse (item 12) had the highest missing value: 14%, 7.7%, and 7.2%, respectively. These missing values were expected because sex and spouse issues were usually sensitive topics and not mentionable to strangers in Chinese culture. During the in-depth interviews, item 7 “chances to live as long as they would like” was reported somewhat difficult-to-answer, because some Chinese believed life was uncontrollable and they have never thought about this question before. After discussing with the original instrument developer (Dr. Carol Ferrans), the percentage of missing data was acceptable; even in the most sensitive sex item, more than 86% of the respondents were still able to report their satisfactions in this life aspect. Although the QLI scores were not influenced by any missing data, missing data were handled by replacing the series mean for reliability assessment. Among the subjects in this study ($n=206$), the internal consistency in the total scale was strongly supported (Cronbach’s $\alpha = .95$, $p < .05$) with an inter-item correlation mean of $.39$ ($p < .001$). The lowest correlation was between “chances to live as long as I would like” and “family’s happiness” ($.07$, $p < .001$) while the highest was between “life in general” and “happiness in general” ($.92$, $p < .001$). Cronbach’s alphas for each subscale ranged from $.82$ to $.92$. The total scores and reliability estimates of the QLI are presented in Table 7. Only the total QLI scores were entered in further regression analyses.

TABLE VII
ITEM SCORES AND RELIABILITY ESTIMATES OF THE QUALITY OF LIFE INDEX

Scale	Number of Items	Item Mean (Range)	Cronbach's Alphas	Inter-item Correlations
Overall QLI	33	4.89 (4.32-5.33)	.954	.392 (.066-.917)
Health and functioning	13	4.81 (4.32-5.33)	.915	.452 (.172-.795)
Social and economic	8	4.94 (4.55-5.24)	.824	.401 (.186-.765)
Psychological/spiritual	7	4.86 (4.45-5.31)	.902	.563 (.277-.917)
Family	5	5.05 (4.87-5.25)	.828	.407 (.137-.716)

k. **The SF-12v2™ Health Survey** (J. E. Ware, et al., 1996)

Permission was obtained for this study to use the brief, reliable measure of overall health status, SF-12v2 (Appendix B). SF-36v2™ was first developed as a measure of general health status in the national Medical Outcomes Study (John E. Ware & Sherbourne, 1992), and SF-12v2™ being a 12-item subset of SF-36v2™ was created as an even shorter survey to measure the same eight domains (J. E. Ware, et al., 1996): role limitations in physical functioning due to health problems, vitality (energy and fatigue), health perceptions, bodily pain, general mental health (psychological distress and well-being), social functioning limitations due to physical or emotional problems, and role functioning limitations due to physical health problems and emotional problems (John E. Ware, 2000). Cited in more than 4,000 publications, translated into more than 50 languages, and widely used among various populations in clinical practice, health policy evaluations, and general population surveys, both SF-36v2™ and SF-12v2™ have established sound psychometrics and a high degree of acceptability and data quality (Gandek et al., 1998; Wagner et al., 1998; John E. Ware, 2000).

Response choices of SF-12v2™ questions were on a 3-point or a 5-point Likert scale. Specific scoring steps were taken to reverse, recalibrate, and recode the raw data. First, corresponding items within each subscale were summed and later transformed to a 0-100 scale. Second, z-standardization was applied according to the scoring manual so that all eight subscale scores had a mean of 50 with a

standard deviation of 10, as in the 1998 general US population. Last, scores of the aggregate physical component summary (PCS) and mental component summary (MCS) were standardized by using a linear t-score transformation to have a distribution which mean equaled to 50 (SD=10).

Both PCS and MCS in SF-12v2™ have shown to be useful in large population health surveys, and both have been extensively used as a screening tool for population health (Gandek, et al., 1998). In this study, only summary measures of PCS and MCS were used for interpretation of the general health status and entered in further regression analyses.

Evidence for reliability of the SF-12v2™ scales was supported by both internal consistency and test-retest reliability. Reliability coefficients have been replicated in more than 200 studies across various populations in terms of socio-demographics and illnesses. Cronbach's alphas for PCS and MCS in these studies were usually above .85 (John E. Ware, 2000; John E. Ware, Kosinski, & Keller, 1994). Results from more than 30 test-retest studies have supported the stability of this instrument (John E. Ware, et al., 1994; John E. Ware, Snow, Kosinski, & Gandek, 1993). Stabilities for PCS-12 and MCS-12 were slightly below those for PCS-36 and MCS-36, but still quite high: the test-retest reliability of the SF-12v2™ PCS summary measures was .90 in the United States and .86 in the United Kingdom; MCS coefficients were .76 in United States and .77 in United Kingdom. In addition, in both samples changes in scores between test and retest averaged less than 1 point for the two summary measures (J. E. Ware, et al., 1996).

Previous studies have supported items in SF-36v2™ have sound content, concurrent, construct, and predictive validity (John E. Ware, et al., 1994; John E. Ware, et al., 1993). SF-36v2™ content validity has been compared with that of other widely used generic health instruments (John E. Ware, et al., 1993), and SF-12v2™ as a subset of this generic health instrument has shown to measure the most frequently measured health concepts, not specific symptoms. Construct validity of SF-12v2™ was proved by differences among subscales, and previous factorial analyses revealed that both PCS and MCS were the two most valid scales for measuring physical and mental health, respectively. (J. E. Ware, et al., 1996; John E. Ware, et al., 1994; John E. Ware & Sherbourne, 1992; John E. Ware, et al.,

1993). This pattern of results has been replicated in cross-cultural and longitudinal studies using the known-groups validity method. Known-groups criteria included various clinical indicators of diagnosis and physical (mental) conditions. Sound construct validity have been reported in 14 studies among groups known to differ in clinical profiles (J. E. Ware, et al., 1996).

Among the subjects in this study the internal consistency for the overall scale and the two summary measures (PCS and MCS) were strongly supported (Cronbach's alphas= .91, .87, and .87, $p<.001$). The inter-item correlation mean for the total scale was .46 (.16-.88, $p<.001$) where the lowest correlation was between a mental health item "Have you felt downhearted and depressed?" and a physical functioning item "Does your health now limit you in moderate activities (such as moving a table, pushing a vacuum cleaner, bowling, or playing golf)?" The highest correlation was expected between two role-physical items: As a result of your physical health, "how much of the time you accomplished less than you would like?" and "how much of the time you were limited in the kind of work or other activities?"

1. **Systems of Beliefs Inventory (SBI-15R)** (Holland, et al., 1998)

Spiritual engagement and activities have positively influenced mortality (McCullough, Hoyt, Larson, Koenig, & Thoresen, 2000), general health status (Matthews et al., 1998), and QOL (life-satisfaction) (Richards & Bergin, 1999). It was now well accepted that people who viewed themselves as spiritual might not necessarily endorse a formal religion; therefore, an instrument that measured only religious beliefs, practices and rituals was incomprehensive for QOL research and EOL research.

A number of inventories have been developed to address spiritual and religious beliefs and behaviors (Allport and Ross, 1967; Reed, 1987; Kass et al., 1991), but a standardized 15-item System of belief Inventory (SBI-15R) (Appendix B) was the first spiritual instrument being incorporated into QOL assessment of patients with life-threatening illnesses. This valid instrument was chosen for this study because the main construct of this instrument focused on individuals' systems of belief, particularly their reflections on the meaning of life, death, illness, and existential concerns. "These

perceptions were frequently brought into bold relief for individuals to cope with a life-threatening illness (p.461)” (Holland, et al., 1998). SBI-15R as a short spiritual measure was suitable for this study and the study interest was in Chinese Americans’ spirituality on their readiness for advance care planning.

The development of this short instrument has undergone four careful phases. The final 15-item version (SBI-15R) as a miniature of the 54-item version (SBI-54) significantly correlated with the original version ($r = .98$, $p < .001$). Response choices of SBI-15R were on a 4-point Likert scale (0= “strongly disagree,” 3= “strongly agree”), on which Chinese American participants responded to a series of belief statements based on their value system. Statements were declarations of a system of belief in two domains: a) presence and importance of religious and spiritual beliefs (subscale I: 10 items), and b) value of support from a religious or spiritual community (subscale II: 5 items). There was no reverse scoring (opposite statement) in the SB-15R. A score for each subscale scale was calculated as the sum of the respondent’s response scores relating to the items belonging to that scale. A summation of the two subscales produced a total score ranging from zero to 45. High scores indicated a positive response towards the items, corresponding to a high pronounced spirituality.

Holland and colleagues (1998) reported sound internal consistencies of .93 for the total scale, .92 for the beliefs and practices subscale, and .89 for the social support subscale. Evidence of convergent validity was provided which significant correlations were found between SBI-15 and two other religious instruments (.84 and .82, $p < .01$). Virtually no correlation was found between the SBI-15 and the SF-36 ($r = .03$) demonstrating a divergent validity. Discriminant validity was supported that the SBI-15R was able to distinguish subjects between religious communities and non-religious groups (Holland, et al., 1998). Convergent, divergent, and discriminant validity (Holland, 1999a; Holland, et al., 1998) were supported in cross-cultural studies among terminally ill populations of melanoma and HIV-positive patients (Holland, 1999a, 1999b).

In this study, the SBI-15R has achieved good psychometric results among Chinese American subjects ($n=206$). The internal consistency was strongly supported for the overall scale, subscales I

(beliefs and practices) and II (social support)(Cronbach's alphas = .93, .90, and .84 respectively, $p < .001$). The two subscales correlated with each other ($r = .81$, $p < .001$) and the total score correlated with the belief and practice subscale ($r = .98$, $p < .001$) and the social support subscale ($r = .92$, $p < .001$). The inter-item correlation mean for the total score was at .65 (.42- .86, $p < .001$). The SBI-15R total score was sufficient for the determination of general spirituality and was entered in further regression analyses.

m. **Chinese Americans' self-rated religiosity**

Chinese-speaking community churches were often seen as a setting of socialization for Chinese American immigrants. This study used a convenient church sample in which many reported becoming Protestant Christians after immigrating to the United States. It was possible that some Chinese American participants, who viewed themselves religious in Christianity, might focus less on the spiritual aspects of religion than on the traditions, social interactions, and rituals.

The other spirituality instrument chosen for this study, SBI-15R, measured a system of beliefs independent from religious beliefs, and neither domains of "intrinsic religiosity" (a combination of religious practices with a more spiritual aspect of religion) nor "extrinsic religiosity" (rituals and practices associated with institutional religions) was included in this measure (C. J. Nelson, B. Rosenfeld, W. Breitbart, & M. Galletta, 2002). As important as spirituality, self-rated religiosity was important among Chinese American believers in understanding their readiness for advance care planning. Instead of using a sophisticated instrument (for example, the Intrinsic/Extrinsic Religiosity Scale (Gorsuch & McPherson, 1989) is a validated, multidimensional measure of religiosity), two questions were created as a simplistic measure of self-rated religiosity (Appendix B) for this study. Respondents were requested to report their frequency of attending religious services and a self-perceived degree of religiosity in religious doctrine.

Response choices of this measure were individually designed on a 5-point and a 6-point Likert scale (1= "never" and 6= "more than twice a week; 1= "not religious at all" and 5= "very religious"), on which Chinese Americans responded based on their perceived religiosity. A summation of these two

scores produced a total score ranging from zero to eleven; the higher the score, the better their self-rated religiosity.

Content validity was first verified and items of this new measure were judged by a panel of three cultural and clinical experts (all of them were doctoral prepared medical professionals). Conceptual definitions and instrument objectives were provided to them. No changes were made after discussing with the panelists, and during the pilot testing none have reported these two questions problematic.

Each of the two questions had 0.4% and 2.9% missing data (total 7 subjects missing), and they were handled by the series mean replacement. The internal consistency was supported (Cronbach's $\alpha = .66$, $p < .001$) with an inter-item correlation of .49.

n. **Demographical measures**

Listed in the final section of the survey were a series of demographic questions for variables of age, gender, marital status, household income, level of education, work status, number of parents who were still alive, religion raised in the original family, and current religion. These variables were selected from an extensive literature review in EOL research.

Response choices of each question were constructed based on the format of a national survey, but for variables of highest education, current work status, household income, and religion preferences, respondents were given more than six response choices (some with an open-ended response of "other"). This approach was designed to avoid ambiguity and elicit accurate and precise answers. Level of education and household income were categorical variables but treated as interval in this study; the more the value, the higher education and income a subject received.

In addition, several questions were designed to be culturally appropriate for elderly Chinese Americans. For example, the age question asked the respondents to provide a real number of age on their last birthdays, instead of asking the respondent to fill out their age. This was to prevent the "lunar year birthday" confusion in Chinese culture. A response choice of "some education but no diploma" was added because some elderly Chinese immigrants might not have official school education, or the school systems might be different in the countries they were born.

Three questions related to religion identification were included in this demographical section. Many Chinese Americans chose to convert to Christianity after immigrating to the United States, and this change of religion, as a result of immigration, might influence their readiness for advance care planning. Chinese American respondents were asked to provide recalled information about a raised religion in the original family and their current religion preference. Six response choices of formal religions were listed with a blank option of “other,” including the option of atheism and no preferred religion. These responses were later recoded into Eastern religions (Buddhism, Taoism, Taiwanese folk religions), Western religions (Protestant Christians and Catholic Christians), no preference, and all others (Atheism, Muslim or other) for further analyses.

3. **Qualitative semi-structured interview guide**

Qualitative data were collected using a semi-structured interview guide, which is a traditional form of data collection for qualitative data (Lofland & Lofland, 1995; Patton, 1990). Questions in the semi-structured interview guide were based on an extensive literature review, pilot data from the researcher’s previous interviews among seven elderly Chinese Americans (five females and two males aged between 68 and 82 years old), and survey questions in the quantitative part of this study. Constructed according to guidelines proposed by Lofland (1995) and Patton (1990), in-depth interview questions were guided by the conceptual model Chinese Americans’ Readiness for Advance Care Planning (Figure 1) in order to understand and explore socio-cultural, knowledge, spiritual, and demographic factors that contribute to Chinese Americans’ readiness for advance care planning (Table 1).

The interview guide was revised during the early stage of data collection and evaluation. Refinement of the interview questions began immediately after the first pilot interview was completed. Then, changes were made to the guide after evaluating the first two pilot interview transcripts so that all important variables in the conceptual framework were incorporated in the interview categories. In addition, revisions were made in the semi-structured interview guide after reviewing preliminary quantitative findings from the questionnaires and during the first four interviews. The final version of

the interview guide consisted of the following sections: a) an introduction section that allowed the researcher to get acquainted with the subject; b) readiness for advance care planning, which included an understanding of their motivation status, pros and cons, and barriers specifically related to advance care planning; c) Chinese death and dying beliefs related to readiness for advance care planning; d) self-perceptions of knowledge needed for advance care planning; e) spirituality, which included relationships with God and other people in the religious community related to advance care planning; f) recommendations for strategies for advance care planning interventions including setting, media, content, and frequency; and g) reflection on the interview (Appendix E).

All interview questions were open-ended which allowed the subjects to freely describe their responses, including personal stories and/or acquaintance with the experience of others. Simple explanations of advance care planning concepts, such as life-sustaining treatment options and advance directives documents were introduced in a standard format in the guide to avoid medical jargon and possible distortion. For example, instead of using the term “advance care planning,” the interviewer explained this term by stating, “In America, people are encouraged to make treatment decisions about medical care they might need if they become seriously ill and would be too ill to let others know of their preference at the time.”

Interview subjects were considered vulnerable due to the sensitive nature of the research, particularly those questions related to their previous EOL experiences of their own illness, loss, or loss of a loved one. Some subjects, yet very few, did cry or seemed to experience emotional sadness when talking about the death of their close family members. Therefore, following recommendations for qualitative research on sensitive topics (Kavanaugh, Moro, Savage, & Mehendale, 2006), questions related to the sensitive topics of death and dying experiences were not introduced immediately but intentionally placed in the latter part of the interview for cultural consideration and conversational intimacy. Each interview was concluded with a question about the experience of the interview itself. The purpose of this final question was to enable the subjects to reflect on how much their knowledge and readiness might be influenced by the interview. This also provided an additional opportunity to

investigate possible adverse psychological consequences caused by the interview (Kavanaugh, et al., 2006). During the interview data collection, the interviewer recognized that although questions in the interview guide attempted to determine whether there existed a correlation between Chinese Americans' readiness for advance care planning and those factors proposed in the model, no presumed relationship among variables was made during interviews, at least the researcher did not deliberately guide the conversation because qualitative research should be inductive in its nature.

E. Data Analysis

1. Quantitative analysis

In this study, descriptive analysis and multivariate linear regression were performed to describe, compare, and delineate statistical relationships among independent variables (factors and demographic characteristics in the proposed conceptual model) and the outcome variable of Chinese Americans' readiness for advance care planning. The computer software SPSS v.16 was used for all quantitative data management and statistical analyses.

a. Descriptive analyses

First, commonly used descriptive statistics were computed for each psychometric instrument and the outcome measure in the survey, including medians and means, standard deviations, skewness and kurtosis, standard errors of skewness and kurtosis, frequency, and confidence intervals. Statistics of Shapiro-Wilk and Kolgorov-Smirnov tests were calculated from tests of normality. Various bivariate analyses were performed in order to examine relationships between each pair of independent and outcome variable, including Chi-square tests, independent-samples T tests, and correlations test. Because the measurement level of variables in this study was not all interval (some were ordinal and dichotomous), a correlation matrix of 25 variables was prepared consisting of appropriate correlation coefficients, including Pearson's r (used between two interval variables), Spearmans' ρ (for ranked data), Phi (for two dichotomies), and Point-biserial's r_{pb} (used when correlating a continuous variable with a dichotomy). In this matrix, the focus was not only on relationships between the independent and dependent variables, but also on the correlations among independents of proposed predictors. Tests of

multicollinearity were performed as well for those moderate to high correlations (all correlations > 0.4).

In order to achieve the first study aim (#1), “To describe Chinese Americans’ readiness for advance care planning,” total and subscale (if available) scores of Chinese Americans’ stage of change, their decisional balance and self-efficacy for advance care planning were descriptively presented along with results of normality tests, item statistics, frequency, and distribution histograms. While examining Chinese Americans’ various stages of readiness, special attention has been given to the distribution of the outcome. From our previous experience in this research area, the majority of Chinese Americans have shown relatively low readiness for advance care planning, so respondents were anticipated to be highly concentrated on one particular stage (precontemplation) and only a small percentage would be identified as contemplators or located at advanced stages. If this was the case, the basic assumption of a normal distribution and constant variance in the outcome variable would be violated, and a standard multiple regression analysis became inappropriate. A revisit of the outcome data might be needed to remedy such a normality violation, either by mathematically converting the data into a computable distribution (such as logarithm or Poisson) or transforming the outcome based on a meaningful cut-point (such as a dichotomization of the variable). More results and manipulations of the outcome variable were described in Chapter IV.

b. **Multivariate regression analyses**

To achieve the second study aim (#2) “To examine the effects of cultural factors, knowledge of advance care planning, spirituality, quality of life, and demographic characteristics on Chinese American’ readiness for advance care planning,” a multivariate regression analysis was required to explore effects of significant predictors and demographic variables on the readiness outcome. The best regression model would provide not only information about the percentage of explained variance (Stevens, 2002), but also the relative contribution of each predictor on the outcome in a mathematical form.

Therefore, significant independents from the bivariate analyses (a p-value less than .05), anticipated to explain the most variance of the dependent variable, were selected as predictors into an appropriate multivariate regression model.

As mentioned earlier, when a violation of normality and extreme skewness existed in the outcome variable, the most appropriate multivariate regression analysis then would be a logistic regression analysis that examined the linear combination and likelihood ratio among selected predictors and the outcome of a dichotomous stage of readiness for change (0= precontemplators and 1= contemplators and above). A series of likelihood ratio (LR) logistic regression analyses were performed to search for the best regression model, including the procedures of standard LR (enter), forward stepwise, and backward stepwise.

To achieve the third study aim (# 3), “To discover strategies that Chinese Americans would prefer to use in advance care planning interventions,” survey respondents’ answers in the strategy component were analyzed and presented by descriptive statistics. Because some of the questions were designed to be multiple responses that respondents could choose all options that applied to them, frequency of the responses and frequency of cases in each answer option were presented together.

2. **Qualitative analysis**

The purpose of obtaining qualitative data from the elderly Chinese American subsample was to support, clarify, augment, and possibly explain the quantitative survey data (more information about mix-method purpose and analysis of this study are introduced below). In qualitative research, data collection and analysis usually occur at the same time, and it is recommended that qualitative data analysis begins as soon as data from the first case are collected (Patton, 1990). In this study, qualitative data analysis was initiated soon after the two pilot interviews were obtained. Interview guide construction, data collection, and the early phase of data analysis overlapped during the first five interview cases. Also, a carefully designed translation process was in place in the early data analysis phase to ensure data equality in Chinese and English. In addition, preliminary findings from the survey were compared with pilot interview data, because at this point of time it was also important for the

interviewer to have an overall understanding of the subjects' responses and the phenomenon of interest explicated from the survey in order to continuously precede a high quality qualitative analysis.

Qualitative data management analysis involved four phases: processing and translating data, constructing a code list and applying codes to the data, describing cases and identifying themes, and ensuring quality of data.

a. **Processing and translating data**

After collecting data from the first five participants (from two pilot and three interview subjects), digitally recorded interviews were transcribed verbatim onto computer files. The researcher (interviewer) listened to the sound clips (in Mandarin and Taiwanese spoken language) and generated five interview transcripts which were written in traditional Chinese. Noted on the transcript printouts were non-verbal behaviors during the interviews, such as pauses between sentences and emotional expressions. Because of the many practical advantages to use a database management computer program (MacQueen, McLellan, Kay, & Milstein, 1998; Muhr, 1997), transcribed data were entered into ATLAS.ti 5.0 (Scientific Software Development) for eventual coding and analyzing key interview statements.

To prepare for the data analysis in English, carefully designed translations were processed to facilitate all Chinese interview data being properly and accurately transcribed into English. Two qualified bi-lingual translators (Appendix F) were recruited to forward translate a portion of data (from Chinese to English) in two phases: First, each of them was asked to independently translate the same Chinese transcript (one case from the two pilot interviews) into English, without reviewing the researcher's version. Both of them have demonstrated good translation quality needed for this study. Second, after all interviews were completed, these two translators were requested again to listen to the same Chinese sound clips of marked data and transcribed them into English. For this approach, three interview scripts were randomly selected from 26 cases (non-pilot data) and compared with each other; and 50% of the interview contents were marked so that a portion of interview data from each of the topical areas in the interview guide was reviewed. These designated data were selected with input from

the dissertation committee chairpersons. The two dissertation committee chairpersons, both cross-cultural research experts (who do not understand Chinese), then checked three translated English transcripts for accuracy and compared various versions to determine whether the researcher's translation has trustworthily and equivalently demonstrated the target Chinese information. They concluded that the transcribed information were at least 90% compatible among three translators, including the researcher. This confirmed the reliability among three transcribers since they have produced very similar translation results from the target Chinese transcripts.

To further examine the validity of translated data, the principle of traditional back-translation method was used with modifications. First, an agreed-on forward version (English) of one interview was selected by the three translators including the researcher. Second, a back translation of this English transcript was independently performed by another qualified translator who is also a bilingual Chinese American but unassociated with this study. The researcher as the cultural expert and the native speaker then compared between the backward translation and the original Chinese transcript. The content equivalence was well established since the source transcript and the back-translated version were 90% compatible.

b. **Constructing a code list and applying codes on data**

1) **Preparation**

After all data were adequately processed, the next important step in qualitative data analysis was the systematic coding of text (Strauss & Corbin, 1998). In this study, several techniques were employed before codes were actually applied to the entire data set, with a systematic evaluation of the utility (quality) of codes and the researcher's ability (in applying codes). Before creating a code list, the researcher reviewed each interview transcript at least twice, and referred to the quantitative findings for a beginning understanding of Chinese American respondents' characteristics and their shared advance care planning experiences.

While a number of coding techniques were available, ranging from quick word counts to in-depth linguistic analyses, "latent coding (Berelson, 1952; Shapiro & Markoff, 1997)" as a subjective

approach was chosen for this qualitative analysis, concerning the meaning and the interpretations of symbolism underlying the data. This type of segment approach is considered appropriate when analyzing subjects' answers to open-ended questions in semi-structured interviews (N.K. Denzin & Lincoln, 2000). It was worth noting that because the analysis was conducted in English (not Chinese Mandarin), the technique of "*in vivo* coding" which codes created based on interview subjects' actual spoken words or terms (Strauss, 1987; Strauss & Corbin, 1998) became unfeasible. The researcher, however, has carefully identified Chinese "local terms" while listening to and translating segments of the interview data.

2) **A mixed-method coding approaches**

In this mix-method study, the same conceptual framework was shared by both quantitative and qualitative analysis. These two types of data were integrated in many phases to complement and support each other, including the approach for coding. In the early phase of codes development, two types of coding guidelines commonly used in the content analysis research, "*a priori coding*" and "*emergent coding* (Stemler, 2001)," were followed in order to create quality codes that were both theory-and data-driven.

In *a priori* coding(Weber, 1990), coding categories are established based upon a theoretical framework "prior to" the qualitative analysis, and then code developers are to discuss, agree on the code categories, and then make revisions of the final code structure. On the other hand, coding categories in *emergent coding* are established "after" some preliminary examination and analysis of the raw data. For this study, key codes already existed "a priori", since key constructs were previously incorporated into the semi-structured interview guide, according to the theoretical framework (Miles & Huberman, 1994). This preliminary, theory-driven code structure had the advantage to explain and contribute observational data of variables in the conceptual model.

Secondly, in order to develop high quality data-driven codes, codes were also established and identified from the raw data by two coders following the *emergent coding* guidelines (Haney, Russell, Gulek, & Fierros, 1998). In this approach, MacQueen (1998) suggested two team researchers taking a

leading role to examine the data and independently develop the initial codes. Once the two coders reached at least 95% agreement of the codes (reliability check), this set of initial codes would be consolidated by the two coders and reviewed by the full research team for the final structure.

3) **Creating an initial code list and refining the final codes**

As previously described, a modification of both emergent and a priori coding approaches was used to enhance code quality. First, the researcher alone generated a list of initial codes from narrative data of two interview scripts. A total of 56 codes were identified during this preliminary emergent coding; and unsurprisingly a large portion of them were “a priori codes” of key constructs in the conceptual framework. Second, both the researcher and a dissertation committee co-chairperson, a qualitative methodology expert, reviewed the initial codes, examined unnecessary codes, and discovered new codes from the same interview data and data from two more cases. An agreement was then reached between these two reviewers on the scope and level of detail for these initial codes. Both dissertation committee co-chairpersons reviewed this initial code structure and minor changes were made in wording of the code definitions with an emphasis on achieving clarity and explicit guidance for code application. Finally, the initial code list consisted of a total of 34 codes (in which eight were data-driven) and each was given an operational definition and tabulated with key constructs in the conceptual model and important interview questions.

As the data coding continued for two randomly selected cases, both the researcher and one of the dissertation co-committee chairpersons, the qualitative methods expert, revised the initial codes. Refinements were made such as clarifying unclear codes, assigning sub-codes, deleting unnecessary codes, merging and separating codes that were broadly defined, and adding new codes emerged from the data. For example, after coding the first five cases, “Filial Piety” and “Chinese son’s responsibility,” “English proficiency” and “doctor-seeking behavior in the States,” “Chinese Americans’ preferred role in advance care planning” and “Self-efficacy for advance care planning” were combined due to their similarities and frequent overlaps in the interviews. “Uncertainty about future,” “isolation,” “death-planning,” “life-sustaining treatment values and opinions” were added as they were phenomena

observed in almost all interviews but not included in the initial code list. “Standard education,” “no codes,” and “social greetings” were determined unnecessary. In addition, codes relating to demographic characteristics were added. These changes to the initial codes were approved by the two co-chairpersons of the dissertation committee.

The final code structure contained a total of 32 codes with five components: the code, a full definition, a guideline for when to use the code, a guideline for when not to use the code, and examples (MacQueen, et al., 1998). The codebook includes a description of how codes were operationally defined and tabulated with corresponding variables and interview questions. At this phase, the final code structure was tested before applying to the entire data set. A coding process was designed for two coders, the researcher and one of the dissertation committee chairpersons, to independently code the same interview data (two cases randomly selected from the total interview sample). This technique served two purposes: first, it was to ascertain the adequacy of the final coding structure so that trustworthiness can be enhanced throughout the whole qualitative analysis; second, by a detailed segment-by-segment review, the researcher’s coding ability could be assessed by a coding expert. There were a total of 221 assignments of codes from both coders, and 212 were applied to the similar segments in the transcripts. Code assignments of the two coders were compared, each code was reviewed with its relation to the conceptual framework, and questions were resolved between two coders. Although some segments had dissimilar boundaries, the researcher and the dissertation committee chairperson remained achieving a 95% resemblance using the same code structure.

To conclude the initial coding process, the same interview transcripts (data from the two pilot interviews and two randomly selected interviews) were coded twice by the researcher and the dissertation committee co-chairperson who had coding expertise. Together they discussed how codes were defined, important interview segments were chosen, and decisions were made about code assignment in the beginning and end of segments.

Through this process, the code structure was constantly refined. After all inconsistencies were noted, discussed, and resolved, this final code structure of 32 theory- and data-based codes was applied throughout the remaining data of 21 interview subjects by using the qualitative analysis software of Atlas.ti.

In this mixed-method study both qualitative and quantitative data were collected under the guidance of one single conceptual framework. Many codes identified from the raw data were established from the conceptual framework, because key constructs had been previously incorporated into interview questions. According to Miles and Huberman (1994), this type of initial coding was developed *a priori* and this theory-driven code structure had an advantage to explain and contribute observational data of variables in the conceptual model. On the other hand, following the *emergent coding* guideline by Haney and colleagues (1998) helped to develop high quality codes that were truthful to the data. Both coders during the initial code development recognized that variables identified in the conceptual model only assisted but not limited the initial coding.

c. **Describing cases and identifying themes**

After all interview data were coded, both within-case and across-case analyses were performed in this study (Ayres, Kavanaugh, & Knafl, 2003). According to the code structure, each subject's interview data were systematically reviewed to prepare 28 within-case summaries: first, all interview transcripts were uploaded into the Atlas.ti software so that all segments assigned in the codes could be retrieved for within-case summaries. The researcher then digested and summarized the coded data to generate descriptions under each code. For example, a 69-year-old female subject's previous misdiagnosis of cervical cancer and this first encounter of a possible death were characterized under the code "self-EOL experience." Her case summary included a total of 32 descriptions which under self-EOL experience were her feelings and concerns about cervical cancer expressed during the interview. Generating within-case summaries served the purpose to described each subject in details, and a special attention could be paid on relationships between codes within each case (Huberman & Miles, 1995). The template used for a within-case summary is presented in Appendix G.

According to the code definitions and similarities, the 32 codes were further clustered into thirteen categories. This categorization of codes was determined after discussions between the two initial coders: 1) immigration (including time and reasons), 2) cultural beliefs (of values and opinions about a good death, filial piety, familism, male paternalism, bedside arrival to say the last good-bye, longevity, karma, death discussion, disclosure of terminal illness, death planning), 3) English proficiency (related to isolation, health-seeking behavior and access to health information in America), 4) EOL related experience (including experiences of self and family), 5) knowledge (related to LST, advance directives, and advance care planning), 6) LST values and opinions, 7) Decision-making (related to EOL decisions made by physicians and uncertainty about future), 8) Decisional balance about advance care planning (including endorsement and concerns), 9) Stage of readiness for advance care planning, 10) Preferred role and self-efficacy for advance care planning decisions, 11) Spirituality (related to religion beliefs, practice, and religiosity), 12) preference for the advance care planning intervention program, and 13) Feedback (including open advice to increase readiness and subjects' reflective feedback). Again, a shorter version of within-case summary was created according to the above thirteen categories for the 28 interview subjects.

While the within-case summary explored links between data in the 32 different codes, across-case analyses focused on similarities and differences across each subject. In order to facilitate this comparison among subjects, a data summary matrix was generated as a convenient tool to display codes (in the rows) and subjects (in the columns); the final matrix included 32 x 28 cells demonstrating the entire interview data by subjects and codes. For example, the self-EOL experience mentioned above was briefly described and tabulated under ID 44 and code 15. By doing so, latent patterns in the self-EOL experience code could be easily identified across 28 cases from this summary matrix.

An example of the theme emerged across the data of 28 subjects was about a general disbelief of karma. From the extracted information displaying in the matrix, it became clear that almost all subjects considered karma an implausible Buddhist belief related to reincarnation—accumulating good deeds was not related to a better after/next life at all. This example showed the advantage of

performing an across-case analysis which themes identified in each code could be easily compared among subjects, in particular for those at various readiness stages for advance care planning.

d. **Ensuring data quality**

The term “data quality” has been used by Punch (1998) to represent the concept of “quality control of data (p. 257). It is the degree to which the collected data meet the standards of quality to be considered valid (trustworthy) and reliable (dependable).” Guba (1981) discussed the two dimensions of constructivist rigor in qualitative inquiries and criteria of *parallel* (the so-called *trustworthiness*) and *authenticity* were recommended for judging the adequacy (goodness, quality) of data. This study has followed a variety of activities suggested by Lincoln and Guba (1986) during and after the study to increase the probability of credible, transferable, dependable, and confirmable findings.

To increase credibility, the researcher has engaged and spent at least two extra weeks at the church setting before the study initiated. This was to allow potential participants to adjust to the presence of the researcher and decrease research as a threat (prolonged engagement). Because in the past seven years, the researcher has interacted with Chinese American community leaders, participated in the church activities, and conducted small focus group studies at the study sites (persistent observation), the researcher was familiar with the study population. However, at the same time she also detached from the study sites and interacted with other cultural and methodology experts (peer-debriefing). Techniques of triangulation (or complementarity in mix-method design)(Creswell, 2003) were performed by combining quantitative and qualitative data collection and integrating both types of analysis. Data were digitally recorded (referential adequacy materials) so findings and interpretations could be tested at a later time. During the entire study, multiple content/cultural and methodological consultants were involved (member check) in research design, instruments and interview guide development, and data analysis. After data collection, interpretations of data were discussed multiple times in search for internal conflicts (establishing structural coherence) among a group of investigators in the research team (member check).

To increase transferability, interview subjects were not randomly selected from the qualified participant pool. The researcher intentionally chose diverse elderly Chinese Americans who were different from their age, gender, acculturation, EOL experience, knowledge, and readiness for advance care planning in order to maximize the range of information uncovered (theoretical sampling). Detailed information was collected from the interview subjects in order to develop “thick” descriptions. During data collection and analysis processes, the researcher kept notes of analytical thoughts (audit trail). This process included completing an interview summary form at the end of each interview. The interview summary form contains a description of: problems arranging interview, environmental and interview situation, summary of impressions about family/provider, and impressions of subject.

Last, employing a mix-method design was a way to increase dependability. As data were separately translated, double coded, and tested among multiple researchers, dependability (analogous to reliability in quantitative inquiry) was increased. The qualitative instrument, the semi-structured guide, was created in congruence with the quantitative survey so that the interview categories had an attempt to explore the constructs the quantitative instruments measured (convergent validity) (Breitmayer, et al., 1993).

3. Mixed-method analysis

Since the late 1980s, a “mixed-method way of thinking” (Greene, Benjamin, & Goodyear, 2001) has been increasingly adopted concerning that neither the quantitative nor the qualitative approach alone provided a comprehensive understanding of human behaviors and their health related needs. A mix of (at least) two methods were widely used in the study design of social, educational, and health related research whereas different source of data, investigators, theories, methodologies, and analyses (Begley, 1996; Cowman, 1993) were integrated “...with respect to their inherent strengths and limitations/biases...”(p.266) (Greene, et al., 1989).

From the time when a growing literature developed around mixed-method issues, the importance of careful planning and defensible rationales, as in any qualitative and quantitative studies, has been progressively recognized in the design and implementation of mixed-method studies. Many studies

were then criticized due to their incapacity to present the merits of mixed-method results—they either lacked a clear purpose for mixing two methods or the contexts and analysis strategies were found inappropriate for the proclaimed purpose.

To avoid such a problem in this study, literatures on the mix-method design were reviewed to realize the full potential of various mixed-method approaches (Creswell, 2003; Creswell & Plano-Clark, 2007). A legitimate mixed-methodological framework (which should not be mistaken as the conceptual model of this study) was chosen to provide a theoretical foundation for a clear purpose to combine and integrate our interview and survey data. In the following section, the mixed-method approach used in this study was analyzed in terms of its a) paradigm stance, b) purpose, and c) design and analysis strategies.

a. **The overall paradigmatic framework: A viewpoint of pragmatism**

Greene and colleagues (Greene, et al., 1989; Greene & McClintock, 1985) has established a widely used mixed-methodology conceptual framework from a comprehensive review of literatures on the theory and practice of empirical mixed-method studies. Five mixed-method purposes were identified from 57 mixed-method studies, and along with the differentiated purposes in this framework were recommended analytical strategies appropriate for the design.

The recommended initial step to begin thoughtful mixed-method planning was the consideration of philosophical traditions, such as meaningfulness, sensibility, and usefulness of mixing two contrasting inquiry paradigms (e.g. Positivism and Interpretivism) in one single study (Rossman & Wilson, 1985; Smith & Heshusius, 1986). From the beginning of this study, the stance (on the paradigm issue) has been determined to be “pragmatic” and context-driven, so the attention in inquiry was never on the philosophical compatibility but rather on the conceptual and theoretical congruence of the phenomenon being studied (Greene, et al., 2001). This consciousness of and adherence to a pragmatic viewpoint throughout the whole study has assisted the design and implementation of this study within one paradigmatic framework.

b. **Mixed-method purpose: Triangulation**

The second important step in mixed-method planning was to provide rationales (purposes) for mixing the quantitative and qualitative methods. This study has a clear purpose, from two methods, to enhance certainty and attain a better understanding of the same phenomenon being investigated. In other words, questionnaires were exploited to obtain quantitative information on Chinese Americans' readiness for advance care planning, and in-depth interviews were employed to understand the nuances of subsample's experiences in similar components. Therefore, with the attempt to complete and confirm both the interview and survey data, "triangulation" was the most appropriate mixed-method design which its classic sense was to seek convergence, corroboration, and correspondence of results "between" methods (N. K. Denzin, 1978; Greene & McClintock, 1985).

c. **Design characteristics**

The third important step in mixed-method planning was to apply appropriate analytical strategies consonant with the proposed triangulation purpose. According to Greene's mixed-methodological framework, design characteristics included four elements. Analytical strategies selected to support the triangulation purpose of this study were analyzed and brief descriptions followed:

1) **Methods:** The first characteristic was the degree to which the qualitative and quantitative methods used in the study were similar (or different) from one another. In this study, a combined use of a scaled questionnaire and a semi-structured interview guide were methodologically and fundamentally different, which fitted the triangulation design well. It was recognized, however, that two methods were arguably similar in the sense to share the same conceptual biases. Grounded in a conceptual framework "Chinese Americans' Readiness for Advance Care Planning (Figure 1)" derived from the Transtheoretical Model (J. O. Prochaska & DiClemente, 1983a; J. O. Prochaska, et al., 2002), quantitative questions in the survey, the semi-structured interview guide, development of interview categories, and actual data coding were constructed based on the same theoretical concepts.

2) **Phenomena:** As recommended in a triangulation design, both methods in this study were intended to assess exactly the same phenomenon. Similar information were obtained and “secured”(Greene & McClintock, 1985) from two different methods about Chinese Americans’ readiness for advance care planning and its contributing factors. It was worth mentioning that although with the strength of the in-depth interviews, additional information might emerge about the phenomenon outside the context of the conceptual framework, the main (triangulation) focus remained on the convergence and corroboration between two types of data.

3) **Status:** The quantitative and qualitative methods had equally important roles with regard to the overall purpose and aims of this study, as normally in the triangulation design. Although the construction of the interview guide was informed by previously developed survey questions, the relative weights on both methods were the same in the data collection, analysis, and interpretation.

4) **Implementation:** In a typical triangulation design, both methods were better conceptualized, designed, and implemented independently and simultaneously within the same paradigmatic framework. In this study, the development and implementation of the survey and in-depth interviews occurred almost simultaneously, independently, and somewhat interactively in the phase of data analysis and interpretation. With some knowledge of the emerging quantitative findings, qualitative data were concurrently collected, refined, and analyzed. This “coordinated design” and “parallel track analyses” well fitted the pragmatic views and a triangulation design (Greene, et al., 1989).

d. **Achieving better understanding through a triangulation design.**

A carefully planned, conducted, and implemented mixed-method study would achieve “better understanding” (Cook, 1985; Greene, et al., 1989), avoid spurious inference, and enhance interpretability from two methods (Shotland & Melvin, 1987). This present study undergone a planning based on Greene and colleagues’ recommendations of a mixed-method triangulation design enabled more comprehensive, enriched, and contingent findings from two types of data than either data set alone.

First, the combined use of a survey questionnaire and in-depth interviews was ideal in the classic mixed-method triangulation design. These two methods of offsetting biases would obtain convergent results from measuring the same phenomenon and thus ruled out various threats to validity and enhanced credibility of inferences.

Second, more comprehensive pictures could be obtained from two different methods. For example, low English proficiency was found to be positively associated with Chinese Americans readiness for advance care planning. In the subsequent interviews, many did respond that English insufficiency actually inhibited their access to health care opportunities in the States. Commonly shared was the personal experience of using limited English to communicate with healthcare professionals and a feeling of being information-isolated and unclear about English medical terminologies. Themes emerged from the interview data provided greater comprehensiveness of findings.

Third, the triangulation design increased better insightfulness of findings. For example, although we were able to classify subjects according to their knowledge scores related to LST, how such types of treatment was defined and comprehended to impact their EOL values and advance directive decisions were only attainable from the in-depth interviews. Insightful understandings did not necessary come from convergent findings. For example, a Christian religious belief was suggestive from the interview data to facilitate interviewees' readiness for advance care planning, but this relationship was insignificant in the quantitative analysis. This conflicting finding might lead to a discovery of new concepts or a conceptual reframing of the religiosity factor to readiness.

To conclude, mixing two different methods required the same thoughtfulness and rigor in planning as in any single methodology. In order to follow the convergence purpose of a triangulation design, this study combined a self-report questionnaire in a survey format and subsequent in-depth interviews using a semi-structured interview guide. With the aims of describing and discovering factors that facilitate or inhibit Chinese Americans' readiness for advance care planning, in the quantitative and qualitative components questions were designed to substantially overlap to investigate the same phenomenon of a

behavioral outcome. Analytical strategies were further planned and implemented in this study to fit the triangulation purpose, so that the two methods elaborated, illustrated, clarified, and validated results from each other. Because the conceptual understanding of Chinese Americans' readiness for advance care planning is still in its infancy, this mixed-method design had great potential to better depict the phenomenon being investigated, allowing the discovery of important factors to explain the variations in readiness stages among Chinese Americans.

F. ETHICAL CONSIDERATIONS

Before collecting data from Chinese American subjects, permissions were obtained from both the senior pastor and the deacon board of each four Chinese church. The researcher began to contact potential Chinese American subjects from the church and collected data after the study was approved by the Institutional Review Board at University of Illinois at Chicago on June 21, 2007. An investigator-initiated amendment was approved on November 29, 2007 to increase the total sample size (from 200 to 211) and request the inclusion of six survey subjects who received the informed consent document (and completed the survey) yet did not wish to sign the consent document. This study was again approved by the continuing review board for data analysis only on May 15, 2008, May 7, 2009, and May 12, 2010.

Careful attention was paid to the sensitive nature of this study (Kavanaugh, et al., 2006) and efforts were made to ensure the protection of human subjects throughout the whole time. Upon recruitment, all potential participants were given a written description of the purpose and data collection procedure of the study. This description was also verbally announced in public by the researcher at the four church settings. This was to ensure that all potential participants understood the scope and purpose of this study. An opportunity was also provided during the announcement to allow Chinese Americans asking questions. All potential participants were informed that there were no direct benefits from participating in this study, as well as no known serious risks related to participation. Although the research topic may be somewhat culturally sensitive, the probability and magnitude of harm or discomfort anticipated in this type of research was not greater than those ordinarily

encountered in daily life. In this study, the participants were told that their participation was clearly voluntary, and they could withdraw from the study at any time. In particular, if interview participants would not want to continue the study, the researcher/interviewer would immediately stop the interview. They were also informed that they could choose not to answer certain questions if they did not wish. Both survey and interview participants were provided with the researcher's name, office, and home phone numbers in case they have any question during the course of the study or after its completion. Completed survey instruments were returned anonymously and directly only to the researcher. For only a small subset of subjects who agreed to be interviewed, their survey responses were linked to study numbers. Otherwise, the majority of survey responses were anonymous even to the researcher. To ensure confidentiality on the part of qualitative interviews, interview subjects were informed that information collected from the interview would be maintained using a code number and kept separately from their names throughout and after the study. During the interviews, participants' privacy was protected by maintaining a safe and private environment. All documents related to participants' responses were kept in a locked file cabinet accessible only to the researcher. All quantitative and qualitative data were kept for at least five years and then destroyed. When the results of this study are published or discussed in any conference and/or workshop, no information would be included that would reveal participants' identities.

IV. RESULTS

The results of data analyses are presented, beginning with descriptive information about the overall sample demographics, descriptive statistics of quantitative measures, logistic binary regression results, and followed by qualitative findings summarized from the in-depth interviews. The phenomenon of interest, Chinese Americans' readiness for advance care planning, was described to include survey and interview findings of a) the readiness stages of change, b) decisional balance, and c) self-efficacy for advance care planning (aim 1). To examine and determine significant relationships between Chinese Americans' readiness and proposed predictors (aim 2), a comprehensive bivariate analysis was first performed along with qualitative themes drawn from the interview data, and a multivariate regression analysis tested in a binary logistic regression model was further conducted to assess the relative contribution of each factor. In the latter part of this chapter, strategies Chinese American subjects preferred in an advance care planning program were summarized (aim 3) from both the survey and interview data. A summary of key findings are included in Appendix H.

A. **Descriptive Analyses**

1. **Demographic characteristics**

Demographic characteristics of the total (quantitative) sample (n= 206) are presented in Table 8. A total of 158 subjects (76.6% of the total sample) agreed to participate in the subsequent in-depth interviews, and selected were 28 cases (17.7%) different in their stages of readiness, self-efficacy, decisional balance, age, gender, marital status, levels of education, income, religion preferences, knowledge, acculturation, traditional cultural beliefs, etc. Although the interview subsample was purposively selected to maximize the variety, interview subjects' descriptive statistics were generally not too different from that of the total sample. Ranging from 65 (the lowest age criterion) to 93 year-old (mean= 77, SD= 10), the majority (53%) of the interview subsample were between 65 and 74 year-old (Table 8). Ratios of gender (60% females) and marital status (64.3% married) were similar to the total sample, yet more singles/widowers were selected (28.6%) to

TABLE VIII
DEMOGRAPHICAL CHARACTERISTICS OF THE TOTAL SAMPLE

Characteris	n	%	Valid	Missing	Mean	Std. Dev	Minimum	Maximum
Age			206	0	59.51	10.09	45	93
≤ 54 years old	68	33						
55-64 years old	79	38.36						
65-74 years old	40	19.43						
75-84 years old	15	7.28						
≥ 85 years old	4	1.94						
Gender			203	3	0.61	0.489	0	1
Male	79	38.92						
Female	124	61.09						
Marital status			204	2				
Single	6	2.9						
Married/partnered	157	77.0						
Widowed	26	12.7						
Divorced/separated	15	7.4						
Parents alive			204	2	0.59	0.747	0	2
None of them alive	116	56.86						
One parent still alive	56	27.45						
Both alive	32	15.67						

TABLE VIII
DEMOGRAPHICAL CHARACTERISTICS OF THE TOTAL SAMPLE (Cont.)

Characteristic	n	valid %	Valid	Missing	Mean	Std. Dev	Minimum	Maximum
Education			205		2.19	1.212	1	7
Doctoral degree	71	34.63						
Master's degree	65	31.71						
Bachelor's degree	42	20.49						
College/Tech school	19	9.3						
Senior High school	4	1.95						
Junior High school	2	0.98						
Elementary school	2	0.98						
Employment status			204	2	3.284	1.231	2	6
Retired	53	25.99						
Employed	97	47.55						
House-wife	20	9.8						
Unemployed	11	5.39						
Others	23	11.27						
Household income (USD)			183	23	3.268	2.472	1	9
> \$100,000	61	33.33						
\$75,000 to \$99,999	30	16.39						
\$50,000 to \$74,999	28	15.3						
\$35,000 to \$49,999	18	9.84						
\$25,000 to \$34,999	11	6.01						
\$15,000 to \$24,999	10	5.46						
\$10,000 to \$14,999	4	2.186						
\$5,000 to \$9,999	11	6.011						
< \$5,000	10	5.46						

TABLE VIII
DEMOGRAPHIC CHARACTERISTICS OF THE TOTAL SAMPLE (Cont.)

Characteristic	n	valid %	Valid	Missing	Mean	Std. Dev	Minimum	Maximum
Raised religions			206	0	3.67	1.70	1	7
Atheist	20	9.7						
Buddhist	48	23.3						
Taoist/Taiwanese tradition	41	19.9						
Muslim	3	1.5						
Christianity (including Catholics/Protestants)	60	29.1						
No preference	32	15.5						
Others	2	1.0						
Current religions			205	1	4.91	0.755	1	7
Atheist	1	0.5						
Buddhist	12	5.9						
Taoist/Taiwanese tradition	4	2.0						
Muslim	5	2.4						
Christianity (including Catholics/Protestants)	166	81						
No preference	13	6.3						
Others	4	2.0						
Religion changed			200	6	0.54	0.499	0	1
No, my religion has never changed	91	45.5						
Yes, after coming to the United States	109	54.5						

TABLE VIII
DEMOGRAPHICAL CHARACTERISTICS OF THE INTERVIEW SUBSAMPLE

Characteristic		N	valid %	Valid	Missing	Mean	Std. Dev	Minimum	Maximum
Age				28	0	76	10.00	65	93
	65-74 years old	15	53.7						
	75-84 years old	10	35.8						
	≥ 85 years old	3	10.7						
Gender				27	1	0.59	0.501	0	1
	Male	11	40.7						
	Female	16	59.3						
Marital status				28	0	2.32	0.612	1	4
	Single	1	3.6						
	Married/partnered	18	64.3						
	Widowed	8	28.6						
Parents alive	Divorced/separated	1	3.6						
				28	0	0.21	0.568	0	2
	None of them alive	24	85.7						
	One parent still alive	2	7.1						
	Both alive	2	7.1						
Highest education				28	0	7.54	1.29	5	9
	Doctoral degree	8	28.6						
	Master's degree	8	28.6						
	Bachelor's degree	5	17.9						
	College/Tech school	5	17.9						
	Senior High school	2	7.1						

TABLE VIII
DEMOGRAPHICAL CHARACTERISTICS OF THE INTERVIEW SUBSAMPLE (Cont.)

Characteristic	n	valid %	Valid	Missing	Mean	Std. Dev	Minimum	Maximum
Employment status			28	0	3.46	1.612	2	6
Retired	13	46.4						
Employed	3	10.7						
House-wife	3	10.7						
Unemployed	4	14.3						
Others	5	17.9						
Household income (USD)			23	5	5.61	3.086	1	9
> \$100,000	7	30.4						
\$75,000 to \$99,999	2	8.7						
\$50,000 to \$74,999	2	8.7						
\$35,000 to \$49,999	1	4.3						
\$25,000 to \$34,999	2	8.7						
\$15,000 to \$24,999	2	8.7						
\$10,000 to \$14,999	0	0						
\$5,000 to \$9,999	5	21.7						
< \$5,000	2	8.7						
Raised religions			28	0	3.14	1.67	1	7
Atheist	3	10.7						
Buddhist	10	35.7						
Taoist Taiwanese tradition	7	25.0						
Muslim	0	0						
Christianity (Catholics & Protestants)	5	17.9						
No preference	2	7.1						
Others	1	3.6						

TABLE VIII
DEMOGRAPHIC CHARACTERISTICS OF THE INTERVIEW SUBSAMPLE (Cont)

Characteristic	n	valid %	Valid	Missing	Mean	Std. Dev	Minimum	Maximum
Current religions			28	0	4.96	0.331	3	7
Atheist	0	0						
Buddhist	0	0						
Taoist Taiwanese tradition	2	7.1						
Muslim	0	0						
Christianity (Catholics/Protestants)	25	89.3						
No preference	1	3.6						
Religion changed			28	0	0.75	0.441	0	1
No, my religion has never changed	7	25						
Yes, after coming to the United States	21	75						

understand the self-efficacy perceived from non-spouses. Two elderly subjects (7.1%) holding senior high school diplomas were purposively sampled to be interviewed to represent opinions from the relatively low-educated individuals. Also particularly included were subjects of low-income, retired, or unemployed (46.4%). More than half of the sample reported they used to follow their parents to believe Buddhism and Taoism, and approximately 10% grew up in the atheist culture. However, at the time this study was conducted only less than 10% in the sample were non-Christians and several of them were purposely selected for the in-depth interviews.

2. **Chinese Americans' readiness for advance care planning**

a. **Measuring the outcome: Stage of readiness**

1) **Advance directives intention, usage and communication**

Regarding advance care planning, subjects in this study had a better-than-neutral psychological intention (mean= 6.52, SD= 2.58, skewness= -.29, SE= .17) (Table 9). More than 66% agreed it was necessary to initiate advance care planning, opposed to approximately 29% who had no such needs. About 43% would like to obtain additional information in this area, yet the majority (45%) was enthusiastic yet unclear about the appropriate time to initiate such EOL related planning. On the other hand, only a total of 36 Chinese-ethnic subjects (17.5%) have executed their advance directives (ADs), including two (< 1%) just recently signed a (Illinois) living will within the last six months. Among those (n= 36) who have completed their advance directives or living wills, nearly one fifth reported such a EOL treatment and care decision was unknown to others (Table 9). The majority (62%) of them had never discussed LST decisions others after completing the ADs; only fewer than 40% have continued to share EOL preferences with family members or physicians (Table 11). The result illustrated a passive pattern of EOL related communication (mean= .19, SD= .67, skewness= -.242, SE= .17) among Chinese Americans.

TABLE IX
DESCRIPTIVES AND FREQUENCY IN THE STAGE OF READINESS INTENTION SCALE (n= 206)

Question	n	%	Mean	Std. Dev	Min	Max
Are you willing to start planning for your future life-sustaining treatment and possible care at the EOL?	206		2.37	1.159	0	4
No, I don't need this planning.	9	4.4%				
I don't know.	35	17.0%				
Yes, but I don't know when would be the best time.	85	41.3%				
Yes, but later (at least 6 months from now).	25	12.2%				
Yes, soon (within the next 6 months).	52	25.2%				
Do you want to know more about "Advance care planning?"	206		2.56	1.11	0	4
No, I don't need to know more.	7	3.4%				
I don't know if I need to know more.	21	10.2%				
Yes, but I don't know when would be the best time.	88	42.7%				
Yes, but later (at least 6 months from now).	30	14.6%				
Yes, soon (within the next 6 months).	60	29.1%				
In your opinion, do you think necessary now to plan for your future life-sustaining treatment?	206		1.60	0.60	0	2
No, I don't think so.	12	5.8%				
I don't know if it is necessary.	59	28.6%				
Yes, I think so. It is necessary.	135	65.5%				
<u>Intention to change</u> (subscale scores)	206		6.52	2.576	0	10

TABLE X
DESCRIPTIVES OF RESPONSES IN THE ADVANCE DIRECTIVE QUESTION

Characteristic	n	%	Valid	Missing	Mean	Std. Dev	Min	Max
Usage of Advance directives (including living wills)	206		206	0	2.66	.75	1	3
Never signed any advance directive documents before	170	82.5%						
Had signed one	36	17.5%	36	0				
Less than 6 months	2	1%						
More than 6 months ago	34	16.5%						

TABLE XI
DESCRIPTIVES OF RESPONSES IN THE ADVANCE CARE PLANNING COMMUNICATION

Characteristic	n	%	Valid	Missing	Mean	Std. Dev	Min	Max
Disclosure about advance directives	36		36	0	.76	.43	0	1
No, I never told others about it	7	19.44						
I had told other people about it	29	80.56						
Continuing communication about EOL decisions in the advance directives	36		36	0	.39	.49	0	1
No, no more communication	22	61.11						
Yes, I continue to discuss and communicate with others	14	38.89						
<u>Advance care planning communication (subscale score)</u>	36		36	0	1.19	.67	0	2

2) **The original ordinal stages of readiness for advance care planning**

Each survey subject (n= 206) was assigned to one of the six stages of readiness, according to their answers related to advance care planning intention, AD usage, and EOL related communication (Appendix D)(Table 12). Based on the TTM principles, the majority (68%) of our Chinese sample were classified precontemplators-believers; only very few (2.9%) disbelieved the necessity, were uninterested in learning, and had no willingness to initiate the planning. These precontemplators, at a relatively low stage of readiness, were quite indecisive and they had no definite timeline to proactively initiate advance care planning in a foreseeable future. The remaining 32% (n= 60) were distributed across stages of contemplation (1.94%), preparation (9.7%), action (12.13%), and maintenance (5.33%).

3) Transforming the ordinal stage of readiness to a dichotomy

When the mass of highly skewed distribution (skewness = 1.27, SE= .17) was concentrated on the left of the distribution curve (Figure 2), it was obvious that the majority were predominately located at the “precontemplators (believes)” stage (mean= 2.73, SD= 1.3). The frequency-histogram and normality of residual (Q-Q) plots too supported a non-normal distribution of the six ordinal stages of readiness, and both Kolmogorove-Smirnov and Shapiro’s Wilk tests further confirmed a violation of normality assumption ($p < .001$) (Table 13).

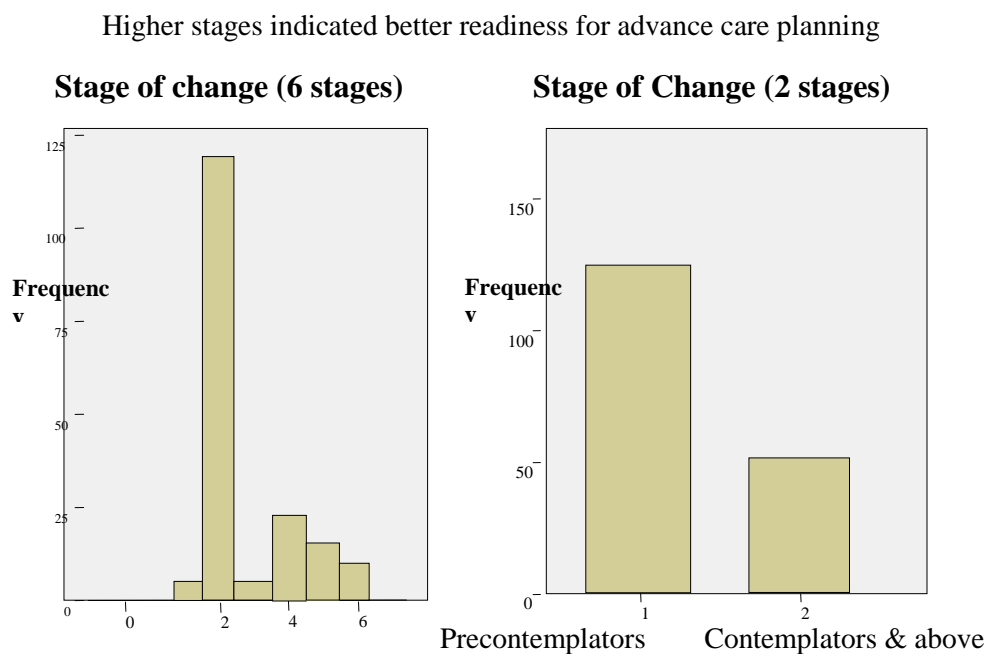


Figure 2. Distributions before and after dichotomizing the outcome of readiness for change

To remedy the non-normal and heteroscedastic data in the outcome variable, a commonly suggested mathematical conversion was logarithm transformation (Tabachnick & Fidell, 2007). However, a log-transformation would be of no use if the skewness in the original data was too severe. In this study, the high positive skewness remained even after the log-transformation (skewness= .74, standard errors of skewness= .17, kurtosis= -.19, standard errors of kurtosis= .34, Kolmogorove-Smirnov $Z = 5.867$, $p < .0001$), and the six log-stages continued to be significantly non-normal, with a peak around stage 2. In addition, since there was no theoretical basis to support a log-transformation in the outcome data, such a mathematical manipulation for statistical convenience

was untruthful to the real data—the actual stages of readiness distribution might possibly be non-normal in the whole Chinese-ethnic American population, and their readiness for advance care planning could very likely be centered in one particular stage, precontemplation. Because less than 30% of the sample had a stage of readiness at or above stage 3 (contemplation), the ordinal six stages of readiness were re-coded and redefined into two categories for further analyses. Subjects were therefore categorized into two groups: “precontemplators= 1 (including both non-believers and believers)” (71%, n= 146) and “contemplators, preparers, actioners, and maintainers= 2” (29.13%, n= 60) (Figure 2), with a mean score of the new dichotomous distribution at 1.29 (SD= .46).

Conceptually it was important to justify and meaningfully support why Chinese precontemplators were differentiated from the whole sample. In the TTM literature, precontemplators’ behavior was commonly focused and discussed. For example, smokers in the precontemplation and contemplation stages were often compared in order to explore how positive stage transition could be facilitated for smoking-cessation precontemplators (M. Y. Pearlman, Wernicke, Thorndike, & Haaga, 2004). Also in dietary behavioral change studies, researchers were often interested in powerful determinants that would move precontemplators forward to contemplators for more vegetables and fruits consumptions (de Vet, de Nooijer, de Vries, & Brug, 2005). Since each stage of readiness led to different patterns of behavioral changes in the advance care planning outcome, identifying facilitators and inhibitors significant to Chinese American precontemplators would assist their stage transition.

Because the dichotomized outcome (precontemplators and non-contemplators) did not completely represent the full range of original data, the interpretation of survey results should be taken into careful consideration. We realized that the ordinal six stages of readiness were collapsed into two categories and detailed information from stage 3 (contemplation) to stage 6 (maintenance) was lost. This issue of simplifying the outcome data was recognized that the variance of outcome data might be reduced, leading to a possible lowering of correlation between the outcome variable and the multiple contributing factors.

TABLE XII
DESCRIPTIVES OF STAGE OF CHANGE IN THE ORDINAL AND DICHOTOMOUS SCALES

Outcome variable	N	%	Mean	Std. Dev.	Min	Max
<u>Six stages of readiness for Change</u> (score determined by an algorithm)	206		2.73	1.30	1	6
Precontemplation (non-believer)	6	2.91%				
Precontemplation (believer)	140	67.96%				
Contemplation	4	1.94%				
Preparation	20	9.7%				
Action	25	12.13%				
Maintenance	11	5.33%				
<u>Two dichotomous stage of readiness for change</u> (score recoded into 2 categories)	206		1.29	0.46	1	2
Precontemplators	146	70.87%				
Contemplators, preparers, actioners, and maintainers	60	29.13%				

TABLE XIII
TEST OF NORMALITY IN THE OUTCOME VARIABLE

	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	df.	Sig.	Statistic	df.	Sig.
6 stages of change	.421	206	.000	.684	206	.000

1) **Qualitative results: Elderly Chinese immigrants' stage of readiness for advance care planning**

Selected for the in-depth interviews, 28 elderly subjects have distributed across six stages of readiness in proportion to the entire study sample, including one precontemplator-disbeliever (3.6%), 17 precontemplator-believers (60.7%), one contemplator (3.6%), four preparers (14.3%), three actioners (10.7%), and two maintainers (7.1%). In their in-depth interviews, 82.1% of the elderly subjects ($n=23$) who have not yet completed their advance directives were asked to self-evaluate and describe their psychological intention (e.g. interests and willingness in learning, perceived necessity, and a projected timeline) to initiate advance care planning. On the other hand, the actioners and maintainers, who have completed their advance directives/living wills (17.8%, $n=5$), were invited to share how they initiated this advance care planning process in the first place, their usage of the advance directive documents, and the communicative status with others. Elderly Chinese Americans' various stages of readiness for advance care planning are characterized and summarized below.

Precontemplators' stage of readiness for advance care planning

The majority of interview subjects, at a fairly low stage of readiness, expressed their indecision and lack of preparation to proactively initiate any EOL planning. Only one older woman disbelieved the benefits of advance care planning, perceived no necessity, was uninterested in learning, and had no willingness/intention (Table 14). The remaining precontemplators ($n=17$), endorsed and perceived the necessity of this idea, were interested in learning and receiving more information about advance care planning, and planned to complete their advance directive documents, yet not in a foreseeable future (not within six months). Being comparatively healthy and generally unknowledgeable, they often described EOL discussions “untimely,” “trouble-making,” and “worthless” at this point of time. Such topics were rare in their daily conversations but only infrequently triggered by encountering terminal patients. Matters of death and dying were never seriously discussed in details within their family. Unsurprisingly, many did not know how to communicate specific LST preferences rather than simply

saying, “Don’t save me if I am hopeless,” or “No CPR or electric shocks for me.” Most were not confident that their family or physicians were clear about their LST values and preferences.

The contemplator and preparers’ stage of readiness for advance care planning

The only contemplator (89-year-old female) was willing to execute her advance directive within the following six months, but the preparers were ready to do so immediately when approached or soon within the next 30 days. The contemplator reported requiring extra time to deliberate the pros and cons, learn about related knowledge, and communicate with families, yet preparers could make this EOL decision right away based on their existing LST values without further discussing with their families. Compared with precontemplators, subjects in this group not only had better understandings about advance care planning but also were psychologically more prepared. In fact, 80% have planned for (after) their deaths and established either a verbal or written will to indicate their final wishes (not necessarily about EOL treatment and care). Although they were highly motivated and intended to complete their advance directives, procrastinations (“I was easily distracted by other life priorities”) because of no urgency (“still in good shape”) were common to explain why most have not put EOL planning into action. Since many preparers had a LST value to forgo EOL treatment (in order to avoid being a burden to others), they often regarded EOL communication important and necessary.

TABLE XIV

SUMMARY OF INTERVIEW SUBJECTS' INTENTION, USAGE, COMMUNICATION, AND RATIONALES IN RELATION TO STAGES OF READINESS FOR ADVANCE CARE PLANNING (n= 18)

Interviewees	Advance directive usage & intention	Communication	Rationales
Precontemplator: one advance care planning disbeliever (n= 1)	<ul style="list-style-type: none"> - Had no intention at all to complete any advance directive documents - Perceived no necessity to plan for EOL - No willingness and uninterested in learning 	<ul style="list-style-type: none"> - Had no plan to communicate with others about EOL - Perceived no necessity to communicate, 	<ul style="list-style-type: none"> - Thought she has planned everything needed for (after) her death such as funerals, heritage, etc. - Could not imagine she could plan for EOL treatment and care - Not too concerned about the way how she died - Preferred no aggressive resuscitation but believed that planning or not made no difference - It was troublesome even to think about such a planning - She would like to obey God's timing and follow the nature - It was fine not to have knowledge in this area - Believed that her son will take care of her LST and her physician will never over treat her, so no need to communicate with families - Believed that no family would be interested in such a discussion of depressing topics
Precontemplators: advance care planning believers (n= 17)	<ul style="list-style-type: none"> - 13 were new learners and 4 were unfamiliar - 7 probably have heard before, realized the importance, but procrastinated - All generally planned to complete ADs yet had no definite timetable - all believed it was necessary to plan for EOL treatment and care in advance - most were interested in learning more 	<ul style="list-style-type: none"> - all felt difficult and troublesome to initiate EOL discussions with families - many have perceived a necessity to communicate LST preference with family surrogates - all felt it was untimely to discuss now 	<ul style="list-style-type: none"> - 13 have never heard about advance care planning before, but endorsed this idea learned from this study - 10 had some death planning but EOL treatment or care was never included - 8 have planned to rely more on family surrogates and physicians' joint decision - 3 did not know the best time to initiate so it was reasonable to procrastinate - 6 did not know what exactly needed to plan - 15 have prepared to receive some information; were interested in learning more about LST options before arriving at any definite decisions - 14 felt no urgency because of the fairly good health status - 8 understood the importance and benefits but have never paid any attention to prioritize advance care planning - 5 said they needed facilitations (such as reminders or forms); it was also difficult to plan from scratch

Actioners' stage of readiness for advance care planning

There were about 10.7% actioners in the interview sample and their readiness for advance care planning was only one stage lower than that of maintainers (Table 14). Only one (78-year-old widow) of them felt that it was unnecessary to discuss with family before executing his living will, because his decision was believed to be “personal,” “unchangeable and all-done,” and “a father’s last wise decision made to protect children.” The rest conformed to the collectivistic expectation to consult family’s opinions for important medical decisions (“This shows to my wife basic respect and trust”). Both believed their EOL decisions would be fully supported by their fairly Americanized and independent adult children. Compared to precontemplators and contemplators, actioners seemed to be relatively less traditional in cultural beliefs, better in English, more knowledgeable about advance care planning, and had higher endorsement in their decisional balance. They admitted in the past they also procrastinated, but once they realized the significance and benefits of advance care planning, they soon made a decision with little hesitancy. Interestingly, these actioners were generally unenthusiastic about continuing learning and communicating, and none of them showed interest in renewing or updating their advance directive documents.

Maintainers' stage of readiness for advance care planning

Maintainer-interviewees (7.1%, n= 2) not only have completed their ADs longer than six months but also continuously communicated their LST preferences with others (Table 14). With a noticeably proactive role in the process of advance care planning, their attitudes were self-portrayed to be positive. Being the “doers,” “executives,” “learners,” and “activists”, maintainers normally took initiatives in the family and often collected information for other family members. Advance care planning was optimistically reviewed by them as a “quite simple” process, with “little pressure” from significant others. Many admitted EOL related discussions were not purposively initiated prior to AD completions, because within the family it was not the first time that EOL issues were brought up or LST values were shared. Such conversations were described very “natural,” “smooth,” “stress-free,” and “constructive

TABLE XIV
SUMMARY OF INTERVIEW SUBJECTS' INTENTION, USAGE, AND COMMUNICATION IN RELATION TO STAGES OF
READINESS FOR ADVANCE CARE PLANNING (Cont.)

Interview subjects	AD usage & intention	Communication	Rationales
Contemplator (n= 1) Preparers (n= 4)	<ul style="list-style-type: none"> - 5 had some understanding about advance care planning, perceived the importance, were interested in learning, and believed the benefits - 1 planned to complete advance directive documents soon (within 6 months) - 4 could complete right away or within 30 days, if the advance directive document were available and accessible (translated) 	<ul style="list-style-type: none"> - 5 have perceived a necessity to communicate LST preference with family members - 3 have shared LST values (what treatment they preferred at the EOL) - 2 have planned to share with families after the interviews - 4 believed that spouses must be clear about their EOL wishes 	<ul style="list-style-type: none"> - All agreed that their motivation to complete advance directives was to avoid being a burden to families - 5 have long thought about EOL and had an "definite" decision in mind to forgo unnecessary LST - 3 were psychologically prepared but have not yet put the decision into action - 4 were eager to complete advance directive documents, when approached - 2 have downloaded the advance directive documents and prepared to read them through - 4 had already established either verbal or written wills, in case of a medical crisis - 3 agreed advance care planning was not urgent - 5 all had general death planning already - 4 got procrastinated and distracted by other priorities; needed facilitation (such as accessible forms for their convenience)
Actioners (n= 3)	<ul style="list-style-type: none"> - 1 completed four months ago from a nursing home - 2 completed their living wills (in the living trusts) longer than 6 months - All had some understanding about advance care planning - All endorsed and perceived the significance of advance care planning, yet not too interested in learning more - Have not renewed or updated their advance directives/living wills 	<ul style="list-style-type: none"> - All perceived a necessity to communicate with family but not primary physicians - 1 never told others about his completion, including families - 2 have briefly shared after completion and have appointed family DOPAs - 3 believed that families must support their EOL wishes 	<ul style="list-style-type: none"> - All disbelieved in the death taboo, had no difficulties in understanding the information, had no problems making the EOL treatment decision according to their personal LST values - Multiple pros were agreed to facilitate them completing advance directives (see endorsement) - All agreed they also procrastinated but the pros outweighed the cons of early EOL planning - 2 have completed living wills because they were included in the living trusts - All had general death planning

and practical.” Although disagreements toward LST values did exist among families (e.g. different opinions on the Terry Shiavo case or the Oregon law about euthanasia), they were viewed as opportunities for a constructive communication, because “keeping family harmony” did not mean they had to withdraw to avoid confrontations. All maintainers have either given a copy of their completed ADs to spouses and children, renewed their advance directives at least once with their loved ones or primary physicians (e.g. “I sat down to go over my LST decisions with my children”), or even promoted this idea with relatives and close friends (e.g. “I forwarded them internet links or got the forms for those who have not signed their advance directives”).

TABLE XIV
SUMMARY OF INTERVIEW SUBJECTS’ INTENTION, USAGE, AND COMMUNICATION IN
RELATION TO STAGE OF READINESS FOR ADVANCE CARE PLANNING (Cont.)

Interviewees	AD usage & intention	Communication	Rationales
Maintainers (n= 2)	<ul style="list-style-type: none"> - Both have completed advance directive documents longer than 6 months - Both had fairly good understandings about advance care planning - Both endorsed and perceived the significance of advance care planning - Both commented it was indeed easy to initiate their EOL planning - Both were interested in learning more in order to educate others - One has renewed and one has updated (put an addendum on) the advance directive - Both preferred spouse DOPAs and keep close contact with primary physicians 	<ul style="list-style-type: none"> - Both perceived a necessity to communicate LST preference with family members - Both have thoroughly discussed LST decisions in the ADs with families, physicians and friends - They have blank AD forms for adult children - Both believed that families knew and supported their EOL wishes 	<ul style="list-style-type: none"> - Both had general death planning for (after) death - Both had life-threatening illnesses so advanced EOL decisions became reasonable - A desire to avoid being a burden has facilitated their decision to complete ADs - Both were open to discuss EOL issues at home and often thought about their own deaths

b. **Decisional balance for advance care planning**

1) **Measuring subjects' pros and cons in advance care planning decision-making**

TABLE XV
DESCRIPTIVES OF DECISIONAL BALANCE TOTAL AND SUBSCALE SCORES (n= 206)

Variable	Mean	Std. Dev	Skewness (SE=.17)	Kurtosis (SE= .34)	Min	Max
<u>Decisional Balance</u> (total score)	26.17	6.25	0.57	-0.08	15	44
Endorsement (pros)	10.60	3.98	.399	-.786	6	21
Concerns (cons)	14.23	4.18	1.164	1.555	8	29
Overall evaluation	1.39	.794			1	3
A good idea (80.1%, n= 165)						
I don't know (0.5%, n=1)						
A bad idea (19.4%, n= 40)						

TABLE XVI
ITEM-MEANS AND STANDARD DEVIATIONS IN DECISIONAL BALANCE (n=206)

Statements of pros, cons, and an overall evaluation		Mean	Std. Dev
1.	Advance care planning (ACP) can give me some time to prepare for a good death	1.88	.85
2.	ACP may save money for my family by reducing medical expenses	1.88	.82
3.	ACP may help me die the way I want	1.85	.86
4.	ACP may decrease my family's burden at the end of my life	1.72	.74
5.	ACP may help my doctor know my wishes at the end of my life	1.64	.65
6.	ACP may help my family know my wishes at the end of my life	1.62	.65
7.	ACP is against my religious beliefs	1.42	.80
8.	ACP is not good because I should not make this decision on my own	2.11	.92
9.	ACP sounds troublesome	2.67	.95
10.	ACP is not necessary because the doctors will know the right thing to do at the EOL	1.85	.91
11.	ACP is bad luck and bad things may happen afterwards	1.26	.65
12.	ACP is uncomfortable because I need to think about my own death and dying	1.67	.85
13.	ACP is not good because the family relationship may change afterwards	1.61	.82
14.	ACP is not good and I do not want to commit to anything	1.63	.89
15.	Overall is ACP a good or bad idea?	1.39	.80

The descriptive statistics of decisional balance scores (Table 15) indicated that Chinese subjects generally favored advance care planning (range= 15 ~ 44, mean= 26.22, SD= 6.28)—they tended to agree more with the pros statements and disagree less with the cons (mean= 10.6 and 14.23, respectively). Subjects' responses to the single evaluative item (range= 1-3) also reflected that advance care planning was viewed as a fairly good idea (mean= 1.39, SD= .80). To be more specific (Table 15),

subjects' decisional balance were centered on a strong disbelief of a death taboo (#11) and advantages that advance care planning would help communicate EOL wishes (#5 and #6) ($SD = .65$). Mostly agreed concerns were the autonomous nature (#8) (mean = 2.11, $SD = .922$) and possible troubles and complications related to advance care planning (#9) (mean = 2.67, $SD = .95$).

2) **Reasons written in the survey about advance care planning decisional balance**

In addition to the survey questions, a total of 157 reasons were provided (53.4%, $n = 110$) to support advance care planning being a good idea. None of the responses were about a bad idea, but some (2.9%) honestly wrote that because they just learned this idea from this study, they had an intuitive, general endorsement (e.g. "Of course I can list all the good reasons, but I don't know if I truly understand what it means or if those were valid points"). Thirteen (8.2% of the responded) also had no explicit explanations ("this sounds good" or "a good idea") and six (5.9%) simply agreed with all pros in the questionnaire.

The majority (40.1%, 63 responses) favored advance care planning and agreed with its potential during medical crises to ensure patient autonomy, protect human dignity, increase a sense of self-control, and raise internal security ("knowing that other people would follow my wishes"). Generally believed was that an EOL plan of treatment and care made in advance (while they were still consciously clear and competent) would lead to better future outcome at the EOL. Secondly, 51 responses (32.4%) thought it would minimize family burdens ("troubles and headaches" 頭疼麻煩), such as decision-making difficulties, care-giving encumbrances, possible disagreements in the family regarding LST, arguments for heritages and properties, and emotional disturbances among (bereaved) family member. Thirdly, a possible benefit to maintain patients' dignity and prevent undue sufferings was mentioned, yet only less than 10%. Advance care planning was believed to help patients face death with less fear and more peace. Last, twelve responses (7.6%) brought up the possible benefit to save medical expenses (money) associated with treatments, procedures, medications, and physical care at the EOL.

3) **Qualitative results: Decisional balance for advance care planning**

(a) **Endorsements for advance care planning**

Elderly interview subjects were requested to comment each of the pros statement in the decisional balance measure (6 items) and explained how likely they would initiate advance care planning and the intervention program (if so) because of these pros. In general, advance care planning was positively described to be “healthy and constructive,” “significant for the whole family,” “everyone needs it sooner or later,” and “worthwhile learning.” A variety of reasons (facilitators) were concluded from more than 85% of the elderly interviewees (Table 17). Their answers supported survey subjects’ written responses mentioned above.

TABLE XVII
ELDERLY INTERVIEW SUBJECTS’ RESPONSES TO ADVANCE CARE PLANNING
PROS (ENDORSEMENT) STATEMENTS (n=206)

Statements of pros: “Advance care planning...”	n	%
1. ...can give me some time to prepare for a good death		
Always true	13	39.3
Never true	1	3.6
2. ...may help to save money for my family by reducing medical expenses		
Always true	13	46.4
Never true	1	3.6
3. ...may help me die the way I want		
Always true	15	53.64
Never true	0	0
4. ...may decrease my family’s burden at the end of my life		
Always true	14	50
Never true	1	/3.6
5. ...may help my doctor know my wishes for the end of my life		
Always true	17	60.7
Never true	0	0
6. ...may help my family know my wishes for the end of my life		
Always true	16	57.1
Never true	0	0

Advance care planning was favored because early preparation is always good

The majority of interview subjects, being quite unfamiliar with this topic, intuitively believed the significance and benefits. This decision-making was better made prior to medical crises and it was always good to plan things ahead of time (“so that everyone won’t be hurry-scurry”). An advanced EOL

planning made sense to them for in this modern society one needed time to prepare for complex EOL options; anyone “competent” (in terms of the decision-making capability) and “educated” should have no excuses to oppose early preparation for the inevitable and unexpected.

Advance care planning helped EOL wishes known to physicians and families

Nearly 90% agreed with a direct benefit of advance care planning that it helped EOL wishes known to physicians and families and avoided possible miscommunications at the EOL. During advance care planning, LST preferences would be explicitly shared to both physicians and families. Making EOL wishes known to others would help to: a) secure patient autonomy, b) ease physicians’ decision-making burdens, and c) prevent physicians overly treating them at the EOL.

Since Chinese family members were mostly involved as major LST decision-maker(s), it was principally favored to make EOL wishes known to significant others. An honest discussion about EOL with their beloved ones was simply therapeutic (81%) because it would increase family coherence and gain a sense of closeness. More than one third of the Christian subjects even believed that a personal EOL sharing would strengthen family members’ faith, providing a chance to optimistically discuss a hopeful eternal life and (a happy and peaceful return to) Heaven.

Advance care planning may reduce family’s decision-making, caring, and economic burdens

Subjects reported that the immediate and most important benefit of advance care planning was to ease family’s LST decision-making burdens. The majority (80%) detailed that a desire of self-control was mainly because they hoped to eliminate family’s possible feelings of regrets or guilt during their EOL decision-making. Subjects who have completed their ADs agreed this was their primary motivation to initiate advance care planning—it provided them a sense of relief and security knowing that their family would be in peace.

Concerning the costly medical care in American health care system, subjects expressed that an advanced decision was made to forgo unnecessary LST, no resources then would be wasted to maintain a meaningless and undignified life. More than 82% believed their medical expenses could be saved for

the next generations, or even social costs for the whole country and the world. Similarly, the benefit of decreasing family's caring burdens was mentioned. In fact, three subjects completed ADs in order to decrease a waste of manpower and set their families free from care responsibilities, since they have been encumbered (from 2 to 14 years) by taking care of their vegetative or bed-ridden family members. For example, a 67-year-old woman said, "They (adult children) would be relieved. I know they will, even though they wouldn't say it out loud. They would be less guilty knowing that I have made my will ahead of time to give up all useless treatments. No need to go thru the painful decision-making process like I had before for my parents."

Advance care planning may facilitate a good death in one's desire

More than 85% interviewees believed this planning could help them die the way they wanted (primarily a peaceful and dignified death). Such a "good" death was "plan-able" and "achievable" through an advanced EOL planning which minimized pain and sufferings during the dying process. Actioners and maintainers shared they wanted to be in control of their EOL and prevent a "worse-than-death" situation.

(b) Concerns about advance care planning

Elderly interview subjects were specifically requested to comment on the nine cons statements in the survey and explained (if so) how likely, because of these cons, they would be hesitant or reluctant to initiate advance care planning (and the intervention program). A variety of concerns and negative feelings (of doubts, reservations, disquiet, and uneasiness) were provided by interview subjects as inhibitors that might decrease their readiness for future advance care planning (Table 18).

A lack of knowledge or misunderstandings related to advance care planning

Many older subjects just learned about terminal patients' autonomy in LST decision-making after participating in this study. Advance care planning was wrongfully presumed, similar to living trusts, to be involved with extra costs, such as paid family attorneys, processing fees, or monthly payments

needed to secure or renew advance directive documents. During the interviews, multiple questions were raised about how to initiate and execute ADs in accordance to federal or state (Illinois) requirements.

TABLE XVIII
ELDERLY INTERVIEW SUBJECTS' RESPONSES TO ADVANCE CARE PLANNING
CONS (CONCERNS) STATEMENTS (n= 206)

Statements of cons: "Advance care planning..."	n	%
1. ...is unnecessary because doctors know what to do at my EOL		
Never true	13	46.4
Always true	2	7.1
2. ...is bad luck because bad things may happen afterwards.		
Never true	24	85.7
Always true	1	3.6
3. ...is uncomfortable because I need to think about my own death/dying.		
Never true	19	68
Always true	1	3.5
4. ...is not good because I should not make this decision on my own.		
Never true	10	35.7
Always true	2	7.1
5. ...is not good because family relationships may change afterwards.		
Never true	18	64.3
Always true	0	0
6. ...is not good because I do not want to commit to anything.		
Never true/A little bit true	18	64.3
Quite true/Always true	0	0
7. ...is against my religious beliefs.		
Never true	23/3	82.1/10.7
Always true	2/0	7.1/0
8. ...may possibly shorten my life (not as long as it could be)		
Never true	13	46.4
Always true	4	14.3
9. ...sounds troublesome.		
Never true	2	7.1
Always true	11	39.3

Difficulties of facing or discussing death, in particular with adult children

The collectivistic culture of a shared medical decision-making was noticeably manifested in approximately 64.3% of the elderly subjects, and about one third could not make their medical decision alone. In fact, patient autonomy was commented somewhat "selfish," "authoritative," and "irresponsible to other family members," and those who were able to make their own LST decisions too preferred an openly (careful) discussion with families, without hurting their feelings. Issues of how to face or discuss

death with families were commonly brought up. Although elderly interviewees were obviously open-minded, regarding death discussion neither a taboo of bad luck (85.7%) nor a topic of discomfort (67.9%) (Table 18), some who highly valued family's input remained concerned about the possible (negative) consequences after initiating advance care planning.

Ten subjects whose families were unreceptive reported that their conservative and traditional family was the major concern that inhibited their readiness. Even though they were psychologically well-prepared to share personal LST values, 80% of them found it difficult to find appropriate occasions, suitable (verbal) expressions, or acceptable examples when making an attempt to converse death topics. They experienced awkwardness, unpleasantness, and discomfiture when mentioning their own death or dying. Family members (especially adult children) appeared to be emotionally disturbed by this “repulsive” topic. They often discouraged or interrupted the conversation (believed to be out of love and filial piety) thinking such a discussion was “disappointing,” “trivial,” “all for naught,” or “untimely.”

A possible unwillingness to make a commitment to future EOL treatment decisions

Approximately one third agreed that making an advanced medical decision was quite a huge commitment (“I feel like drafting my last words”). Their procrastination came from a reluctance to undertake any decisions (about future EOL treatments), for fear that their physicians would stop actively treating them (n= 7) or their families (adult children) would give them up for unspeakable reasons (n=3). On the other hand, those who were more knowledgeable about advance care planning (n= 11) did not have this particular concern—ADs were subject to change (renew). “Getting it done once and for all” was incorrect which should not be taken as a concern to influence advance care planning.

Possible religious conflicts were some subjects' minor concerns

Nearly 18% were reluctant to initiate advance care planning due to religious concerns: a) forgoing LST would probably lead to an early termination of life (“killing myself too early is also a sin”) and b) no treatment decisions should be made in advance to determine one's life (or death). They rather followed the natural flow, instead of making any definite EOL decisions in advance. The remaining

(83%) believed this planning was not in conflict with their religious beliefs. In fact, 70% of them have never associated their religious beliefs with EOL before. Among these, seven Christians (25%), on the other hand, believed their religion actually facilitated advance care planning—God’s ultimate authority and great mercy could be manifested by humans’ autonomous decision (made in advance to forgo LST), with a purpose to end unnecessary sufferings or achieve a natural death at God’s perfect timing.

A (possible) shortened length of life was not taken as a concern

Many fatalistically believed in Chinese belief, one’s life would never be any shorter (or longer) than it was designated to be, with or without advance care planning. More than 70% of the elderly subjects said their life would “never (46.4%)” or “possibly and slightly” (25%) be shortened if they had advance care planning; it was superstitious to think so (85%). Another 28.6%, with a desire to live shorter with better QOL, less pain, and fewer tortures, tended to agree and endorsed this health planning for it may (possibly) shorten the last part of their useless, functionless life.

It was indeed troublesome and complicated to initiate advance care planning

Advance care planning was perceived by most elderly subjects to be “always (39.3%)” or “quite (32.2%)” troublesome; more than 28% admitted they felt impatient and weary when learning about this (“I hate to deal with one more thing in life;” “Oh, boy, I need to find time to study about it; I am tired already when thinking about it”). Multiple troubles and difficulties were brought up to describe this “complicated” and “somewhat niggling” planning: prioritize time for such matters, seek for correct and appropriate information, obtain legally valid advance directive documents, consult accessible medical professionals, make unfamiliar medical and legal decisions, spend extra time and money, and bother families (mostly adult children) for their (translation or transportation) assistances. Last, one fifth mentioned that dealing with medical and legal documents written in English was troublesome.

The major inhibitor of a sense of no urgency and procrastinations

Reported by nearly 60% of the interviewees, one major concern, as to why elderly Chinese Americans had no advance care planning, was a sense of no urgency. Self-perceived to be still young

and healthy, the only medical crises they concerned were unpredicted accidents, despite of an intuitive interest in the topic

Individuals who were precontemplator-procrastinators' readiness was typically quoted as follows, "I will plan when I feel so (when it was more urgent)," "Without knowing the best time to start, I will think about it later or when I know what terminal disease I get," "I will seriously take this into concern, maybe after a while when almost dying," and "It is not what I care for now...I am too busy to plan for this." About one fifth honestly shared that since this planning was not a priority, they were uncertain if additional education or facilitations would increase their readiness ("I think studying more right now may not help. Only when I feel I need it, I will start studying more"). For this reason, many were not enthusiastic about any intervention programs and preferred receiving written materials to self-study at their own convenience.

About 44% of these subjects who were irresolute based their procrastinations on a confidence that when they became incompetent, their authorized family surrogates would make the best LST decisions for them (with or without the physicians). In a way, this elderly group has implicitly initiated their advance care planning, except that the responsibility of EOL decision-making has postponed and deferred to others. Similarly, a small group (18.8%), relatively low educated, naïvely believed that their physicians would make their LST decisions for them. These subjects either thought they would die immediately without being aggressively treated or trusted that their physicians would perform euthanasia, when their QOL became no longer tolerable ("No such need to plan. The doctor will just give me a shot and let me die").

While the majority of interviewees admitted that procrastinations equaled to no decisions ("I knew it was an excuse. I am actually postponing what I need to do some time later in my life"), they explained their indecisiveness was probably originated from a feeling of uncertainties at (or beyond) EOL—it was difficult to presume or plan for any hypothetical EOL situations: without knowing which LST decision would be the most appropriate in the long run, a fairly reasonable decision was to procrastinate ("How

would I know which terminal diseases I would ultimately get and how medical technology would be developed at that time”).

c. **Self-efficacy for advance care planning**

1) **Measuring self-efficacy in relation to advance directives**

Subjects’ responses to a situational confidence in completing documents of advance directives or living wills have revealed their self-efficacy for advance care planning (mean= 2.32, SD= 1.48) (Table 19). When Chinese subjects were requested to make advanced EOL decisions, the majority were confident that they were independent from their significant others’ opinions. However, Chinese family’s influence remained noticeably obvious, in particular among those who refused to complete ADs on the day being approached (13.5%). One fifth even admitted they needed to obtain approvals from their spouses or adult children.

2) **Written responses in the survey questionnaires: Reference persons for advance directives approval and discussions**

Among those who provided their reference persons (n= 21) prior to completing ADs, approvals were needed from “family in general” (61.9%) and “my spouse” (38.1%). Similarly, the majority would like to discuss about advance care planning with their “spouse” (47.9%), followed by “family members in general” (31%), and “adult children” (9.8%).

TABLE XIX
DESCRIPTIVES AND FREQUENCY OF RESPONSES TO SELF-EFFICACY QUESTIONS (n= 170)

Questions	n	%	Mean /Median	Std. Dev.	Min	Max
1. If you have not signed an advance directive, are you able to sign one today?	170		1.40/2	.72	0	2
No, I cannot.	23	13.5%				
I don't know if I can decide today	56	32.9%				
Yes, I can sign one today.	91	53.5%	3.72			
2. Do you need to get someone's approval to sign an advance directive document?	170		1.44/2	.81	0	2
Yes, I need someone's approval.	34	20.0%				
I don't know if I need any approvals	27	15.9%				
No, I don't need any approval from others.	109	64.1%				
3. I prefer discussing with others before signing this document about my future life-sustaining treatment.	170		.88/1	.92	0	2
Yes, I think I need to discuss with someone	82	48.2%				
I don't know if I need to discuss with others	26	15.3%				
No, I don't need to discuss with others.	62	36.5%				
<u>Self-efficacy</u> (total score)	170	82.5%	2.32 / 2	1.49	0	4
The higher the better self-efficacy						

TABLE XX
PERSONS CHINESE AMERICANS PREFERRED TO DISCUSS WITH BEFORE COMPLETING
THE ADVANCE DIRECTIVES

Questions	Count	Valid responses
1. I need to get someone's approval to sign an advance directive document? (n= 34, missing= 13)		
Spouse (wife/husband)	13	61.9%
Family in general	8	38.1%
Adult children	0	0%
2. I prefer discussing with someone before signing the document about my future life-sustaining treatment (n= 82, missing= 11)		
Spouse (wife/husband)	34	47.9%
Family members in general	22	31%
Adult children	7	9.8%
Relatives and friends	4	5.6%
Doctors	3	4.2%
Lawyers	1	1.4%

d. **Qualitative results: The self-perceived right in EOL decision-making**

1) **Preferred role and self-efficacy in EOL decision-making**

Precontemplators' relatively low self-efficacy for advance care planning

Among all 18 precontemplators, about half were found to have little self-efficacy.

Almost all of them admitted it was not critically important for them to have patient autonomy or self-control in EOL decision-making. What mattered was whether their final LST could be made in accordance with a family's consensus within a harmonious ambience. Most chose to defer their LST decisions to family surrogates who had previously handled medical information for the family. One woman said, "If my sons think it's unnecessary to perform resuscitations, I follow whatever they decide for me. You know I believe they have the full power to decide for me at that time." However, they actually had no confidence whether their preference of no aggressive treatment would be followed.

Precontemplators' mid level of self-efficacy for advance care planning

Another 50% of the precontemplators believed that they had full control to make autonomous EOL decisions, if they desired. One woman said, "I prefer to make my own EOL decision in the future, because this is my own body. I think if this is the decision I made on my own, I won't regret myself." The importance of advance care planning was recognized, and with an intention to provide guidance for their family at their EOL, it was highly probable for them to execute ADs sometime in the future. This group would never defer their right to families or easily compromise during family confrontations or disagreements. Most had a hierarchy of DOPAs, which were spouses followed by physicians and adult children. Many in this group still preferred to discuss and include family's input, because this EOL decision-making, described as a value-exchanging communication process, must maintain a harmonious family relationship.

Contemplators and preparers' relatively high self-efficacy for advance care planning

Comparatively, the contemplator and preparers had fairly high self-efficacy in their EOL decision-making. Recognizing the importance of advance care planning, they had all the self-control, requiring no approvals from others, for their EOL decisions ("I deserved the ultimate right for my own LST"). As they were clear about what they desired at the EOL, all preferred to make their LST preference explicit to families or physicians within 6 months. Although this group felt it was extremely crucial to discuss with families prior to executing ADs, this sharing of LST values and details of EOL preferences was not urgent. They felt confident that their physicians and family members would be supportive (or left no choice but) to follow their wishes shared prior to the medical crises.

In particular, subjects in the preparation stage had a hierarchy of family DOPAs in mind: spouses only, spouses with physicians, spouses with adult children, and the whole family. Physicians' professional opinions seemed to be highly valued. These preparers of higher self-efficacy somehow intentionally limited their adult children's involvement in their EOL decision-making—they preferred not to bother children who have their own family duties, and would only inform them the final LST decisions.

Actioners and maintainers' self-efficacy regarding advance care planning

These subjects at the highest stages of readiness believed full self-control and patient autonomy was vital in EOL decision-making. One person said, "I am my own master and responsible for myself only; this is my own business why bother others? I do not allow others to mess up with my body, not even doctors; I don't leave my own things to others." During the time they executed their advance directives/living wills, they recalled being clear about what they desired at the EOL. The original intention to complete ADs, accordingly, was to finish their own business in order to alleviate families' burdens in making difficult EOL decisions. Their strong will to initiate advance care planning and a preference to forgo unnecessary LST were firm and unaffected by attorneys, physicians, or significant family members.

2) Qualitative results: The uncertainty of the future

A common theme of an uncertainty of the future was noticeable among almost all elderly subjects (92.3%). Many have expressed reservations toward advanced EOL planning due to an insecure or unconfident feeling of a) LST decision-making, b) illnesses, medical miracles, and a change of QOL, and c) death and the world/life after death.

Most (64.2%) admitted their uncertainties came from unfamiliarity of the planning itself. With various inquiries and doubts, they were willing to learn more yet not completely ready for it. More than half (57%), being relatively healthy, said an advanced planning for LST seemed quite vague and unimaginable. A confirmed diagnosis or predictable prognosis of a terminal illness, in that case, would then be a sufficient reason to initiate such a planning. About 15% concerned the odds of a medical miracle even during an irreversible and incurable course of a terminal illness. When such a hope in the future could never be assured, no patients should be given up before all efforts were made to save life. Similarly, some (21%) expressed a difficulty to envision or predict the QOL after having a terminal illness. They wondered their QOL criterion or the standard of a "worth-living condition" would accordingly change over time, if a life-threatening condition or the medical technology continued to

advance. The majority of them anticipated and believed their ability to gradually endure a decreased QOL at the EOL. Therefore, at this point it might be too early and too ideal to evaluate a hypothetical QOL at EOL, since advance care planning might very likely a) miscalculate the effectiveness/feasibility of future LST, b) underestimate terminal patients' vitality and endurance, c) preclude a possibility of medical miracle.

More than half of the elderly interviewees (53%) felt uncertain about their deaths, and those relatively older (mean= 83.3 years) and sicker were prepared to die at any time, but they still concerned how they would leave this world. Five (17.9%) mentioned the uncertainty of afterlife—where the spirits would go after they passed away remained a mystery. However, the uncertainty toward death and the world of unknown was not related to subjects' EOL decision-making.

e. **Relationships among stage of readiness to change, decisional balance, and self-efficacy**

To further describe subjects' readiness for advance care planning (aim 1), relationships among stage of readiness, self-efficacy and decisional balance are presented in Table 21 by correlations between pairs of the three outcome measures. The principle in the TTM research predicted that when readiness progressing through stages, self-efficacy and the pros would increase and the cons would decrease accordingly (J. O. Prochaska, et al., 1994).

The results showed that subjects' stage of readiness was moderately correlated with their overall decisional balance ($\rho = -.433$ and $rpb = -.404$, $p < .001$), indicating that higher levels of readiness was moderately associated with higher levels of endorsement and lower levels of concerns in the decisional balance. The following correlation tests showed that the stage of readiness was moderately related to endorsement (Spearman's $\rho = -.400$, $p < .001$; $rpb = -.377$, $p < .001$) as anticipated, but fairly weakly related to concerns for advance care planning (Spearman's $\rho = -.182$, $p < .001$; $rpb = -.197$, $p < .001$). Self-efficacy was not a significant correlate of either the ordinal or dichotomous stages of readiness ($p = .273$ and $.083$). In other words, Chinese subjects at the advanced stages were not shown to exhibit

better self-efficacy as the TTM theory predicted. Self-efficacy only was weakly related to overall decisional balance (Spearman's $\rho = -.193$, $p < .05$) and endorsement (Spearman's $\rho = -.179$, $p < .05$), suggesting that Chinese subjects' decisional balance about advance care planning was irrelevant to their perceived confidence when making EOL related decisions. In other words, Chinese subjects at the advanced stages were not shown to exhibit better self-efficacy as the TTM theory predicted.

Self-efficacy only was weakly related to overall decisional balance (Spearman's $\rho = -.193$, $p < .05$) and endorsement (Spearman's $\rho = -.179$, $p < .05$), suggesting that Chinese subjects' decisional balance about advance care planning was irrelevant to their perceived confidence when making EOL related decisions.

TABLE XXI
CORRELATION MATRIX AMONG READINESS VARIABLES

	Stage of change (6 stages)	Stage of change (2 stages)	Self-efficacy (total scores)	Decisional Balance (total scores)
Stage of readiness for change (6 stages, the higher the better readiness)	1.00			
Stage of readiness for change (2 stages, precontemplators vs. others)	.952** ^a	1.00		
Self-efficacy (the higher the more self efficacy)	.085 ^c	.133 ^c	1.00	
Decisional Balance (the higher the less favor)	-.433** ^b	-.404** ^a	-.193* ^d	1.00
Endorsement subscale (pros, the higher the less endorsement)	-.400** ^b	-.377** ^a	-.179* ^d	.711** ^e
Concerns subscale (cons, the higher the more concerns)	-.182** ^b	-.197** ^a	-.120 ^d	.728** ^e

a. Point-biserial's r_{pb} ($n = 206$), b. Spearman's ρ ($n = 206$), c. Spearman's ρ ($n = 170$), d. Pearson's r ($n = 170$),

e. Pearson's r ($n = 206$)

* Correlation is significant at the 0.05 level (2-tailed)

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

TABLE XXII
CONSTRUCTS, VARIABLES, AND LEVEL OF MEASUREMENT

Constructs	Variables	Level of Measurement
Chinese Americans' Readiness for Advance Care Planning Variables related to outcomes	1. Stage of change for Chinese Americans' advance care planning (six stages)	Ordinal
	2. (Outcome variable) Precontemplators and contemplators & above (2 stages)	Dichotomous
	3. (Outcome indicator 1) Decisional balance for advance care planning	Interval
	4. (Outcome indicator 2) Self-efficacy for advance care planning	Interval
	5. Cultural beliefs regarding advance care planning	Interval
	6. English proficiency for advance care planning	Interval
Cultural factors related to Chinese Americans' advance care planning	7. Horizontal Individualism	Interval
	8. Vertical Individualism	Interval
	9. Horizontal Collectivism	Interval
	10. Vertical Collectivism	Interval
	11. Chinese Americans' acculturation level	Interval
Knowledge factors related to Chinese Americans' advance care planning	12. Knowledge about life-sustaining treatment, advance directive documents, and advance care planning	Interval
	13. Chinese Americans' previous experiences related to end-of-life	Interval
Quality of life factors	14. Life satisfaction	Interval
	15. General health status—Physical health	Interval
	16. General health status—Mental health	Interval
Spirituality factors	17. Spirituality—System of Beliefs	Interval
	18. Self-perceived religiosity	Interval
Demographics	19. Age	Dichotomous
	20. Gender	Dichotomous
	21. Life-partner status	Ordinal
	22. Parent alive status	Ordinal
	23. Highest education level	Ordinal
	24. Annual household income	Dichotomous
	25. Employment	Dichotomous
	26. Raised religion, 27. Current religion, and 28. Religion change	Dichotomous
		Dichotomous

TABLE XXIII
CORRELATION MATRIX OF ALL MEASURED VARIABLES IN THE PROPOSED CONCEPTUAL MODEL

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Six stages of readiness	1																
2. Two stages	.95**	1															
3. Decisional Balance	-.43**	-.40**	1														
4. Self-efficacy	.085	.13	-.19*	1													
5. Cultural beliefs	.18**	.17*	-.45**	.11	1												
6. English proficiency	.23**	.19**	-.07	-.15	.19**	1											
7. Horizontal individualism	.001	.01	.01	.17*	-.15*	.04	1										
8. Vertical individualism	-.11	-.12	.20**	.10	-.30**	-.07	-.44**	1									
9. Horizontal collectivism	.05	.06	-.17*	-.13	-.05	.02	.04	.31	1								
10. Vertical collectivism	-.08	-.07	.12	-.17*	.25**	-.01	.04	.16*	.35**	1							
11. Acculturation	.15*	.13	-.09	-.19*	.12	.58**	-.08	-.07	-.02	.04	1						
12. Knowledge	.27**	.26**	-.28**	-.09	.15*	.34**	-.04	-.08	.95	.04	.41**	1					
13. Previous EOL experience	.17*	.18*	-.20**	-.10	.02	.08	.00	-.06	.04	.03	.18**	.25**	1				
14. Life satisfaction	.09	.03	-.13	-.09	.15*	.25**	.02	-.16*	.25**	.01	.15*	.14*	-.03	1			
15. Physical health	-.07	-.09	.02	-.03	.02	.30**	.09	.13	.10	.14	.21**	.13	-.14	.36**	1		
16. Mental health	.11	.10	-.15*	.05	.27**	.16*	-.01	-.14*	.11	.05	.05	.10	-.07	.57**	.08	1	
17. System of beliefs	-.02	.02	-.02	-.15	.01	-.14*	-.03	-.03	.18*	.27**	-.07	.03	.04	.13	-.05	.02	1
18. Self-rated religiosity	.11	.09	-.16*	-.20**	.14*	.11	-.04	-.11	.10	.05	.15*	.14	.06	.19**	.12	.06	.54**

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

* Correlation is significant at the 0.05 level (2-tailed)

TABLE XXIII
CORRELATION MATRIX OF ALL MEASURED VARIABLES IN THE CONCEPTUAL MODEL (Cont.)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
19. Age	.14*	.16*	-.02	-.05	-.07	-.26**	-.06	-.05	-.21**	-.02	-.24**	-.11	.13	-.03	-.45**	-.01	-.01	-.48	1								
20. Gender ^a	.08	.13	-.11	-.07	.13	-.15*	-.06	-.15*	-.10	.06	-.12	-.05	.00	-.13	-.16*	-.11	.10	.04	-.01	1							
21. Life partner	-.01	-.09	.04	-.16*	.01	.15*	-.03	-.09	.02	-.03	.13	.02	-.13	.13	.14*	.11	.03	.12	-.24**	-.20*	1						
22. Parents alive ^b	-.59**	-.09	.01	-.13	.05	.16*	.07	.05	-.14*	.04	.14	.09	-.11	-.02	.21**	.04	-.12	.10	-.59**	-.06	.16*	1					
23. Education ^c	.05	.09	.04	-.13	-.04	.58**	.09	.01	-.10	-.05	.51**	.28**	.11	.25**	.25**	.23**	-.18*	.17*	-.20**	-.37**	.15*	.19**	1				
24. Income ^d	.02	-.05	.02	-.06	.00	.43**	.15*	-.06	-.08	.03	.38**	.34**	-.10	.29**	.33**	.20**	-.10	.12	-.43**	-.20**	.35**	.25*	.49**	1			
25. Employment	-.06	-.07	-.08	-.07	.18**	.23**	.15*	-.01	-.08	.01	.13	.06	-.18**	.17*	.37**	.14*	-.06	.06	-.53**	.12	.18**	.37**	.20**	.37**	1		
26. Raised religion	.06	.02	.15*	.05	-.03	-.01	.00	.05	.03	-.02	.03	.13	.05	.15*	.00	-.06	-.09	-.06	.13	.09	-.04	-.07	.02	-.04	.08	1	
27. Current religion	.04	.04	-.14*	-.15	.08	.09	-.00	-.07	.01	.03	.22**	.09	-.06	.00	-.05	-.06	.27**	.42**	.03	-.01	-.07	-.03	.12	.03	-.08	-.14*	1
28. Religion change ^e	.09	.04	-.03	.02	.03	.00	.11	.03	.01	-.15*	.03	.02	-.04	.06	-.03	-.03	-.02	.10	.04	-.13	.07	.00	.08	.03	.08	.21**	.16*

* Correlation is significant at the 0.05 level (2-tailed)

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

a. n= 203, b. n= 204, c. n= 205, d. n= 183, e. n= 200

Pearson's r: used between two interval variables

Spearman's rho and Kendall's tau: used with two ordinal variables or an ordinal and an interval variable (Rho for ranked data)

Phi and Cramer's V: used when both variables are dichotomies, Point-biserial' rpb: used when correlating a continuous variable with a dichotomy

3. **Cultural factors related to Chinese Americans' advance care planning**

a. **Chinese Americans' traditional cultural beliefs**

1) **Measuring Chinese traditional beliefs related to EOL decisions**

Chinese subjects were not culturally stereotypical, since most beliefs were considered “not always true (Mean= 37.04, SD= 6.26, range= 17-51)” The well-known bad luck belief that “discussing deaths would hasten or lead to unexpected deaths (#11)” was mostly regarded as a superstitious statement (mean= 3.68, SD= .65), and traditions regarding male paternalism (#7), physician paternalism (#10), and disclosure of the terminal illness (#8) were also rated untrue most of the time. As a whole, the level of cultural tradition was just a weak correlate of the readiness outcome ($\rho = .18$ and $r_{pb} = .17$, $p < .001$). Among the few significant correlations, the significant relationship between readiness and a cultural custom to “let the family head (#10) or physicians (#12) make EOL treatment decisions” were fairly weak (Spearman's $\rho = .15$ and $.18$ respectively, $p < .05$), as well as the strength between subjects' readiness and the belief of “filial piety is keeping dying parents alive as long as possible (#6)” ($\rho = .22$, $p < .001$) (Table 24).

The overall level of cultural beliefs, moderately correlated with decisional balance ($r = -.45$, $p < .001$), showed that those who conformed to more traditional beliefs were associated with more concerns for advance care planning, particularly believers of the death taboo (#11) ($r = -.57$, $p < .001$). Self-efficacy was unrelated to the level of tradition as a whole (Table 23), yet it was weakly correlated with two beliefs, “Talking to family members before making any medical decisions (#3)” and “not fighting over treatment decisions in the family” (#4) ($\rho = .20$ and $.22$, $p < .001$), indicating a possibility that subjects with less self-efficacy were related to a higher tendency to compromise their EOL decisions, for the sake of preserving family harmony. Family members' influence was also shown by the preference of shared decision-making (#3) (mean= 1.94, SD= .801). Chinese subjects who were less traditional in their cultural beliefs were related to a better level in English proficiency, knowledge for advance care planning, satisfaction with life, mental health, and religiosity, but not the degree of acculturation or any demographical characteristics, not even age or socio-economic status (Table 23).

TABLE XXIV
DESCRIPTIVE STATISTICS OF THE CULTURAL BELIEF SCALE (n= 206)

Items	Mean	Std. Dev	AD completion ^a	6 Stage of readiness ^b	2 Stage of readiness ^a	ACP Endorsement ^a	ACP Concerns ^a	Decisional balance ^a	Self -efficacy ^b
1. Accumulating good deeds in the present life will lead to a better next life.	2.96	1.10	-.025	.074	.055	-.044	-.258**	-.220**	-.154
2. I need to save my family's face (not embarrassing them).	2.23	.83	.102	.129	.142*	.077	-.292**	-.153*	.076
3. I should talk to my family before making any medical decisions.	1.94	.80	.010	.008	.032	.002	-.222**	-.150*	.212**
4. Keeping harmony in the family means not fighting with each other over treatment decisions.	2.74	.97	-.046	.033	.053	-.049	-.390**	-.295**	.224**
5. Filial piety is to respect parents' wishes to die.	2.54	1.05	-.081	-.049	-.039	.190**	-.125	.046	-.093
6. Filial piety is to keep dying parents alive as long as possible.	2.90	.96	.157*	.20**	.22**	-.079	-.423**	-.351**	.079
7. Family head (Father or Big Brother) should make the final treatment decision.	3.24	.85	.062	.14*	.15*	-.024	-.481**	-.339**	.099
8. Not telling terminal patients their medical condition is for their own good.	3.02	.86	.034	.081	.048	-.059	-.466**	-.365**	.157*
9. Doctors should make the final treatment decisions because they know better.	2.66	.91	.016	.15*	.18*	-.040	-.368**	-.285**	.002
10. Questioning doctors' professional suggestions for treatment is rude and inappropriate.	3.32	.84	.030	.091	.122	-.062	-.176*	-.151*	-.025
11. Talking about death and dying brings bad luck.	3.68	.65	-.005	.117	.094	-.111	-.566**	-.466**	.053
12. Mentioning death and dying in front of elderly people is rude and disrespectful.	3.25	.82	.001	.043	.066	-.063	-.415**	-.321**	.079
13. Treatments should be used to keep a dying family alive so that other family members can have some time to come and say goodbye	2.62	.91	.077	.129	.100	.057	-.330**	-.193**	.120
<u>Cultural beliefs (total score)</u>	37.04 (17-51)	6.26		.18**	.17*			-.45**	.11

a. Point-biserial's rpb (n= 206), b. Spearman's rho (n= 206), ** Correlation is significant at the 0.01 level and * is significant at the 0.05 level (2-tailed)

2) **Written responses in the survey: Definition of a good death**

A total of 147 definitions (n= 112) were summarized to categorize a good death: the majority (25.9%) depicted a peaceful, calm death as the most perfect and desirable. Closely related to this definition was the concept of “a comfortable death with no pain” or “a dying process of no physical sufferings or tortures at the end (20.1%).” A considerable number of subjects (14.3%) quoted an old Chinese saying, “To die naturally and return to the nature,” to insist no overtreatment, accidents or severe illnesses at the EOL. In this case, a good death referred to no extra efforts made to sustain life. That was why many actually preferred to die “from unexpected heart attacks,” “quietly during my sleep,” “fast and relatively easy (clean in Chinese) without disturbing others.

A good death was described in the survey to be associated with religiosity. Nearly 13% closely connected their desired death with Christian God and Heaven. Only two referred to the concept of Buddhist karma—both of them believed that accumulating good deeds would lead to a good death and a start of another good (after) life. Another 13% believed that in order to define a good death “responsible and fair” to others, the consequence of one’s death and the impact to the rest of the family must be taken into consideration. A good death then would happen after one’s responsibilities have been properly handed over to others, no debts or burdens were left to the family and relatives, and no hatred feelings stayed toward him/her.

Only a few (4%) associated a good death with a Chinese traditional belief (longevity) and provided an age criterion for it—they must have lived a blessed and long life (for at least 80 years), with both filial sons and daughters, with no severe illnesses or prolonged sufferings at the EOL. Last, to our surprise, only less than 4% mentioned “a dignified death,” It was speculated that this type of desirable death might have been embedded in the previous category of a peaceful and natural death with no sufferings.

3) **Qualitative results: Chinese traditional cultural beliefs**

(a) **Karma**

All elderly interviewees acknowledged the strong influence of karma on Chinese people (described as accumulating good or evil deeds which in sequence would shape humans' past, present, and future experiences), as well as the Buddhist beliefs of transmigration and reincarnations. Many recalled that when choosing to perform good or evil by free wills, they were often reminded by the karmic effect. More than 52% reported disbelieving in karma or a next life any more after they converted to Protestant Christianity in the States. No subjects have connected EOL decision-making to karma, and they agreed the karmic effect neither reinforced nor inhibited advanced EOL planning. This traditional belief seemed to be unrelated to stages of readiness.

(b) **Longevity**

Longevity was a proverbial belief highly desired in the Chinese culture. Contrasted to the cultural taboo of mentioning death in front of the old and sick, longevity has long been customarily connected with luck and prosperity and well-received by elderly Chinese. However, more than 70% in fact regarded longevity something of a lottery, and one's life length was predestined. Many Christians (53%) also believed that initiating advance care planning had no influence on one's life-expectancy. About 30% thought the item ("If I have advance care planning, I will not live as long as possible") reflected a superstitious belief, yet some (17.8%) agreed that, their life would be possibly and "meaningfully" shorten by advance care planning.

Longevity (the quantity/length of life) was constantly defined and weighed against the concept of quality of life (QOL). Concluded from 90% of the interview sample, a long life with poor QOL due to deteriorating health satisfactions was "no longevity" at all, and only those who were 80 years and above, surrounded by the offspring, and physically and psychologically well-functioning without burdening family members could be qualified as seniors with longevity in Chinese culture. A majority (65%, mean age = 79.5 years) admitted they were not obsessed with longevity, had no desire to live a long(er) life

(than they should have), and would be satisfied with a shortened life with acceptable QOL. Often quoted was a renowned Chinese old saying, “Men who reach the age of seventy have always been a rarity,” so many believed they have already fulfilled multiple life responsibilities and were prepared to leave this world at any time.

Unsurprisingly, EOL treatment decisions were often made (for others and self) by weighing the quantity against the quality at the EOL. More than 90% have previous experiences of elongating dying parents’ (or relatives) life, but their intent was reportedly not a pursuit of longevity. Universally natural among Chinese all over the world, initiating all possible medical treatment for parents was an act to respond to parents’ love and exhibit children’s filial piety. However, 85% of these subjects preferred not to be treated as their parents; and a total of 57% have regretted doing so particularly after witnessing their terminal parents’ unbearable and unacceptable QOL with LST. Many Christians also reported feeling apologetic for prolonged a “function-less, worthless, resource-wasteful” life (which was unlikely to be God’s wills). On the other hand, artificial hydration/nutrition was considered a LST option “worthwhile making”—one fifth who have initiated tube-feeding for their parents believed this life support has largely increased patients’ life expectancy yet just moderately compromised their QOL. Clearly, longevity as a Chinese cultural desire did not directly influence subjects’ willingness to initiate advance care planning. A deliberation of QOL and the intent to prevent meaningless life elongation, however, help engage Chinese Americans for advanced EOL planning.

(c) **Filial Piety**

Subjects reported that the most difficult and inescapable filial obligation was making LST decisions for terminal parents. Those who have been primarily involved in such a decision (53%) reported this experience “painful,” “always in guilt,” “emotionally draining,” or “burdensome;” they recalled constantly facing the dilemma whether to let go of their parents. Overall, the majority (71.5%) agreed that most of the time the desire to sustain parents (keep them alive as long as technologically possible) was originated from children’s love and a reluctance to give up parents,

instead of a traditional filial duty. This yearning to keep terminal parents physically present was described “human’s nature,” “universal across cultures,” and “sometimes irrational.” Many believed they were therefore left no other choices but to sustain parents.

A substantial number (46%) agreed that “Filial piety was to keep dying parents alive as long as possible.” To them, forgoing parents’ LST was culturally unusual and unacceptable, equaled to passively abandoning parents and precluding a possible hope (medical miracles). About 70% in this group would never forgo their parents’ LST, as long as financially affordable; more than half of them (and their siblings) have already initiated parents’ LST with no hesitancy. The only exception would be when parents were at a vegetative status or consciously unclear; only in this case parents’ QOL would then be taken into consideration to outweigh a resuscitation decision and their filial responsibility would not be judged by others.

The filial duty of making parents’ EOL decisions was often connected with a concept of “saving (family’s) face.” Only 25% agreed that adult children’s filial piety should be evaluated only by parents, and subjects who have initiated their parents’ LST (28.5%) admitted that at that point in time they were vulnerable and under great pressures of others (especially paternal relatives’). Forgoing LST might ruin the whole family’s reputation, since all Chinese (paternal) relatives carrying the same family name would share the un-filial humiliation, which they failed to provide “wise” consultations to sustain terminal patients.

On the other hand, only less than 36% agreed with the statement, “Filial piety is to respect parents’ will to die (rated it quite or always true)” and preferred to let parents die without using any LST. Based on a belief that children had no right to determine parents’ life, they also strongly disagreed with the statement, “Filial piety is to keep dying parents alive as long as possible.” For these subjects, Chinese children’s filial obligations were interpreted as “putting an end to parents’ sufferings (maintaining good QOL), not opposing parents’ final wills, and letting the terminal leave the world peacefully with dignity as they wished.”

Last, many subjects (57.1%) were afraid their children, out of emotion and filial duties, would keep them alive by LST, worrying that they might overlook the possible consequential burdens and enormous medical cost. A total of 65% were motivated to initiate advance care planning mainly to prevent children's "foolish filial responsibility."

(d) **Male Paternalism**

This cultural tradition existed in most subjects' original (parents') families (86%). Since males were habitually higher educated, more socialized, emotionally tougher, and often medically trained, 36% agreed that males, being conferred additional responsibilities and burdens, did deserve more right than females to speak for the whole family. All subjects (100%, n= 28) agreed that Chinese family head, such as their grandfather, father, or the eldest son, was typically bestowed an ultimate power to make important decisions, including decisions for family members' medical decisions. Women were normally assumed a social role to provide only physical care to patients—more than 42% recalled that the primary family caregivers were their moms, wives, daughters, or hired female relatives. Many female subjects were not the stereotype of Chinese women (often portrayed to be "indecisive," "unconfident," "shy," and "fatalistic") yet were under a great influence of male paternalism: they followed husbands' authoritative wills (57%), kept silent if different opinions (28%), and had little input during important decision-making (14.3%). More than half of the male subjects too believed their wives holding this cultural tradition. Almost all have conformed to male paternalism during their parents' EOL decision-making. Over 71% have trusted their eldest brother in the past to make dying parents' LST decisions; according to them, opinions of sisters (bearing different last names so as "outsiders" of the family) were normally not included. When parents were announced incapable and hopeless, their eldest brother or the eldest son-in-law soon became the representative for the whole family (as in the old sayings, "Eldest brother was now as respectful as Father"). They acted as the screener of medical information, the gate keeper of bad news, the center of family consensus, parents' comforter, protector, and informer, the payer and accountant of medical bills, and the final decision-maker of LST.

Although some (21%) agreed that having the eldest son being the spokesperson (and ultimate decision-maker) have avoided superfluous misunderstandings and quarrels in their family, 71.4% preferred no male paternalism in their own EOL decisions. What highly preferred, apparently, was an earnest sharing and discussions about EOL treatments among core members in the family (65%). Paternalism accordingly has been less emphasized or further modified by these subjects in this day and age, and this cultural belief was found only practiced among a few traditional males (<15%) who would authoritatively determine their parents' LST without discussing with other siblings. In addition, spouses (if alive), rather than the family head or the eldest son(s), were generally given higher priority as the DOPAs in LST decision-making (86%).

(e) **Non-disclosure of the medical bad news**

All Chinese interview subjects were familiar with this tradition and often undisclosed was the adverse medical truth, mostly a terminal illnesses or treatment futility. Nearly 80% reported that in the past they have chosen not to disclose a cancer diagnosis or a poor prognosis to an ill family member, and among them, 86.3% (n= 19) agreed it was the whole family's consensus, for fear that the terminal might lose their strength to strive for life. Their life-threatened families were believed too "sensitive," "neurotic," "weak (not tough)," or too "pessimistic" to handle the cruel truth. However, this non-disclosure was not always successful—more than 60% recalled and suspected that their beloved ones have already known the truth before they passed away. It was described emotionally "disturbing," "challenging," and "excruciating" to veil the truth; some during their interviews seemed to remain bearing the burdens and sorrows. Only a small group (28.5%) believed that the terminally ill patients needed to know all the medical details, and they themselves were completely fine with full disclosure. Interestingly, the majority of these subjects (75%) had no previous experiences of concealing bad news.

The majority of interviewees required to be skillfully and fully informed about their own medical conditions, particularly those who have had life-threatening illnesses (21.4%). They shared that when facing the bad news, they were actually calmer than their families thought they would be. On the other

hand, though they wanted to know all the truth, their family's intentions and thoughtfulness to protect them by concealing the information were being understood and appreciated, because it would be also "hurtful," "inappropriate," "unwise," "impolite," or "dispiriting," if the medical bad news was brutally or bluntly revealed without any embellishments.

Four medical clinicians (physicians and nurses) further shared their experiences of non-disclosure: since it was a prevailing cultural tradition, they were frequently requested by terminal patients' families to conceal medical information, both in America and overseas Chinese countries. Three of them have followed family's consensus in Asia, but not under the American healthcare system. The other two remained checking with family at the first place before directly disclosing the medical information to Chinese patients.

It was true that non-disclosure often led to an initiation of LST without patients' knowledge, and patients' EOL treatment preferences have never been clearly communicated. More than 70% (n= 16) admitted that their non-disclosure led to an initiation of LST without terminally ill family's permissions, and as a consequence, patients' EOL treatment preferences were never clearly communicated. Many first learners (precontemplators) in this study have never made any connections between non-disclosure (of medical truth) and their readiness for advance care planning, but those who have completed their ADs believed that a non-disclosure was a waste of energy and time for both the terminal patient and the family—it would seriously inhibit patients' planning for EOL treatment and the upcoming death.

(f) **Discussions related to death**

All elderly subjects (100%, n= 28) agreed that it was typical in Chinese culture that death was an untouchable topic. One recurrent theme was that discussing death and dying was associated with bad luck (觸霉頭) and mentioning a death topic within the Chinese family was as impolite as cursing the elderly (such as grandparents) and the chronically ill to die sooner. More than

half of the subjects (53.5%, $n=15$) confirmed that this taboo was a tradition, or a way of life originated from the Chinese culture, as they were raised in a milieu to be afraid of death in overseas Chinese countries (Taiwan, China, or Hong Kong). They recalled being constantly warned by the elderly to keep away from anything related to death (such as detouring from coffin shops, graveyards, funeral homes or processions, etc), and most importantly, to avoid seeing or touching corpses for fear that the wandering (evil) spirits of the dead would follow them home, put a spell, or bring bad luck to the whole family. This death taboo was generally believed very difficult to break, particularly among traditional Buddhist and Taoist seniors, and subjects commented most Chinese were reluctant to die and terrified about deaths and the afterworld.

Nonetheless, in this study, elderly Chinese immigrants' overall attitude toward discussing death and dying was shown fairly positive in the face of a death taboo. Subjects believed this prominent death taboo has been increasingly deemphasized in a Westernized American culture, and only 17.8% (precontemplators of various religions) slightly conformed to this cultural tradition. The majority (66%) self-rated being more open-minded in their attitudes and less avoidant of death than overseas Chinese, such as their parents. About 50% reported still concerning death topics in front of the elderly and terminally ill, yet none of them actually believed participating in this study or discussing EOL planning would bring bad luck. Other than the influence of acculturation, two factors were concluded to possibly optimize their attitudes toward discussing death and dying. First, many Protestants (88%) believed their Christian religion has contributed to decrease "fears," "burdens and worries," or "uncertainties" about death and dying. Second, some shared that the older they became, the more open-minded, flexible, and confident they were to be able to let go life, face imperfections in life, handle life tragedies, and discuss the inevitable death.

Previous experiences of discussing death and dying with others

A great number (82%) of elderly subjects in fact have made attempts to share personal values with their families; occasions ranged from EOL (treatment or care) planning to casual talks of death

preparations (mostly triggered by random cases of dying patients), but they rarely talked about death with non-family friends. The majority did report lacking vocabularies or knowledge needed for carrying a constructive death conversation. Precontemplators' family members also seemed to be mostly unsupportive and less tolerant about a death topic (Table 25), so many subjects, without hurting their family's feelings, discontinued after being interrupted or discouraged. Subjects at the highest stage of readiness, including three actioners and two maintainers, reported often thinking about their own death and having little or no hesitance to initiate such discussions with close family members. Their advance care planning was fully supported by families as well. Actioners believed this topic was "depressing," "unwelcomed," "energy-draining to explain," and "very personal (none of others' business)" which might shun friends away. Compared with actioners, maintainers discussed death and shared LST values with not only families but also other friends. As one would expect, not all of their friends were receptive or enthusiastic, particularly those traditional Chinese seniors who held a strong death taboo.

It was worth to mention that fewer than 8% had previous discussions about deaths or LST values with healthcare providers. One fifth of the interviewees admitted that it was the first time a health professional has outspokenly brought up death issues in their face. Most, however, felt "comfortable about the topic (no hesitance)," "fortunate to be able to help with the study," and "benefited" because of the gained knowledge and a chance to share with a nurse researcher.

TABLE XXV

ELDERLY SUBJECTS' ATTITUDES AND EXPERIENCES TOWARD DISCUSSING DEATH AND DYING WITH OTHERS

Attitude	Experiences of discussing death and dying with families
A subgroup of precontemplators (n= 5) who were very traditional	<ul style="list-style-type: none"> • A total of five precontemplators self-described themselves very traditional (conservative, and old-school), and they felt uneasy, awkward, and unused to conversations containing death topics • All of them agreed with the Chinese death taboo, however, three said they did not mind discussing death in the interviews
Another subgroup of precontemplators (n= 13) who believed they were relatively open-minded in their death attitudes and have treated death as a natural part of life	<ul style="list-style-type: none"> • Ten precontemplators said they were comparatively young and healthy so rarely thought about their own death • Seven have thought about death only before a major surgical procedure or taking the airplanes, but eight did so because of an increased age • Nine in this group preferred no death topics in the family right now (not even after life-threatening experiences in two cases): nine said they felt it was too early and no need to depress families and six among them felt unnecessary since they trusted and fully authorized family surrogates anyways • A total of 13 precontemplators have briefly shared their LST value with families, when they had a chance, but two admitted they only knew things like “don’t save me if I am hopeless” and (1) expressed “I want euthanasia.” • To this group, their family’s responses were generally unsupportive: two had their families disagreeing with their values to forgo LST; four families shortly acknowledged or were reluctant to follow; five had families who felt sad, awkward, and bad luck so the death conversation was interrupted; only two had successful, positive experiences. As a result, four continue the death discussions (even after being discouraged) but (8) chose to discontinued the communication A total of 16 precontemplators believed it was rude and un-filial to discuss death with parents; and none have done so All of them did not mind people discussing death in their face, depending on their attitudes
Contemplator (n= 1) and preparers (n= 4) were completely fine with death discussion	<ul style="list-style-type: none"> • Four rarely thought about their own death, but more often recently because of the increased age • Five believed it was rude and un-filial to discuss death with parents; none have done so • Five would like to share values and make their LST preferences known to families. • Two have briefly initiated death related conversations with spouse, starting by “miserable” cases of their terminally ill friends; family’s responses were mostly short yet somewhat neutral
Actioners (n= 3) and Maintainers (n= 2) were enthusiastic in discussing death and dying	<ul style="list-style-type: none"> • Three actioners have never discussed EOL planning with parents because of the cultural concern • One maintainer has carried out a difficult, careful discussion with her parent • Two actioners have rarely discussed with others after completing their ADs; because they believed their spouses had similar LST values, it was unnecessary to overly discuss, and it was unnecessary to discuss their LST with friends; one actioner has never discussed with adult children, not to mention friends • Two maintainers have thoroughly discussed their LST with the whole family (including an adult son) many times; smooth communications were reported and families were understanding, supportive and responded well to their LST decisions; they have discussed and shared their advance care planning with friends

The cultural taboo of death as an inhibitor to Chinese Americans' readiness for advance care planning

Nearly 90% agreed that the key to successful advance care planning was to break the Chinese taboo of (discussing) death. They have suggested to increasing an overall awareness and receptivity of advance care planning through education by well-planned interventions, which aimed to skillfully desensitize negative responses about discussing death, introduce the significance and knowledge of ADs, and enhance their endorsement for advance care planning. More than one third felt that after the standard education embedded in the interviews, they became more apt to initiating death discussions with family members and more prepared for advance directives/living wills.

(g) Good death

Qualitative descriptions of a good death from elderly interviewees included thick data of rationales, examples, previous life experiences/stories, and personal values, which was not majorly different from survey participants' (n= 106) written definition and criteria. About one third admitted that they have never clearly thought about death before, not to mention what comprised a good death. Commonly brought up was the higher importance of living a good life rather than pursuing a good death. However, a good death was generally conceptualized more than just a nice and easy dying process. The majority (85%) fatalistically believed that one's death was pre-destined (trusting either the authority of God in Christianity or the Buddhist karmic effects). In addition, more than 78% (n= 22) believed that the perfect death in their mind was a relatively easy (effortless), smooth, and fast (sudden) death. Only when subjects planned to have a pain- and suffering-free death, their desire for a peaceful dying process with no LST was related to their readiness for advance care planning. Otherwise, characterizations of a good death might not be achieved by advance care planning.

(h) Seeing the last face

This concept (見最後一面) was well-known and commonly practiced among Chinese in America and overseas Chinese countries. In general, nearly 90% of the interview subjects were familiar with sustaining dying patients' life or keeping their vital signs, for the purpose to wait for

important families, particularly patients' offspring, to arrive at the bedside for the last goodbye. The majority (71.4%) endorsed and supported this idea. In fact, sustaining the dying so he/she could be seen by all families was not only doable but also legitimate. More than half of the interviewees have returned to Asia to see their parents' last face, and some shared that one of the greatest regrets in life was not being able to make it.

"Seeing the last face" was mostly agreed as a personal decision—if the patient insisted to do so for families to arrive, it was his/her EOL preference that ought to be respected. Nonetheless, a fair number of elderly interviewees (39%) commented that temporarily sustaining the dying was doable, humane, and legitimate (Table 26). It was apparent in the survey result that the more subjects believed treatments should be used for the sake of a last face; the more willingly they agreed to be sustained for their family. Subjects at high stages of readiness, who desired self-control and preferred no LST at the EOL, clearly did not take this cultural custom as true. Although the belief of "seeing the last face" has a great influence on Chinese Americans' LST values, it did not seem to strongly facilitate subjects' willingness or readiness for advance care planning.

(i) **General death planning**

Half of the elderly subjects have had some sort of planning for their death (n=14). The majority believed they have prepared "everything" needed, including the location to die, burial clothing, an arrangement of internment or cremation, and a funeral plan. Quite many have planned to follow a Chinese tradition to return (the ashes) to China.

Another half who have not thoroughly planned for their death were relatively physically healthy and younger (mean age= 77.4 vs. 84.6 years). The "contingency plan" for emergencies (such as sudden deaths) was mostly a will written before traveling indicating where the valuables were stored or to be distributed. Their final words were not beyond an arrangement of heritages or an ultimate expectation on the rest of family members to take care of each other.

TABLE XXVI
INTERVIEW SUBJECTS' OPINIONS ON INITIATING DYING PATIENTS' LST FOR "THE LAST FACE"

Interviewees' survey answers	Opinions	Reasons and concerns to support or oppose initiating LST for the purpose of "seeing the last face"	Subjects' personal LST preference
Always true (n= 2)	A total of 39.2% (n= 11) believed this decision was humane and justifiable	<ul style="list-style-type: none"> - A ritual-like opportunity for the whole family to have a closure - For non-Christians, this is truly the last meeting - This is a chance to be surrounded by families so that their eyes could be closed with no regrets (瞑目) - It is an occasion for children to show filial piety - It makes leaving final words and handing over duties to the next generation possible 	(5) would like to be sustained for the rest of their family (6) preferred no LST but they were flexible if family insisted to sustain them
Quite true (n=11)	32.1% (n= 9) conditionally agreed with this tradition	<ul style="list-style-type: none"> - All conditionally agreed with the reasons above - They concerned about the timeframe of and sufferings from using LST—when LST become permanent, it may lead to patients' unnecessary sufferings and family's inevitable burdens (the maximum allowed length of time was agreed to be one to two weeks) - Seeing the last face would be pointless and a waste of resources if the dying patient was unconscious 	(2) would be sustained for their beloved ones (3) preferred no LST but were flexible if their families insisted (4) absolutely wanted no LST
A little bit true (n= 9)	28.5% (n= 8) disagreed: Compared to patients' possible sufferings using LST, this decision was meaningless, unpractical, unnecessary, and unfair to the dying	<ul style="list-style-type: none"> - Christians considered this purpose a myth, for they will reunite again in Heaven some day - Most agreed with the above concerns and disagreed that this act was connected to filial piety or the unfinished business - In the past, seeing their families' "last face" (with LST) has instead made them sad and regretful for sustaining their life - It was truly unimportant whether they got to see families' (parents) last face (n= 6) or whether their families (children) could see their own last face (n= 5) 	(3) preferred no LST but were flexible if their family members insisted (5) absolutely wanted no LST (even just for hours or days)
Never true (n= 6)			

b. **Triandis and Gelfands' Individualism and Collectivism Scale**

The results showed that Chinese American subjects were quite collectivistic and not individualistic, where their strong emphasis was on family integrity, in-group goals, interdependence, and a non-competitive nature. Among the four subscales, there were moderate correlations with a positive relationship between subjects' vertical collectivism (VC) and horizontal collectivism (HC) ($r = .35$, $p < .001$) and a negative relationship between horizontal individualism (HI) and vertical individualism (VI) ($r = -.44$, $p < .001$). None of the IC orientations were significantly correlated to any of the outcome variables, including ordinal and dichotomous stages of readiness, decisional balance, and self-efficacy (Table 27).

TABLE XXVII
DESCRIPTIVES OF THE FOUR IC CONSTRUCTS AND 16 IC ITEMS (n= 206)

Triandis & Gelfand's IC constructs	Mean	Median	Std. Dev	Min	Max
Horizontal individualism	15.22	16	3.29	5	20
Vertical individualism	12.44	12	3.06	5	20
Horizontal collectivism	15.8	16	2.70	4	19
Vertical collectivism	16.37	16	2.85	4	18

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

c. **The Suinn-Lew Self-identity Acculturation Scale (SL-ASIA)**

Subjects in this study were all raised in overseas Chinese countries. Along the acculturation continuum (range= 1 ~ 5), most immigrants identified themselves “only” or “mostly” Chinese (mean= 2.03, SD= .31), instead of “bicultural Americanized Chinese.” The level of acculturation could be best predicted by the preference of their chosen (reading and written) language ($r > .70$, $p < .001$), which a better level of English proficiency was associated with a higher level of acculturation.

TABLE XXVIII
DESCRIPTIVE STATISTICS OF ACCULTUATION SCORES (n= 206)

Acculturation	Valid	Mean/ Median	Std. Dev	Skewness	Std. Error Skewness	Kurtosis	Std. Error Kurtosis	Min	Max
<u>SL-ASIA</u> (total score)	206	2.03/2.05	0.31	-0.31	0.169	-0.15	0.34	1.24	2.86

Anticipated to be an important cultural factor of AD completions, Chinese subjects' acculturation (Americanization orientation), however, was not considered a significant correlate of most outcome variables, such as the ordinal stage of readiness ($\rho = .15$, $p < .001$) and self-efficacy for advance care planning ($r = -.19$, $p < .001$). Surprisingly, acculturation was not correlated with traditional cultural beliefs related to EOL decision-making and only very weakly correlated with age ($r = -.24$, $p < .001$), it was moderately and positively correlated with levels of education ($\rho = .51$, $p < .001$), income ($\rho = .38$, $p < .001$), and overall knowledge for advance care planning ($r = .41$, $p < .001$).

d. **English proficiency related to advance care planning**

1) **Measuring English proficiency among Chinese immigrants**

A lack of English proficiency was anticipated to hinder Chinese Americans' access to and engagement in advance care planning in the American health care context. Overall, Chinese immigrant subjects in this study self-rated their English "quite good" (range= 2~8, mean = 5.92, SD= 1.95), and only approximately 15% reported a strong language barrier which the majority had no problems using English in daily life (47.1%) or handling a doctor's appointment (36.9%).

TABLE XXIX
CORRELATIONS BETWEEN PAIRS OF ENGLISH PROFICIENCY AND OUTCOME VARIABLES

Items	ACP Endorsement ^a	ACP Concerns ^a	Decisional Balance ^a	Self -efficacy ^b	AD completion ^c	6 Stages readiness ^d	2 Stages ^d
<u>English Proficiency</u> (total score)	.043	-.130	-.071	-.147	.097	.230**	.190**
Problems in daily life	.046	-.123	-.120	-.130	.091	.184**	.143**
Problems during a doctor-visit	.118	-.117	-.015	-.142	.087	.234**	.203**

a. Pearson's r ($n = 206$), b. Pearson's r ($n = 170$), c. Point-biserial's r_{pb} ($n = 206$), d. Spearman's ρ ($n = 206$);

** Correlation is significant at the 0.01 level (2-tailed); * Correlation is significant at the 0.05 level (2-tailed)

English proficiency as a factor was found to weakly relate to the stage of readiness ($\rho = .23$ and $r_{pb} = .19$, $p < .001$) but not linked to other outcome variables of decisional balance, self-efficacy, and AD completions. In addition, English proficiency, moderately and positively associated with acculturation ($r = .58$, $p < .001$) and knowledge for advance care planning ($r = .34$, $p < .001$), yet was unexpectedly

weakly associated with cultural beliefs ($r = .19$, $p < .001$). Subjects who were older ($r = -.26$, $p < .001$), poorer ($\rho = .435$, $p < .001$), less educated ($\rho = .58$, $p < .001$), and the unemployed ($rpb = .23$, $p < .001$) were associated with a lower level of English proficiency.

2) **Languages preferred by Chinese Americans in written information related to health**

It was obvious that the majority of highly educated and English-proficient subjects still preferred receiving health related information written in their mother language. A total of 46 survey subjects have explained why Chinese was preferred in the written information: 44 % of them wanted to completely comprehend the contents with no incorrectness or misunderstanding, 39.1% had a language barrier so Chinese was their only option, 13% thought it was easier and faster to read and digest Chinese, and 4% would like to communicate with other Chinese-speaking family or friends. Another group of subjects ($n = 79$) who preferred English with Chinese translations wrote that information provided in two languages ensured a complete, comprehensive understanding, because nearly one third of them concerned about English medical terminologies and 11.3% said they frequently found errors in Chinese translations after comparing information between two languages.

A total of 25 subjects preferred health related information written only in English. Twenty have provided written explanations: 35% were now more comfortably in reading English, 50% believed that English information would be more truthful and clearer, and 15% would like to learn the correct English medical terms. Last, those who had no preference ($n = 19$) said since they were bilingual, it was really unimportant in which language the health related information was written.

e. **Qualitative results:**

1) **Immigration history**

Each interview subject had a unique immigration story, yet their reasons for an immigration decision were seemly common, including a pursuit of American dream (opportunities for better education and higher living quality), a need to babysit grandchildren, or a political drive. Nearly

68% have stayed in America for more than 30 years. Commonly mentioned were the “immigration prison,” the long waiting process for their resident status to be legally effective, a separation from families in Asia, a lack of social support, and the high medical costs in America. Although most elderly Chinese were satisfied with their current life, some found living in America was not what they originally expected. The period of time arrived and the length of time spent in the States was not found to be associated with subjects’ readiness for advance care planning.

2) **Qualitative results: English proficiency and doctor-visiting experience in the States**

About one third of the interview subjects were English-fluent (in both everyday life and during medical visits); they were able to make medical appointments and handled complex discussions with English-speaking health care providers on their own. Generally agreed was that medical jargons were problematic during doctor-visits: even a professional synchronized translator admitted that extra efforts were needed in order to comprehend and digest medical terminologies. Five Master’s prepared subjects (two PhDs) who received their professional degrees in the States still encountered difficulties if doctors spoke too fast, with strong accents, or used too many medical jargon.

Unsurprisingly, the majority of elderly interviewees (68%) reported a strong language barrier. Among them, 32% could only carry out simple conversations or mindless activities where little English was involved (i.e. buying groceries, dropping mails, or greetings to the neighbors). The other 43% were English illiterates who required spouses, children, relatives or friends to serve as medical interpreters. Although these subjects did not limit themselves to Chinese-speaking doctors; committed medical interpreters and transportation providers were difficult to arrange.

These Chinese-only speakers described they were nervous and afraid of missing important information or misinterpreting the healthcare providers, kept nodding heads to pretend they have understood, were suspicious about physicians’ facial expressions, felt they were often forced to answer “yes” or “no,” could only repeat symptoms in simple English words, or felt guilty as primary caregivers

who could not follow physicians' directions. Even with their family interpreters, a few felt that their physicians became impatient about the intermittent communication. Because of these negative experiences, more than 76% were not enthusiastic about regular medical visits in the States: some have turned to Chinese-speaking doctors only, and a few even intentionally missed their appointments if no interpretations or transportations were available, since many felt guilty, dependent, powerless, and uncomfortable to "owe other's a favor," even to close family members. As anticipated, none of the English iterates in this study have heard about ADs or advance care planning, showing the importance of English proficiency to elderly Chinese Americans' knowledge, access to health information, and stages of readiness in this area.

3) **Qualitative results: English proficiency and access to health care in America**

English illiterates (61%) reported being information-isolated in Chicago: some recalled they used to receive more Chinese health information while residing in San Francisco, New York, and Los Angeles. Information sources included Mandarin/ Taiwanese media (e.g. newspapers, biweekly newsletters, medical news of TV or radio programs, Internet/health websites), social networks of families and church friends, Chinese-speaking assisted living and healthcare institutions. Fluent English speakers (39%), on the other hand, reported receiving a fair amount of health information (mostly written in English) from the mainstream society. The multiple sources included: Internet web pages, libraries, bookstores, both Chinese and English media, advertisement flyers/mails from health insurance commercials or retirement plans, and their social networks. Physicians and nurses (n= 4) also have regularly received updated health information from medical newsletters, professional journals, conferences, and continuing trainings.

More than 80% (including four health professionals) have received little or no information from their primary healthcare providers, even during a long-term hospitalization. Four cancer survivors recalled receiving some post-surgery or chemotherapy information from hospitals and pharmaceutical companies, yet no information was from their primary physicians about how to maintain a healthy

lifestyle or how to plan for future (EOL) treatment or care. The remaining subjects shared that the only information they received were flyers/pamphlets about vaccines or screenings, not the type of health regimen information they were looking for. Approximately one third were familiar with using Internet to search for health related information online, and one fifth of them browsed mainly Chinese web pages. These computer users were relatively younger (< 75-year-old), better in English, wealthier, and more available (mostly retired).

Subjects' preference of (written) language in health information was a good predictor of their English proficiency. For those who were limited in English, a language barrier apparently has inhibited their exposure, amount, and further access to updated health information in Chicago, depending on the quality of translated (Chinese) information. However, fluent English speakers believed their access to state-of-the-art health information was unaffected by their level of English proficiency—this group was confident that the amount, breadth, and depth of information they received were no less than that of other Americans.

4) **Qualitative results: Elderly immigrants' self-perceived isolation**

More than 81% of the elderly interviewees have expressed being isolated from the outside world. This self-perceived isolation was found relating to transportation inconvenience, physical limitations, and a language barrier. About one fifth were unable to drive, yet if unnecessary, many preferred not going through the troubles to request or “beg” for rides from family members or friends. Understanding and accepting the fact that their adult children had their own life priorities, subjects chose (or pretended) to be independent without conflicting family's schedule, so many had little access to other places. Another 18% reported being physically restricted and isolated due to their (or spouses') deteriorated health and a decreased stamina. Impaired vision and hearing were also commonly reported among elderly subjects, resulting in a lack of motivation to receive or seek for new information. Some felt they could never leave their ill spouses alone and being the only caregivers they were bounded at home all the time.

Other than the physical and transportation immobility, approximately 40% described their poor English has isolated them from the American society. Words they used to express this feeling of dependence and frustration included, “like a dumb person,” “speechless,” “coward,” “afraid to see the White,” “always need a spokesperson,” and “no English please.” Several recalled they were socially active in Asia or Chinatown but not anymore. Because these subjects have long counted on their family members (mostly children) to translate and make important decisions, commonly described was how dependent and lonely they were when family (mostly children) gradually became less available for them. In addition, a few widow(er)s shared that making friends after their spouses passed away was difficult. In fact, this was the main reason why they chose to stay in a Chinese assisted living facility.

4. **Knowledge factors related to Chinese Americans’ advance care planning**

a. **Overall knowledge related to advance care planning**

1) **Total scores of knowledge related to advance care planning**

The non-normal distribution (kurtosis= -.72, SE= .34, skewness = 0.54, SE= .17) of the total knowledge scores (range= 0 ~ 12, mean= 4.25, SD= 3.40) illustrated a general lack of overall knowledge related to advance care planning among Chinese American subjects. All scores of the 10 knowledge items ($r = .45 \sim .92$, $p < .001$) and three knowledge subscales were moderately to highly correlated with the total knowledge scores (a summation of three subscale) ($r > .83$, $p < .001$) (Table 30). Subjects’ overall knowledge about various types of ADs ($r = .282$, $p < .001$) was associated with the AD completion, followed by two single knowledge items about ADs ($r_{pb} = .244$ and $.225$, $p < .001$), however, these correlations were fairly weak, suggesting that an increase of knowledge did not necessarily guarantee an increased rate of AD completions.

TABLE XXX
DESCRIPTIVES OF RESPONSES IN THE KNOWLEDGE SCALES (n= 206)

Subscale/total scores	n	Valid	Mean	Std. Dev	Skewness/ SE (.169)	Kurtosis /SE(.34)	Min	Max
Knowledge about life-sustaining treatment	206	206	1.65	1.61	.434	-1.13	0	5
Knowledge about advance directives (including living wills)	206	206	2.00	1.56	.610	-.345	0	6
Knowledge about the advance care planning process	206	206	.928	1.33	1.26	.418	0	5
Overall knowledge about advance care planning (total scores)	206	206	4.25	3.40	.539	-.723	0	12

Almost all knowledge items were positively yet weakly correlated with the ordinal stage of readiness (spearman's $\rho = .165 \sim .310$, $p < .005$). After dichotomizing the outcome of readiness, knowledge about LST (the Chinese term) and advance care planning (the English term) became unassociated with subjects' readiness (of being precontemplators or not). Last, among all single knowledge items or subcategories, subjects' overall knowledge (a summated understanding about LST, types of ADs, and advance care planning) was the highest correlate of readiness ($\rho = .273$, $p < .001$), but the strength was still quite weak. While the self-perceived understanding about LST ("How much do you think you understand LST") was highly correlated with the overall knowledge in this area ($r = .830$, $p < .001$), a simple thumb of rule was that those who considered themselves knowledgeable about LST, correlating with a higher level of overall knowledge, were associated with a better stage of readiness for advance care planning ($r = .31$, $p < .001$).

TABLE XXXI
CORRELATIONS BETWEEN EACH KNOWLEDGE ITEM AND STAGE OF READINESS VARIABLES

Questions	LST knowledge ^a	AD knowledge ^a	ACP knowledge ^a	Overall knowledge ^a	AD completion ^b	6 Stage of readiness ^c	2 Stage readiness ^b
1. BEFORE TODAY, have you heard this English term "life-sustaining treatment"	.819**	.505**	.471**	.733**	.150*	.179**	.144*
2. BEFORE TODAY, have you heard this Chinese term "life-sustaining treatment"	.716**	.405**	.438**	.619**	.014	.118	.130
3. How much do you think you understand "life-sustaining treatment?"	.936**	.590**	.597**	.830**	.206**	.310**	.291**
Knowledge about LST	1.00	.614**	.617 **	.884 **	1.70**	.254**	.251**
4. I have heard the English term "Advance Directives."	.364**	.643**	.531**	.830**	.192**	.222**	.154*
5. I have heard the English term "Living Wills."	.369**	.590**	.292**	.557**	.127	.222**	.172*
6. I have heard the English term "Durable Power of Attorneys"	.369**	.716**	.335**	.515**	.225**	.255**	.176*
7. How much do you think you understand Advance Directives?	.580**	.857**	.648**	.560**	.244**	.252**	.189**
Knowledge about advance directive documents	.614**	1.000	.655**	.851**	.282**	.267**	.241**
8. BEFORE today, have you heard this English term "advance care planning"	.521**	.549**	.858**	.730**	.145*	.165*	.119
9. BEFORE today, have you heard this Chinese term "advance care planning"	.455**	.450**	.765**	.614**	.208**	.233**	.203**
10. How much do you think you understand advance care planning	.585**	.642**	.927**	.770**	.171*	.242**	.206**
Knowledge about the advance care planning process	.617**	.655**	1.000	.830 **	.199**	.177*	.208**
Overall knowledge about advance care planning	.884**	.851**	.830**	1.000	.234**	.273**	.259 **

a. Pearson's r (n= 206), b. Point-biserial's rpb (n= 206), c. Spearman's rho (n= 206)

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

* Correlation is significant at the 0.05 level (2-tailed).

Knowledge about the advance care planning process was shown to be insignificantly related to decisional balance and self-efficacy. Nonetheless, subjects' overall knowledge and knowledge about ADs were weakly to moderately related to decisional balance ($r = -.28$ and $-.32$, $p < .001$) (Table 32), since a higher level of knowledge were weakly related to a higher level of endorsement ($r = -.163$, $p < .05$) and a lower level of concerns ($r = .223$, $p < .001$) for advance care planning. As mentioned previously, the level of overall knowledge related to advance care planning was only moderately and positively correlated with English proficiency ($r = .34$, $p < .001$), acculturation to the American mainstream ($r = .41$, $p < .001$), overall EOL experience ($r = .25$, $p < .001$), and the socio-economic status (education $\rho = .28$, $p < .001$, income $\rho = .34$, $p < .001$).

TABLE XXXII
CORRELATIONS BETWEEN KNOWLEDGE SUBSCALES AND OUTCOME INDICATORS

Questions	ACP Endorsement ^a	ACP Concerns ^a	Decisional Balance ^a	Self -efficacy ^b
Knowledge about life-sustaining treatment	-.158*	-.153*	-.229**	-.076
Knowledge about AD documents	-.191**	-.257**	-.319**	-.135
Knowledge about the advance care planning process	-.098	-.150*	-.182**	-.030
Overall knowledge about advance care planning	-.163 *	-.223 **	-.282 **	-.086

a. Pearson's r ($n = 206$), b. Pearson's r ($n = 170$)

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

* Correlation is significant at the 0.05 level (2-tailed)

b. Knowledge related to the concept of advance care planning

**1) Measuring subjects' understanding about life-sustaining treatments (LST),
advance directives documents (AD), and advance care planning as a continuous
communication process**

The frequency results showed a general lack of knowledge related to advance care planning, because no subjects have heard all seven terminologies and 14% were responded "no" in every question. Terms of "advance directives" (mean= .16, SD= .367) and "advance care planning" (mean= .17, SD= .372 in Chinese; mean= .25 SD= .435 in English) were unfamiliar to Chinese subjects which approximately 90% did not know advance care planning was a continuous process of making

advanced EOL decisions. “Life-sustaining treatment” was a term comparatively more subjects have heard of (mean= .42, SD= .50), but still approximately 70.6% reported having little or no understandings, neither in English (57.8%) nor in Chinese (70.9%)(Table 33).

Similarly, only less than 3% reported knowing about advance directive documents very much; terms of advance directives (ADs), living wills, or durable power of attorneys were foreign to most subjects (84%, 26.7%, and 63.6%, respectively), not to say the content and purpose about them. Among three types of AD documents, living wills seemed to be mostly heard yet this knowledge might be overestimated. We learned from the subsequent in-depth interviews that many have mistaken living trusts for living wills and some were confused between living wills and wills.

2) **Sources of advance care planning information**

Although almost all subjects answered where they first learned about LST and the process of advance care planning the validity of data in this section was questionable. Many subjects in the previous section answered they have never heard about these two terms, but only a few (24% and 47.1%) responded “never heard” in the question of source (where did you first learn). Since this discrepancy has suggested an invalid report that some subjects might just circle one from the multiple answer options, the result was not presented here.

3) **Written responses in the survey to define and exemplify LST and advance care planning**

Only half of the subjects have attempted to define and give examples of advance care planning (Table 34). The level of thoroughness and comprehensiveness in the understanding of advance care planning was obviously much lower than that of LST.

TABLE XXXIII
DESCRIPTIVES AND FREQUENCY IN THE KNOWLEDGE SUBSCALES (n= 206)

Questions		n	%	Missing	Mean	Std. Dev	Min	Max
1.	BEFORE TODAY, have you heard this English term "life-sustaining treatment?"	206		0	.42	0.50	0	1
	No. Never.	119	57.8%					
	Yes, I have.	87	42.2%					
2.	BEFORE TODAY, have you heard this Chinese term "life-sustaining treatment?"	206		0	.29	0.46	0	1
	No. Never.	146	70.9%					
	Yes, I have.	60	29.1%					
3.	How much do you think you understand "life-sustaining treatment?"	206		0	.94	0.94	0	3
	Not at all	84	40.8%					
	A little bit	63	30.6%					
	Moderately	46	22.3%					
	Very much	13	6.3%					
4.	Before today, have you heard about the term "Advance directives?"	206		0	.16	.367	0	1
	No. Never.	173	84%					
	Yes, I have.	33	16%					
5.	Before today, have you heard about the term "Living wills?"	206		0	.73	.443	0	1
	No. Never.	55	26.7%					
	Yes, I have.	151	73.3%					
6.	Before today, have you heard about the term "Durable Power of Attorneys?"	205		1	.38	.511	0	1
	No. Never.	131	63.6%					
	Yes, I have.	74	36.4%					

TABLE XXXIII
DESCRIPTIVES AND FREQUENCY IN THE KNOWLEDGE SUBSCALES (Cont.)

	Questions	n	%	Missing	Mean	Std. Dev	Min	Max
7.	How much do you think you understand "advance directive documents?"	206		0	.73	.817	0	3
	Not at all	99	48.1					
	A little bit	71	34.5					
	Moderately	30	14.6					
	Very much	6	2.9					
8.	Before today, have you heard the English term "Advance care planning?"	206		0	.25	.435	0	1
	No. Never.	154	74.8%					
	Yes, I have.	52	25.2%					
9.	Before today, have you heard the Chinese term "預立醫囑?"	206		0	.17	.372	0	1
	No. Never.	172	83.5%					
	Yes, I have.	34	16.5%					
10.	How much do you think you understand "advance care planning?"	206		0	.50	.722	0	3
	Not at all	127	61.7%					
	A little bit	57	27.7%					
	Moderately	19	9.2%					
	Very much	3	1.5%					

TABLE XXXIV
SURVEY SUBJECTS' UNDERSTANDING ABOUT LIFE-SUSTAINING TREATMENT AND
ADVANCE CARE PLANNING

What is LST to you?	185 responses (n= 145, 70%) to the open-ended question
Incorrect definitions from subjects of no knowledge	<ul style="list-style-type: none"> - 43 had no ideas at all; they have never heard about it - 16 shared their LST values and opinions instead of properly defining them - 12 were able to relate LST to a device or machine that sustains life - 8 incorrectly believed that LST could be used to cure EOL patients or improve terminal illnesses - Incorrect LST definitions included: hospice, three meals, air and sunshine, patients in the nursing home, alternative medicine, a comatose patient, pain-free, or sleep and rest
Correct purpose of the LST	<ul style="list-style-type: none"> - 132 have heard the term and correctly defined what LST is - 62 did not provide examples but simply recognized a purpose of life-support, such as "keep a person alive," keep breathes and heart beats," or "keep vital signs" - 30 did not specify what treatments were but only listed, "extreme methods," "machines" or "the devices."
Examples of LST	<ul style="list-style-type: none"> - 49 have provided correct examples of LST, including "incubation and ventilator," "electric shots for the heart," "tube-feeding" and "drugs, IV, and oxygen," etc.
Timing to use LST	<ul style="list-style-type: none"> - 18 mentioned the timing of using LST, including: "when no cure is possible," "when dying," "LST was only for extra days or months," and "at the EOL.
Patients' conditions applicable for LST	<ul style="list-style-type: none"> - 13 described the situations about patients' conditions when LST was to be used, such as "by incompetent and comatose patients," "unconscious, no active breathing and no voluntary heart beats," "brain death" and "vegetative patients."

TABLE XXXIV (Cont.)
SURVEY SUBJECTS' UNDERSTANDING ABOUT LIFE-SUSTAINING TREATMENT AND
ADVANCE CARE PLANNING

What is advance care planning to you?	101 responses (50%, n= 101) to the open-ended question
Where they first learned about this term	<ul style="list-style-type: none"> Only 4 have heard about the term: 2 were informed by the advertisement letters (sent from their attorney's office), 1 read about it in a insurance magazine, and 1 heard when establishing his living trust 42 have never heard about this term and 25 referred to this study (e.g. "here," "from you in the church," "in this questionnaire" or "today") 101 have attempted to define and give examples of advance care planning, yet 42 were merely guessing; 9 have given unclear and vague answers
Correct definitions and examples of advance care planning	<ul style="list-style-type: none"> Only 10 were completely clear and correct about the definition, purpose, timing, and patient conditions of advance care planning. 25 have touched upon the idea of patient incompetency and an advanced plan for the care and treatment needed at the EOL 5 mentioned ADs as the examples of advance care planning Only 1 provided a valid example of advance directive in Illinois, "Five Wishes," but ironically this lady has never heard about the term advance care planning before
Improper responses and incorrect definitions	<ul style="list-style-type: none"> 7 only shared their values and opinions about LST 17 misunderstood and gave incorrect examples, including: long-term care (5), nursing care plan (4), nursing home (3), an insurance plan (2), a death plan (1), hospice (1), and a plan signed by the lawyer (1).

c. **Qualitative results**

1) **Knowledge regarding LST**

Elderly interview subjects were generally unfamiliar with the types and purposes of "life-sustaining treatment 維生治療;" 54.6% have never heard about the term before, neither in English or Chinese. The Chinese term/translation of LST seemed not a common sense to most elderly immigrants. The majority (53.6%) did not know about LST and first learned about this term in this study (Table 35); most who have completed their advance directives/living wills knew LST in English. Those who knew LST only in Chinese seemed to be comparatively knowledgeable when asked to define LST, and none of them have completed ADs. Except for those of medical backgrounds, most learned about LST through media (mails, flyers, internet, radio, TV, and newspapers) or previous EOL experiences of

family or friends' illnesses. Quite a few related LST to cases of Terry Chiavo or Shiao-Ming Wang (a famous Chinese vegetative girl) and described how they first learned about the idea of sustaining life via artificial tube-feeding. Chinese internet webs and newspapers were sources where subjects learned the Chinese LST term. Those who learned about LST through previous family's EOL situations were more knowledgeable compared to those who learned through media, as many were able to describe the purpose, types, timing, and futility about LST. Although they were clear about the intention or purpose of using LST, their understanding varied greatly. Those at higher stage of readiness were fairly knowledgeable because many could provide specific examples or listing common LST options.

TABLE XXXV

INTERVIEW SUBJECTS' KNOWLEDGE RELATED TO LIFE-SUSTAINING TREATMENT

Interview subjects' exposure to LST	Usage of ADs	Sources of learning	Definition
A total of 46.4% (n= 13) have heard about LST: in English (n= 6), in Chinese only (n= 2), or both (n = 5),	<ul style="list-style-type: none"> - 6 completed either an AD or a living will; all have heard about LST in English, and two have heard LST in both languages - 7 have not signed any ADs. Two have heard the term in both languages. 	<ul style="list-style-type: none"> - 4 healthcare professionals learned from medical textbooks or school education (ex. Iron lungs and CPRs) - 2 from nursing home - 5 from friends and families - 5 from health care providers in ICUs and hospitals - 4 from the Terry Chiavo case - 4 from written info sent to house such as living trust and life insurance materials - 2 from Chinese newspapers 	All were correct about either the English (n= 11) or Chinese term (n= 7). Their levels of understanding varied greatly.
53.6% of the interview sample (n= 15) have never heard about LST before this study	None of them have completed any advance directives or living wills	First heard from this study.	<ul style="list-style-type: none"> - 21 were correct with insufficient understanding - 13 were incorrect and surmises included: the surgery permit, Do-Not-Resuscitate orders, a legal form to forgo treatment, tubes to be plugged in, IV shots for vegetative patients

The English term “life-sustaining treatment” was reported easy to understand. Questions were raised concerning the popularity and consistency of the Chinese translation (“維生治療” in the survey).

Several have seen other Chinese translations some places elsewhere, and some subjects critiqued that the Chinese term was misleading (protecting life or maintaining life?).

On the whole, Chinese subjects were generally modest in self-evaluation. Many who were correct and quite knowledgeable about LST have humbly underestimated their knowledge (1 on a 0-3 scale) and expressed their understanding was limited. Only 14% in the total sample believed they knew “very much;” even four healthcare providers (including three clinical practitioners) rated their self-understanding about LST “only moderate (2 on a 0-3 scale).” On the other hand, the self-perceived understanding from subjects who first learned about LST (n= 15) has accurately reflected their innocence. Surmises of LST were provided and LST was often wrongfully defined as DNRs, surgery permits, or euthanasia (Table 35). After receiving standard education of LST, subjects’ understanding has largely increased. At the end of the interview, more than 78% were able to give specific LST examples, distinguish LST among other treatment options, and define the term “incapacity.”

Several subjects shared that compared to their parents’ generation they did have more knowledge about what medical technology could do to sustain life and prolong the dying, yet making LST decisions in advance was still a relatively foreign concept to most Chinese Americans. While most knowledge subjects considered LST a common sense and a realistic option, first learners seemed to be more indecisive and believed such decisions could wait (“LST is not for me but only for the very old and very sick).” They believed still not equipped well enough with the knowledge needed to execute such a plan. Obviously to them an increase of LST knowledge did not necessarily facilitate their readiness to be as high as that of those knowledgeable ones.

2) **Qualitative results: Knowledge regarding advance directive documents (ADs),
living wills and DOPAs**

Elderly interviewees were less knowledgeable about (the types and purposes of) advance directive documents than about LST: the majority has not heard about ADs (64.2%) or DOPAs (60.7%), a total of 42.8% were completely clueless, and only one (out of 28 interviewees) had heard all three different terms. Although 67% believed they knew what living wills were, this understanding (only 29% were correct) was in fact not any better than that of ADs and DOPAs. This lack of AD related knowledge was revealed in the survey that elderly interviewees candidly self-rated their understanding at “zero” (on a 0-3 scale) (43%) or “a little bit (1) (24%).”

Actioners and maintainers’ AD knowledgeable

Valuable insights were provided from six knowledgeable subjects who have completed their ADs. All reported receiving no guidance from their health care providers, and three believed that being physically healthy it was unnecessary to inform their family physicians about an AD decision. They had no difficulties understanding and reading through the documents but recalled that medical jargons in the ADs were somewhat “deep.” Three originally did not plan to complete their ADs but living will forms were included in their living trusts. Two commented that the public media presented only controversial EOL cases, shedding no lights on the “know-how.” Four have self-studied AD materials from multiple sources with no involvement or assistance from attorneys (Table 36). It was worth noting that two actioners (who have completed either a living will or a DOPA) only had little AD knowledge (one had never heard about these terms before); they reported filling out the form from their husbands, showing the influence of paternalism on the AD completion.

These actioners and maintainers wished there were Chinese translations or examples provided, so that they could read faster and digest the information better. Although health care providers or attorneys were considered unnecessary during their AD completion, it would be nice if experienced experts were physically present to “share some tips or give pointers.” Many regretted they did not know LST well

enough before signing their ADs. Further facilitations were also suggested, such as a deadline or a letter/phone reminder, because people tended to procrastinate.

TABLE XXXVI
INTERVIEW SUBJECTS' KNOWLEDGE RELATED TO ADVANCE DIRECTIVE DOCUMENTS

Exposure to ADs	Usage of ADs	Sources of learning	Definition
About 51% have heard either an AD (n= 6), a living will (n= 13), or an DOPA (n= 11)	- 6 were knowledgeable and completed either an AD or a living will.	Advertisement mails/flyers from: (9) Lawyers' offices living trust materials (4) Life insurance (2) Friends and families (2) Nursing home (2) ICUs and hospitals (2) Hospital seminars (1) Chinese newspapers (1) Brochures from the State Government	73.3% (n= 11) were incorrect, and their surmises included: Living trusts, wills, Do-Not-Resuscitate orders, heritage laws, general legal documents about death
The rest 42.8% (n= 12) have never heard any of these terms before	Only two have completed either a living will or a DOPA but with little AD knowledge	First heard from this study.	100% (n=12) were incorrect Surmises included: Living trusts, financial wills, Do-Not-Resuscitate orders, final wishes/words left to the family, doctor's treatment advice or instructions, power of attorney, lawyers, attending physicians, etc.

Precontemplators' AD knowledgeable

Common patterns of AD misunderstandings were found among unknowledgeable subjects (Table 36): ADs were usually misinterpreted as general wills (encompassing house and bank properties or heritages), a do-not-resuscitate (DNR) order, doctors' medical advice or instructions, or verbal directives of patients' last wishes or final words (which could be anything) left to the family. DOPAs were normally misapprehended as financial POAs, lawyers, or attending physicians. Living wills were wrongfully misread as financial wills, wills, or living trusts. In addition, many believed an execution of AD was costly and (hired) attorneys or notaries must be involved to legally complete the forms.

Once all subjects have obtained standard education of AD documents, their overall AD knowledge has largely increased. More than 80% have realized how insufficient their knowledge was in this area, and what they learned the most were reportedly the distinctions among various types of ADs, the purpose and timing to execute an AD document, and the fact that ADs could be updated. The interviews also have motivated them to search additional AD information, learn more from others who knew better, seek for attorneys or health care professionals, initiate discussions or leave verbal LST directives to families, and even go further to complete AD documents.

With better knowledge, interviewees seemed to become more interested in ADs—the idea of ADs was believed to a) benefit their EOL, b) help decrease children's burdens in care-giving and decision-making, and c) increase the quality of death. Many who just learned about ADs shared they favored the idea of appointing DOPA, instead of an autonomous LST decision made by self. What elderly Chinese valued the most were family involvement and flexibility during EOL decision-making.

3) **Qualitative results: Knowledge regarding advance care planning as a continuous decision-making and communication process**

The idea of advance care planning was not prevalent among elderly interviewees: no one was familiar with the Chinese term 預立護理計畫 (used in California and Canada) and only 17.85% (n= 5) have heard the English term from the public media (commercial advertisement flyers), not from any health care professionals, family or social network. One physician commented, “Not every medical doctor knows about this planning...and I am sure 99% of the Chinese patients would not get this information from their family doctors.” The most knowledgeable elderly subject (out of 28 interviewees) actually has participated in a seminar related to advance care planning.

As anticipated, subjects who have never exposed to this term were unable to properly define advance care planning. Their incorrect surmises of this health care option were not any different from those who have heard but misunderstood it (Table 37). Both English and Chinese terminologies of

advance care planning were considered “vague,” “misleading,” “troublesome,” and “confusing.” The poor (verbatim) Chinese term/translation (預立護理計畫) has made it difficult to relate to a planning for EOL treatment and care. The intention to avoid words of “death” or “terminal,” however, was understood. Almost all subjects believed if the term was made more clear and straightforward, they probably would hear about it earlier or more often. Ironically, without knowing about the term, three subjects already completed their ADs.

TABLE XXXVII
INTERVIEW SUBJECTS’ KNOWLEDGE RELATED TO ADVANCE CARE PLANNING

Interviewees	Advance directives	Source	Definition
17.85% (n= 5) have heard the term	80% (n= 4) completed	Advertisement mails/flyers from: (2) Lawyers’ offices (1) Life insurance company (1) Nursing home (1) Hospital seminar	60% (n= 3) were incorrect and their surmises included: living trusts, long-term care plans, a plan for general physical care, Medicare, wills, or the plan to select an EOL care facility, such as a hospice
82.15% (n= 23) have never heard the term before, neither in English or Chinese	13% (n= 3) completed	First heard from this study. Reasons they believed were: (19) no such thing existed in their original Chinese countries (2) insufficient English (1) isolated from the “outside” world (1) illiteracy	100% (n= 23) were incorrect; they mistook advance care planning for: funeral arrangement, a nursing home contract, a type of nursing care plan, a plan to get living wills, financial and saving plan for EOL, home care, a plan to get nursing assistant at the EOL, and something related to living trust

After obtaining basic education about advance care planning, more than 82% first learned that this planning, as a continuous decision-making process, was specific about EOL treatment and care. Many were motivated to learn more before committing to this planning, and two knowledgeable actioners wished they had learned this much before signing their ADs. Along with subjects’ increased knowledge was a greater endorsement for advance care planning—it was considered as meaningful and important as financial or funeral planning.

Still, questions were raised about the cultural applicability of this fairly American idea for Chinese and a necessity to make a distinction between ADs and advance care planning. Some (<80 years old, n=6) commented advance care planning was only for the very old or actively dying, not for them at this point in time. Overall, unknowledgeable subjects agreed that a lack of advance care planning awareness led to a relatively low readiness.

For those five subjects who claimed having some basic understanding about advance care planning, their knowledge was found quite questionable as well (Table 37). Subjects who misunderstood commented that the phrase of “advance care” was vague, and their misapprehension might come from the confusing English term or Chinese translation. Only two subjects (40%) were able to correctly define it—one of them signed his living will one year ago from an EOL seminar (hosted by a medical center) and the other one recently read a pamphlet from her husband’s nursing home (but was still indecisive about her own AD). Both of them admitted that knowing about the term did not necessarily facilitate their AD completion, and not all of them were prepared to discuss personal EOL decisions.

d. Chinese Americans’ previous end-of-life (EOL) experiences

1) Measuring previous EOL related experiences

Chinese American subjects were mostly EOL inexperienced (mean= .27, SD= .60). Only 6 (2.9%) were experienced in all three categories, and the majority had never had life-threatening illnesses (or accidents) (83.5%) or stayed in ICU (90%) before. Experiences about their terminally ill family member(s) have contributed most to the overall EOL experiences that more than two thirds reported at least one of their family were once life-threatened (Table 38). While 53% have taken care of terminally ill families, only less than 30% have participated in discussions related to EOL treatment. The correlation results showed that these EOL experiences were quite independent from each other, and all types of EOL experiences were not significant correlates of decisional balance and self-efficacy for advance care planning (Table 40). All EOL related experiences were not significantly related to most factors or demographical variables proposed in the study.

TABLE XXXVIII
DESCRIPTIVES AND FREQUENCY OF EOL EXPERIENCE ITEMS (n= 206)

Questions	n	%	Mean/ Median	Std. Dev	Min	Max
1. I have had a life-threatening illness (or accident) before	206		.17/0	.372	0	1
No. Never.	172	83.5%				
Yes, I have.	34	16.5%				
2. I have been a patient in the intensive care unit (ICU)	206		.11/0	.310	0	1
No. Never.	184	89.3%				
Yes, I have.	22	10.7%				
Self EOL experience (subscale scores)	206		.27	.596	0	2
3. One of my very close family members has had life-threatening illness (or accident)	206		.66/1	.473	0	1
No. Never.	69	33.5%				
Yes, I have.	137	66.5%				
4. One of my very close family members has stayed in ICU.	206		.60/1	.491	0	1
No. Never.	82	39.8%				
Yes, I have.	124	60.2%				
Family EOL experience (subscale scores)	206		1.27	.862	0	2
5. I have taken care of a dying family member	206		.47/0	.499	0	1
No. Never.	109	52.9%				
Yes, I have.	97	47.1%				
6. I have participated in discussions regarding life-sustaining treatment for a very close family member	206		.30/0	.458	0	1
No. Never.	145	70.4%				
Yes, I have.	61	29.6%				
Family care-giving experience (subscale scores)	206	206	.77	.846	0	2
<u>Overall previous EOL experience (total scores= 0~6)</u>	206		2.30	1.62	0	6

TABLE XXXIX
CORRELATIONS BETWEEN EACH EXPERIENCE ITEM AND STAGE OF READINESS VARIABLES

Questions	Self-EOL experience ^a	Family-EOL experience ^a	Family caregiving experience ^a	Overall EOL experience ^a	AD completion ^b	6 Stage of readiness ^c	2 Stage of readiness ^b
1. I have had a life-threatening illness or accident.	.897**	.151*	.107	.466**	.121	-.023	.003
2. I have been a patient in the intensive care unit (ICU).	.847**	.222**	.133	.499**	.047	.025	.055
Self-EOL experience	1	.209**	.136	.550**	-.081	.029	.030
3. One of my very close family members has had life-threatening illness or accident.	.169*	.890**	.243**	.663**	-.100	.162*	.161*
4. One of my very close family members has stayed in ICU.	.205**	.898**	.316**	.719**	-.064	.116	.128
Family-EOL experience	.209**	1	.313**	.773**	.006	.15*	.161*
5. I have taken care of a dying family member.	.108	.340**	.894**	.688**	-.065	.124	.144*
6. I have participated in discussions regarding life-sustaining treatment for a very close family member.	.133	.207**	.872**	.614**	.147*	.131	.122
Family-caregiving experience	.136	.313**	1	.739**	.097	.145*	.152*
Overall previous EOL experience	.550**	.773**	.739**	1	.024	.164*	.176*

a. Pearson's r ($n = 206$), b. Point-biserial's r_{pb} ($n = 206$), c. Spearman's ρ ($n = 206$);

** Correlation is significant at the 0.01 level

* Correlation is significant at the 0.05 level (2-tailed)

TABLE XXXX
CORRELATIONS BETWEEN TYPES OF EOL EXPERIENCE AND OUTCOME VARIABLES

Questions	ACP Endorsement ^a	ACP concerns ^a	Decisional Balance ^a	Self -efficacy ^b
Overall previous EOL experiences	-.172*	-.087	-.198**	-.098
Self-EOL experiences	-.062	-.025	-.070	.005
Family-EOL experiences	-.167*	-.083	-.187**	-.063
Family-Caregiving experiences	-.116	-.064	-.139*	-.131

a. Pearson's r (n= 206), b. Pearson's r (n= 170)

** Correlation is significant at the 0.01 level (2-tailed); * Correlation is significant at the 0.05 level (2-tailed)

2) **Qualitative results: Previous life-threatening experience of self**

The majority (67.85%) had no life-threatening illnesses, medical crises or accidents before their interviews; their (relatively good) health status was described “still lucky,” “in good shape,” or “as strong as a bull.” Many therefore reported no urgent needs to pay attention to issues related to EOL or deaths, and this was why advance care planning was never taken seriously.

On the other hand, the remaining 32.2% (n= 9) have been life-threatened or stayed in the ICU before. Undergoing severe illnesses (e.g. malaria, various types of cancers, and tumors in major organs), multiple surgeries, chemotherapies, car accidents, even resuscitations, these survivors once felt death was dreadfully real, yet they were never completely overwhelmed or entirely hopeless. When they were given the medical bad news, they felt they were forced to face death, and the first thing came to mind was not themselves but their family, in particular children. For these subjects, personal life-threatening events (or in their terms, “close to death” and “pass through death” experiences) have generally facilitated a re-evaluation of life priorities. Often thought were the decreased days left in the world, the dying process, an unknown world after death, and possible burdens brought to the rest of the family. Some were motivated to draft general wills (n= 5) or triggered to consider discussing their own deaths with others (n= 7), but only four successfully initiated a family conversation of an EOL topic, mostly casual talks about a LST preference (not being kept alive if becoming vegetative) and the financial decision of heritages, properties, etc.

Subjects admitted that self-EOL experiences did not necessarily promote AD completion or increase readiness for advance care planning. In fact, no subjects have heard about this health option before their life-threatening circumstances, and only a few were mentioned about ADs during their medical crises. Some remembered their family members were requested to fill out “some documents” related to resuscitations, but being the critically ill, none of them were involved in such EOL discussions. Two elderly, being aware of ADs, procrastinated as their health condition continued to improve—one cancer survivor recalled it actually took her three years to complete the AD. A physician shared that before his open-heart bypass surgery (knowing that he could plan for LST in advance), he was also uncomfortable to explicitly specify LST preferences. Instead, he gave verbal directives to appoint his wife as the legal DOPA.

3) **Qualitative results: Previous caregiving experiences related to a close dying family member**

The majority (67.85%) had (at least) one close family member (mostly referring to a parent, spouse, or child) once life-threatened, but only 42% have cared or accompanied an actively dying family. The time spent with the terminally ill was reported ranging from a few days to 12 years, and dying patients’ attitudes greatly varied—some were very calm and ready to be “taken away,” but some acted childish, dependent, irrational, and were afraid to die. This family caregiving experience was “heart-breaking,” “quite burdensome,” and both physically and psychologically “overwhelming;” many were constantly struggled whether to let go of their family, yet felt guilty and sad to do so. The majority of them (82%) reported experiencing great emotional pain during the moment their loved ones passed away, and many still vividly remembered many details.

This family related EOL experience was concluded the most influential that greatly impacted subjects’ personal LST values and death attitudes, yet not a significant dominant factor to facilitate AD completion or readiness for advance care planning. Five recalled their loved ones died relatively peaceful and fast without sufferings. This positive experience of family’s “good death” has made them

never doubt that they would also leave the world as simple and natural as their families. Many of them agreed this might be why they were unenthusiastic about advanced EOL planning. On the hand, seven shared that their close family members died from multiple aggressive resuscitations. Witnessing a close family's sufferings at his/her EOL has made them re-evaluate their LST values—most of all, their death attitudes were impacted (to question the purpose and meaning of a technology-sustained life) but this experience did not necessarily motivate subjects to plan for EOL treatment or care in advance.

4) **Qualitative results: Previous experiences of EOL treatment discussions**

Only 32.7% have been involved or participated in discussions related to their close family's EOL treatment or care, and the majority of them were the eldest or the most educated sons in the family. Two physicians who were often involved in their extended family's EOL discussions believed it was because they were "elderly male doctors" highly respected in the society. More than 90% of these subjects reported that with insufficient knowledge, they were psychologically unprepared to discuss complicated EOL issues with the dying and the physicians. They felt their family's important LST decisions were made fairly rushed with no guidance from health care providers. Even two physicians shared that their parents' EOL decisions were made without sufficient medical information; they could only trust their own instincts. Many recalled being forced to decide for their loved ones within only a few days or even a couple of hours; when facing this difficult moment, subjects described they were first shocked and confused, then felt helpless and troubled, and some were burdened by guilt.

In addition, subjects commented EOL discussions seemed to be much more difficult between parents and children than between spouses. They explained it was quite natural for husband and wife to discuss death and LST values, but for children to discuss this topic with elderly parents, special efforts were required. According to these decision-makers, only a few (14.3%) described a relatively smooth discussion and clearly remembered the LST communication with their deceased loved ones. This comparatively effortless decision-making process was because all the terminal patients have either left verbal directives (no resuscitations at the EOL) or assigned the subject(s) as their DOPA(s).

The remaining majority (67.8%) had no experiences discussing EOL related treatment or care for their family members. The geographical distance was believed as the main reason why they were not involved (or invited) in their family's (mostly parents') EOL decision-making. Trusting that the final EOL decision would be properly made by other family members who knew more details in Asian countries, they shall provide no opinions ("if not part of the care network, we had no right to speak"). Paternalism was also playing a role that many females (married to another family with a different last name) perceived less right (than their brothers) in parents' medical decision-making.

In general, LST decisions of subjects' close family were made in three circumstances where EOL related discussions were absent: 1) without knowing patients' preferences, LST was naturally initiated without giving up hopes (71.4%); 2) their beloved ones passed away because LST was not brought up as an option by physicians (25%); and 3) according to patients' previously stated values or wishes, LST was mostly withheld by the family without any further discussions (5%). One physician admitted that he always recommended LST for his Chinese patients. In fact, he himself just made a resuscitation decision for his 92-year-old mother who had a recurrent stroke. A great number of subjects also said that without the knowledge to initiate any LST discussions with the patient or health care providers, they simply followed doctors' suggestions or directions. These subjects recalled that they "sort of feeling that a LST would be futile," so they agreed to let the nature take its course. Only a few have forgone family's LST based on what they believed to be patients' preference and LST values. Compared to other subjects who initiated their family's LST, these subjects expressed a sense of relief knowing that they have made the best decision for the whole family. Among them, the majority let go of the patients due to an increased age (> 80 years); they believed their parents would agree they have lived enough.

It was worth to mention subjects' EOL discussions about tube-feeding. Five subjects have made such LST decisions for their loved ones, however, only one has personally communicated with the patient; the other four initiated tube-feeding without any prior discussion. These subjects felt being left no other choices but to initiate this LST for fear to starve the patient to death. Time has proved that

artificial hydration and nutrition, different from other LST options of resuscitations, were highly favored by the whole family.

The impact of previous EOL experiences on the readiness for advance care planning

During the interview, many had difficulties to relate previous EOL experiences to their own advance care planning. Only two (7%) agreed that being experienced might have positively increased their knowledge (and confidence) in this area, yet the majority could not make a connection between categories of EOL related experiences and an advanced planning of EOL treatment and care. On the other hand, self-EOL experience was concluded by actioners and maintainers not a direct facilitator for their AD completion, and witnessing or caring for family's death and dying also did not trigger their own EOL planning. In fact, these subjects at better stages of readiness believed it was their personality (a built-in nature) that urged them to plan things in advance. Their readiness was not majorly facilitated by previous EOL experiences.

This was not to say previous EOL experience had no influences on advance care planning at all. Many subjects shared that such experiences did arouse a thinking of their own death and dying which have provided an opportunity for them to revisit personal LST values—mostly, their close families' death and dying has brought about a realization of how fragile, unpredictable, and limited a human's life could be. Subjects then were motivated to seize the time for a general planning, not necessary related to EOL. More often than not, EOL related experiences have strengthened an existing LST value of pursuing a dignified death (without undue sufferings). Agreed was that such personal and caregiving experiences would help their LST decisions made more realistically (with less emotion involved) yet did not directly lead to advance care planning.

5. Quality of life factors related to Chinese Americans' advance care planning

a. Life satisfaction

The total QLI scores were not normally distributed (Kolmogorov-Smirnov $z = 1.73$, $p < .05$). Slightly skewed to the left (skewness = $-.93$, $SE = .17$), the mass of distribution was concentrated on the right (range = $0 \sim 30$, mean = 23.29 , median = 24 , and mode = 25), showing an overall good life-satisfaction (QOL) (mean = 23.29 , $SD = 4.07$, item-mean = $4.8 \sim 5.1$) among the Chinese American subjects. The four subscale scores, moderately to highly correlated with each other ($r = .52 \sim .78$, $p < .001$) were all highly correlated with the total QLI scores ($r = .74 \sim .93$, $p < .001$), where the highest was between overall and health and physical functioning satisfaction (HF) ($r = .983$, $p < .001$) (Table 42). The overall and sub-domain life-satisfaction were moderately associated with another two QOL related variables, physical health ($r = .36$, $p < .001$) and mental health ($r = .57$, $p < .001$). However, Chinese subjects' life-satisfaction as a whole and in the four sub-domains were not significantly related to the outcome related to readiness for advance care planning and most independent variables proposed in this study.

TABLE XXXXI
DESCRIPTIVES OF RESPONSES IN QLI-PART I (n= 206)

Subscale/total scores	Mean	Median	Std. Dev	Skewness/ SE (.169)	Kurtosis /SE(.34)	Min	Max
Overall quality of life (life-satisfaction)	23.29	24.00	4.065	-.925	.918	10	30
Health and functioning	22.83	24.00	4.637	-.947	.707	7	30
Social and economic	23.12	24.00	4.951	-.971	1.165	6	30
Psychological/spiritual	24.36	25.20	4.648	-1.246	1.569	7	30
Family	23.52	24.00	4.161	-.902	.981	9	30

TABLE XXXXII
CORRELATIONS BETWEEN QOL AND STAGE OF READINESS VARIABLES

Subscale/total scores	QOL	HF ^a	SE ^a	PS ^a	FS ^a	AD completion ^b	6 Stage of readiness ^a	2 Stage of readiness ^b
Overall QOL life-satisfaction	1	.93**	.87**	.90**	.74**	.055	.087	.026
HF	.93**	1				.028	.062	.032
SE	.87**	.70**	1			.055	.089	.013
PS	.90**	.78**	.75**	1		.053	.043	.025
FS	.74**	.60**	.62**	.56**	1	.089	.054	.015

a. Pearson's r ($n=206$), b. Point-biserial's r_{pb} ($n=206$), c. Spearman's ρ ($n=206$)

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

* Correlation is significant at the 0.05 level (2-tailed).

TABLE XXXXII
CORRELATIONS BETWEEN QOL AND STAGE OF READINESS VARIABLES (Cont.)

Subscale/total scores	ACP Endorsement ^a	ACP Concerns ^a	Decisional Balance ^a	Self-efficacy ^b
Overall life-satisfaction ($n=206$)	.019	-.187**	-.129	-.085
Health Function (HF)	-.011	-.186**	-.146*	-.059
Socio-Economic (SE)	.023	-.189**	-.124	-.041
Psycho-Social (PS)	.004	-.164*	-.122	-.078
Family Satisfaction (FS)	.104	-.085	.000	-.165*

a. Pearson's r ($n=206$), b. Pearson's r ($n=170$)

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

* Correlation is significant at the 0.05 level (2-tailed).

b. General physical and mental health status

The interpretation of Chinese American subjects' general health status was made by comparing norm-based statistics of the eight scores and two component summaries of the SF-12 scores (Table 43). Compared with the 1998 healthy U.S. population (norms of no chronic condition), Chinese subjects' overall physical and mental health were generally poorer (mean= 48.02/SD= 9.32 and mean= 48.29/SD= 8.66, respectively). Also subjects' were physically healthier yet mentally poorer compared to people similar to their age in the 1998 U.S. population (55 ~ 64 and 65 ~ 74 years old). PCS and MCS, as anticipated, were not significantly correlating with each other, because the factor-scoring coefficients (weights) used in the algorithm to estimate both health summaries were orthogonal (uncorrelated). Our data showed that each domain was highly correlated to its corresponding physical or mental component summaries ($r=.73 \sim .83$ and $.62 \sim .87$ respectively, $p<.001$) (Table 44).

TABLE XXXXIII
DESCRIPTIVE STATISTICS IN EIGHT HEALTH DOMAINS AND TWO SUMMARY SCALES
COMPARED WITH 1998 U.S. NORMS BY AGE (n=206)

SF-12 (no total score)	Mean (min/max)	Mean of no chronic conditions	Mean of age 55-64	Mean of age 65-74	Median	Std. Dev
PF	49.29 (22.11/56.47)	54.25	47.61	44.87	56.47	9.86
RP	45.17 (20.32/57.18)	54.61	48.26	45.28	47.96	9.42
BP	50.52 (16.68/57.44)	54.62	48.79	47.97	57.44	9.08
GH	44.58 (18.87/61.99)	55.05	48.27	46.72	44.74	12.44
VT	54.39 (27.62/67.88)	54.19	50.21	50.10	57.81	8.02
SF	45.73 (16.18/56.57)	53.59	49.93	50.27	46.47	9.03
RE	42.89 (11.35/56.08)	53.49	49.83	48.34	44.90	10.03
MH	51.43 (27.97/64.54)	53.37	51.40	52.60	52.35	8.22
2 component summaries						
PCS	48.02 (19.65/62.84)	54.30	46.90	43.93	50.79	9.32
MCS	48.29 (20.55/67.40)	52.29	50.84	51.57	48.18	8.66

Results of the correlation coefficients (Spearman's rho and Point-biserial's rpb) indicated that none of the general health domains and component summaries was significantly correlated with outcome variables for advance care planning. In addition, neither PCS nor MCS was found to associate with cultural beliefs, overall knowledge and EOL experience, and spiritual factors for advance care planning, except that physically healthier subjects were weakly associated with a better level of English proficiency ($r = .30$, $p < .001$).

Both PCS and MCS were moderately to highly related to the overall life-satisfaction ($r = .36$ and $.57$, $p < .001$). Physically and mentally healthier subjects, as anticipated, were associated with a better satisfaction in their health and functioning ($r = .48$ and $.56$, $p < .001$). Physical health was found irrelevant only to life-satisfaction in the family domain, and it was moderately associated with age in a negative relationship ($r = -.45$, $p < .001$) and weakly associated with employment ($rpb = .37$, $p < .001$), education and income in a positive relationship ($\rho = .25$ and $.33$, $p < .001$). Mentally health was moderately and positively correlated with psycho-spiritual life-satisfaction ($r = .54$, $p < .001$).

TABLE XXXXIV
CORRELATIONS BETWEEN PAIRS SF-12 SCALES AND VARIABLES RELATED TO THE OUTCOME

Summary scores	PCS ^a	MCS ^a	AD completion ^b	6 Stage of readiness ^c	2 Stage of readiness ^b	ACP Endorsement ^a	ACP Concerns ^a	Decisional Balance ^a	Self-efficacy ^d
PF	.83**	.16*	-.14*	-.13	-.15*	.05	.05	.07	-.13
RP	.73**	.44**	-.04	-.06	-.08	-.02	-.12	-.08	.02
BP	.72**	.25**	-.07	-.01	.01	.07	-.10	-.01	-.01
GH	.73**	.30**	-.00	.01	.02	.06	-.12	-.05	.04
VT	.47**	.62**	-.06	-.06	-.05	.12	-.08	.03	-.00
SF	.45*	.69**	.01	.05	.04	-.01	-.12	-.09	.04
RE	.40**	.81**	-.04	.05	.03	.02	-.21**	-.13	-.02
MH	.125	.87**	.00	.06	.06	-.03	-.25**	-.19**	.05
PCS	1		-.09	-.07	-.11	.06	.00	.05	-.05
MCS	.08	1	.02	.11	.09	.00	-.25**	-.18*	.06

a. Pearson's r (n= 206), b. Point-biserial's rpb (n= 206), c. Spearman's rho (n= 206), d. Pearson's r (n= 170),

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

* Correlation is significant at the 0.05 level (2-tailed).

5. **Spirituality factors related to Chinese Americans' advance care planning**

a. **Qualitative results: Chinese immigrants' religious beliefs and practices**

TABLE XXXXV

RELIGIOUS BELIEFS AND PRACTICES IN THE ORIGINAL AND CURRENT FAMILIES

Interview subjects	Previous (parents') religious beliefs & practices
61% (n= 17) were raised in a Chinese/Taiwanese family of traditional folklore religions, Taoism, or Buddhism	<ul style="list-style-type: none"> - Worshipped multiple Gods (beings with divine natures), such as stones, trees, and humans in the folklore religions, and Buddhism - Burnt incenses, chanted, and kneeled down to venerate, feed, and pray to idolized Gods, ghosts, and ancestors in long-hour ceremony Practicing Taoism, some have been devoted by parents to be Gods' foster sons (n= 6) in order to survive critical illnesses and medical crises - The whole family has donated money to monks, nouns, and temples. - Fasted on religious holidays
21.4% grew up in the Catholics (n= 1) and Protestant (n= 5) culture	<ul style="list-style-type: none"> - They had no clues about Chinese traditional religions or practices - Still had regular weekly attendance of church services or Sunday schools
17.85% said their parents had no particular religions (n= 2) or were atheists (n= 3)	<ul style="list-style-type: none"> - Since religion was not an important aspect of life, no religious rituals were performed, including ancestor veneration - Subjects were educated to passively treat matters of life and death - Chinese death taboo was believed a mere superstition - Buddhist beliefs of karma, after (next) life and transmigration were fallacies - Believed in God's saving faith, believed in Father, Son, the holy spirits, and angels, many forms of Satan in this world
89.2% (n= 25) were now self-identified Catholic or Protestant Christians	<ul style="list-style-type: none"> - Practices: praying for self and others, constant reading bible scriptures, attending bible studies, church activities, serving in the religious community, celebrating on religious holidays, continuously searching for truths and trusted in God, seriously devoting themselves for meaningful things God planned for them to achieve - Spiritual benefits: being comforted by meditations and prayers, many were not afraid of death and believed that God would prepare a place afterwards
11% (n= 3) had no particular religions	<ul style="list-style-type: none"> - Raised in families of traditional folklore religions yet were not serious Taoist or Buddhist believers; had no interest in Christianity - Religions were all the same which eventually led to good acts—without knowing what exactly to believe, they believed in everything. - Religion has no importance in life, so no religious rituals were performed, including ancestor veneration
17.85% were atheists (n= 5)	<ul style="list-style-type: none"> - Subjects were educated to passively treat matters of life and death - Chinese death taboo was a mere superstition and Buddhist beliefs of after (next) life and transmigration were fallacies

TABLE XXXXVI
INTERVIEW SUBJECTS' REASONS TO CHANGE THEIR RELIGION IN THE STAGES

Subjects	Frequency & facilitators of religion change
25% (n= 7) have never changed their religion	<ul style="list-style-type: none"> - Subjects who have never changed their religions preference were Protestants (n= 5) and no particular religion believers (n= 2) - Immigration has never influenced their preference for religions - Living in the States, however, was agreed as an important facilitator for most Chinese to convert to Christianity, because of the great influence of American culture and Chinese immigrant churches - One Catholic believer converted to “no particular religion” because this religion gradually had no impact on her life - A total of 20 subjects who used to believe in Chinese folklore religions, Atheism, or had no religion preferences have converted to Protestant Christians in the States - 10 were influenced by Christian families and friends: they have been constantly receiving love and support from Christian family members and the religious community; reportedly this religion and the religious network have helped and comforted them during hardships, such as financial crises and critical illnesses - 4 admitted their initial motivation to go to church was to socialize and “see other Chinese faces.” However, they gradually identified themselves with Christianity and subsequently confirmed this faith by baptisms; all of them were the first Christian in their families - 6 self-described them as active seekers of Christianity after immigrating to the States: the American mainstream Christian culture was key why they became interested in and convinced by Christianity (“I have found what I have long been looking for”). All of them were the first Christians in their families and three have received religious pressures from their families - They commented what they used to worship were “idols and creatures” deserving no reverence; their previous religious practices were reported providing them little or no spiritual outcomes
75% have converted to Christianity (n= 20) or no particular religion (n= 1)	

Although nearly 90% during the interviews self-identified themselves Catholic or Protestant Christians, they were raised by parents of various relations (Table 45). Among them, nearly 75% have converted their religions from Chinese/Taiwanese religions to Christianity after immigrating to the States (Table 46). Almost all subjects admitted the immeasurable and subconscious influence of childhood religions on their death and dying views, and the majority reported being imbued in a Chinese tradition of venerating and fearing multiple Gods and ancestors.

b. **Measuring spirituality: System of beliefs**

The SBI-15R total scores were not normally distributed among Chinese American subjects that the mass of distribution was concentrated on the right (item-mean= 2.5~2.75, range= 3 ~ 45, mean= 39.9, SD= 6.72) with a peak (kurtosis= 9.9, SE= .34) and extremely skewed to the left (skewness = -2.6, SE= .17), suggesting subjects had a relatively high overall spirituality (Table 47). Spiritual beliefs and practice (BP) (mean= 26.9, SD= 4.51) were rated by subjects better than perceived social support (SS) from the spiritual community (mean= 13, SD= 2.54). Table 48 shows the correlation coefficients (Pearson's r , Spearman's ρ and Point-biserial's r_{pb}) between pairs of SIB-15R total/subscale scores, subjects' completion of advance directives, and stages of readiness (both ordinal and dichotomous scales). Both SBI-15R subscale scores, highly correlated with each other ($r = .81$, $p < .001$), have highly correlated with the total SIB-15R scores ($r = .98$ and $.92$, $P < .001$) as well. Subjects who scored higher on spiritual beliefs and practice were related to a better spirituality, so Chinese subjects' needs and religious emphasis seemed to be placed on the intrinsic rather than extrinsic spirituality. None of subjects' overall or sub-domain spirituality was associated with AD completion, both ordinal and dichotomous stages of readiness, endorsement or concerns, and self-efficacy for advance care planning. Only three cultural factors and two demographical characteristics were significantly correlated with spirituality but the strength was quite weak.

TABLE XXXXVII
DESCRIPTIVES OF RESPONSES IN SBI-15R (n= 206)

Subscale/total scores	Mean	Median	Std. Dev	Skewness/ SE (.169)	Kurtosis /SE(.34)	Min	Max
Overall system of beliefs	39.90	42.00	6.72	-2.60	9.89	3	45
Spiritual beliefs and practice	26.90	29	4.51	-2.61	9.44	2	30
Spiritual social support	13	14	2.54	-2.11	6.24	1	15

TABLE XXXXVIII
CORRELATIONS AMONG SPIRITUALITY AND STAGE OF READINESS VARIABLES

Scores	System of beliefs	BP ^a	AD completion ^b	6 Stages of readiness ^a	2 Stages of readiness ^b	ACP Endorsement ^a	ACP Concerns ^a	Decisional Balance ^a	Self-efficacy ^c
Overall spirituality	1		-.066	-.036	.018	-.029	.025	-.018	-.150
BP	.98**	1	-.059	-.040	.024	-.054	.027	-.031	-.142
SS	.92**	.81**	-.070	-.025	.005	-.013	.023	-.009	-.141

a. Pearson's r (n= 206), b. Point-biserial's rpb (n= 206), c. Pearson's r (n= 170)

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

* Correlation is significant at the 0.05 level (2-tailed).

c. Religiosity

1) Chinese Americans' self-rated religiosity

The non-normal distribution of the total scores (range= 2~11, mean= 8.72, SD= 1.81), revealed a fairly high self-rated religiosity (a high level of piety 虔誠). Most subjects were regular attendants of their religious activities with a frequency of “more than twice a week” (mean= 5.2, SD= .1.18); the majority have perceived themselves “moderately to highly pious” (mean= 3.53, SD= .92). Subjects' overall self-rated religiosity was not a correlate of outcome variables related to advance care planning (Table 49). It was worth noting that although self-rated religiosity moderately correlated with spirituality ($r = .54, p < .001$), they were in fact two dissimilar concepts, which explained why self-rated religiosity correlated with factors different from correlates of spirituality. Similar to findings of spirituality, the level of self-rated religiosity was not significantly associated with knowledge for advance care planning, previous EOL related experiences, or general health status.

TABLE XXXIX
DESCRIPTIVES OF SELF-RATED RELIGIOSITY SCORES (n= 206)

Scores	Mean	Median	Std. Dev	Skewness/ SE (.169)	Kurtosis /SE(.34)	Min	Max
Self-rated religiosity	8.72	9.0	1.81	-1.20	1.41	2	11
1. How often do you participate in your religious activities?	5.19	6	1.18	-1.62	-2.25	1	7
2. How pious are you compared to other people in your religion?	3.53	3.53	.92			1	5

TABLE XXXX
CORRELATIONS BETWEEN SELF-RATED RELIGIOSITY AND OUTCOME VARIABLES

Variable	AD completion	6 Stage of readiness	2 Stage of readiness	ACP Endorsement	ACP Concerns	Decisional balance	Self -efficacy
Self-rated religiosity (total scores n= 206))	-.054	.095	.086	-.115	-.091	-.155*	-.198**
Frequency of religious activity participation	-.095 ^a	.065 ^b	.072 ^a	-.118 ^c	-.045 ^c	-.132 ^c	-.205** ^d
Self-rated piety compared to other people in the same religion	.014 ^a	.107 ^b	.078 ^a	-.075 ^c	-.122 ^c	-.137* ^c	-.126 ^d

a. Point-biserial's rpb (n= 205), b. Spearman's rho (n= 205), c. n= 205, d. n= 169

**Pearson's correlation is significant at the 0.05 level (2-tailed).

*Pearson's correlation is significant at the 0.05 level (2-tailed).

2) **Qualitative results: Chinese immigrants' religiosity related to advance care planning**

(a) **Chinese Christians' religious views on death and dying**

Most elderly subjects' death and dying views rested largely on spiritual roots of Protestant Christianity. Although there was some diversity in the ways in which faith was interpreted and expressed, a number of shared perceptions were apparent across these Christian subjects: 1) a common belief of eternal life and a psychological preparation for death, 2) the sovereignty of God over life, 3) a positive attitude toward death and relating discussions, and 4) humans' responsibility of stewardship and an endorsement to forgo futile LST when life becomes unworthy to continue (Table 51). These fundamental beliefs have shaped Chinese subjects' EOL treatment values and influence their attitude toward advance care planning.

(b) **Taoist and Buddhist subjects' religious views on death and dying**

The group of non-Christians (11%), including one atheist and two folklore religion believers, were comparatively less serious about religion(s). A total of 18 Christian subjects (64%) have revisited their former beliefs of Chinese religions and commented that they were little influenced by their parents' traditional religions. Also many recollected no peace or joy through former Buddhist or Taoist practices. Only one subject, also a fatalism believer, said when his son was critically ill he has once received spiritual comfort from worshiping Taoist Gods.

According to these non-Christians and former Chinese religion believers, more than 60% were (or used to be) very afraid of death while residing in Asia. Ghost veneration and funeral related chanting and rituals might have sowed the seeds of fear in their childhoods. Death was usually connected to negative feelings and painful experiences, such as corpses, a suffering dying process, deceased families, and the unknown afterlife; so culturally anything related to death was a possible arousal of resentful feelings. In addition, death topics normally lead to uncomfortable and unpleasant breakup on bad terms in social relationships, which in Chinese culture were regarded mostly unnecessary and impolite.

3) **The religious influence on Chinese Americans' advance care planning**

During the interviews, it was apparent that Christian subjects were comparatively more hopeful and less fearful than non-Christians when discussing EOL issues. Generally reflected was that Protestant beliefs and practices have shaped these subjects' values and optimized their attitude toward death and dying. However, this religion was concluded not a direct facilitator to increase elderly Chinese subjects' willingness or readiness for advance care planning. According to actioners and maintainers, their intention to initiate, execute, and maintain advance care planning was mostly from a consideration of family's burdens and the pursuit of desired death, irrespective of religions.

TABLE XXXXXI
CHRISTIAN INTERVIEW SUBJECTS' RELIGIOUS VIEWS ON DEATH AND DYING

Christian beliefs	Impacts on elderly Chinese Americans' death views
A common belief of eternal life and a psychological preparation for death	<ul style="list-style-type: none"> - More than 70% (n= 20), regarded death as a natural part of life, were prepared to die anytime - All Christians (n= 25) believed in an eternal life to be with God - Many stated that their religious belief would be a source of strength when approaching death in the future - Eight felt more spirited facing death after converting to Christianity (this courage was from God's promises and blessed assurance) - Being prepared to die without fear was generally evaluated as "a good testimony" of genuine Christians, in particular for their non-Christian families and friends
The sovereignty of God over life (related to a destined length of life)	<ul style="list-style-type: none"> - All Christians (n= 25) reportedly worried little about their health and death, given that God would be in control of their future - Praying has brought them peace and strength in the past when encountering previous threats from terminal illnesses, uncomfortable treatments, and death - Agreed was that God has an ultimate plan and timing to die for each one - Several Christians who held this fatalistic belief ("God has already determined how our life would end") preferred to authorize their family to make their future LST decisions.
The Christian attitude toward death and relating discussions,	<ul style="list-style-type: none"> - All 25 Christian subjects were able to freely talk about their own (or other people's) death and dying - All of them credited this openness (of death topics) to a positive Christian attitude toward death: it was superstitious to believe that discussing death would lead to a foreseeable, hastened death - More than half (n= 12) of these Christian subjects used the term "God's grace" or "very blessed" to describe prior spiritual experiences through severe illnesses or medical crises - All were open-minded about planning for death
Humans' responsibility of stewardship	<ul style="list-style-type: none"> - The majority were not interested in and some even opposed the idea of mercy killing and euthanasia - Many (n=17) believed part of one's value of life was on the basis of his/her capability to provide service in the religious community - All Christians (n=25) agreed if they could no longer glorify God (as good testimonies), life was unworthy or meaningless to continue; in this case, almost all endorsed forgoing futile and burdensome LST - The majority of Christians, therefore, favored an advanced decision to prevent unnecessary sufferings caused by aggressive EOL treatment

In contrast, beliefs and practices of Atheism and Chinese traditional religions seemed to negatively influence subjects' readiness for advance care planning. Non-Christians in this study, generally passive about religions, were less interested in topics of death and dying. Former Atheists, Taoists, and Buddhists (n= 23) also agreed that Chinese folklore religions have brought about an avoidance or fear of death or the afterlife. These now-Christian subjects commented that reluctance and avoidance of death and dying (originated from culture, religion, or both) did exist among elderly Chinese, in particular non-Christians, which have possibly inhibited their readiness advance care planning.

In terms of the spiritual foundations in advance care planning, Chinese traditional religions provided no guidance. All Protestant and Catholic subjects agreed that this planning was not seriously conflicting with their Christian beliefs (but euthanasia and suicide did), and the occurrence of illness and one's life expectancy were incontrollable and unaffected by any planning. Even with this shared perception, subjects' interpretations and readiness for advance care planning varied—two required more time to double-check with their pastors or in the bible, four were not completely sure if an advanced EOL planning would contrast God's authority, but the majority (n=16) have found spiritual roots to endorse this health care option. These Christians (n=14) agreed that their preference to forgo LST, based on a pursuit of dignified and suffering-less death, was supported by the Christian doctrine.

7. **Demographic variables**

a. **Age**

The total of 206 subjects had a mean age of 60 years old (range= 45-93, mean= 59.51, median= 58.5, SD= 10.09). Age is surprisingly a very weak positive correlate of both ordinal and dichotomous stage of readiness ($\rho = .14$ and $\phi = .16$, $p < .05$), and it was not related to AD completion, endorsement and concerns, overall decisional balance and self-efficacy for advance care planning (Table 13). Negatively and moderately associated with the general health ($r = -.45$, $p < .001$), age also was not associated with cultural factors, knowledge and overall EOL experiences, QOL and spiritual factors related to advanced EOL planning as well.

b. **Gender**

Amongst those who reported their gender (n= 203), approximately 60% were females (n= 124). Results have shown no gender differences in subjects' AD completion, stage of readiness (both ordinal and dichotomous scales), endorsement and concerns, overall decisional balance and self-efficacy for advance care planning. Gender seemed to be unrelated to most proposed factors in this study, such as cultural beliefs, knowledge and previous EOL experiences for advance care planning, life-satisfaction and general health status, and spiritual factors.

c. **Marital status**

To our surprise, almost all reported their marital status (n= 204) despite this question might be culturally interpreted very private. Since the majority (77%) was in a marriage or lived with a life-partner, this variable was later re-coded into a dichotomous variable of "spouse/life-partner (1= married/partnered)." Pearson's chi-square and correlation results (Table 13) showed that whether having a spouse (with and without a life-partner) was unrelated to AD completion, stage of readiness (both ordinal and dichotomous scales), endorsement and concerns, and overall decisional balance for advance care planning.

d. **Numbers of parents alive**

Among the total 204 subject who answered this question, more than half (56.3%, n= 116) reported both of their parents have passed away, opposed to 15.5% had both parents alive. The number (of parent alive), highly correlated with age in a negative relationship ($\rho = -.59$, $p < .001$), was not associated with any outcome variables related to advance care planning.

e. **Levels of education and income**

These two variables have long been discussed together as they were commonly interrelated with each other and viewed as indicators of one's socio-economic status (SES). As mentioned previously, while all other demographical questions were responded with less than 2% missing, 11% (n= 23) of the total sample intentionally left their annual income unanswered. Chinese

American subjects in this study were highly educated and earned a fairly high annual income: approximately 67% were Master's (degree) prepared (34.6% even had a doctoral degree), and one thirds had an annual income higher than \$100,000 U.S. dollars per year.

As anticipated, both education and income moderately correlated with each other ($\rho = .49$, $p < .001$), yet neither of them was a correlate of subjects' AD completion, stage of readiness (both ordinal and dichotomous scales), endorsement and concerns, decisional balance and self-efficacy for advance care planning (Table 13). Results have indicated that Chinese American subjects with better SES were moderately to highly associated with a better level of English proficiency ($\rho = .58$ and $.43$, $p < .001$) and acculturation ($r = .51$ and $.38$, $p < .001$) and weakly to moderately associated with overall knowledge ($\rho = .28$ and $.34$, $p < .001$), life-satisfaction ($\rho = .25$ and $.29$, $p < .001$), and physical health ($\rho = .28$ and $.35$, $p < .001$). More specifically, both education and income were significantly correlated with knowledge subscales of LST and ADs. However, SES was shown unrelated to specific knowledge about advance care planning. This might be because subjects' knowledge of advance care planning was extremely poor across various SES levels. Less wealthy subjects seemed to be weakly related with more self-EOL circumstances ($\rho = -.23$, $p < .001$), irrespective of their highest level of education.

f. **Employment status**

All but two subjects ($n = 204$) have reported their employment status. Only 47.6% of the sample was currently employed and others were retired ($n = 53$, 26%), unemployed ($n = 11$, 5.4%), house-wives ($n = 20$, 9.8%), or others ($n = 23$, 11.3%). The results showed that employment was not a correlate of any variables related to outcome readiness for advance care planning.

g. **Raised (parents') religion**

All subjects have reported their parents' religions ($n = 206$)—approximately 43% ($n = 89$) were raised in a family of Chinese traditional religions, such as Buddhism (23.3%), Taoism or Taiwanese religions (20%); nearly 30% were raised by Christian parents ($n = 60$). Although immigrants from China were mostly expected to be raised in the atheist culture, only 9.7% ($n = 20$) reported so. The

remaining said their parents either had no religious preference (16%) or believed in Muslim (1.5%) and others (n= 2, 1%). The correlation findings (Table 13) indicated that in which religion subjects were raised was unassociated with outcome variables for advance care planning.

h. **Current preferred religion**

Almost all subjects have reported their preferred religion (n= 205) at the time this study was conducted. The majority in the sample (80.6%) were Christians and the remaining either had no religion preference (6.3%) or believed in Muslim (5.9%), Buddhism (2.4%), Taoism or Taiwanese religions (2%), others (2%), or atheism (0.5%). Results (Table 13) showed that Christianity as a factor was not significantly correlated with AD completion stage of readiness (both ordinal and dichotomous scales), endorsement and concerns, and self-efficacy for advance care planning.

i. **Religion change after immigrating to the States**

A total of 200 subjects have reported whether their religion preference has changed after immigrating to the States (0= unchanged and 1= changed), and more than half (54.5%, n= 109) have changed their religion. Subjects were not asked in the questionnaire from or to which religion they converted, but in the consequent in-depth interviews, the majority of subjects have converted to Protestant Christians after immigrating to the States.

Correlation result (Table 13) concluded that a religion change (as a result of immigration) had little to do with outcome readiness. In addition, whether subjects have changed their religion seemed to be unassociated with most factors proposed in this study.

B. Multivariate Analyses: A Logistic Binary Regression Analysis

As stated previously, the distribution in the ordinal outcome data was extremely skewed. The commonly used multiple regression analysis, therefore, became inapplicable when the normality assumption in the dependent variable was violated. A theoretically justifiable solution was provided to dichotomize the outcome variable (pp. 150) and survey subjects were categorized into two groups with the majority located at a precontemplation stage for advance care planning.

A logistic binary (binomial) regression analysis from the multivariate regression family was selected to examine the linear combination among selected independent variables and the dichotomous outcome of stage of readiness. Applying the maximum likelihood estimation, the dichotomous stage of readiness was transformed into a “logit” variable (the natural log of the odds of the outcome variable occurring or not). What predicted in this study were the odds of a behavioral change occurrence, how possible Chinese Americans would transit from a precontemplation to contemplation stage.

The logistic regression equation used in the analysis is illustrated below:

$$\text{Odds} = e^{b_0 + b_1X_1 + b_2X_2 + b_3X_3 + \dots + b_kX_k}$$

$$\text{Ln} [(\text{probability (event)} / \text{probability (non-event)})] = b_0 + b_1X_1 + b_2X_2 + b_3X_3 + \dots + b_kX_k$$

In this equation, the logit, Ln (odds) is the log odds of the dependent variable, b_0 is the constant, b terms are the logistic regression coefficients (parameter estimates), and there are k independent (X) variables. Comparable to the ordinary least square (OLS) regression, logit coefficients b corresponded to b terms in the standard regression equation, the standardized logit coefficients corresponded to beta (β) weights, and a pseudo R^2 statistic available in the logistic regression was to summarize the strength of the relationship between variables. This mathematical equation was applied in this study to a) predict the outcome, on the basis of 11 continuous (and/or categorical) independents, b) determine the percentage of variance explained by the independents, and c) rank the relative importance of independent variables. In other words, important predictors that significantly increased the likelihood ratio (LR) of readiness could be identified to facilitate Chinese Americans moving toward advanced stages.

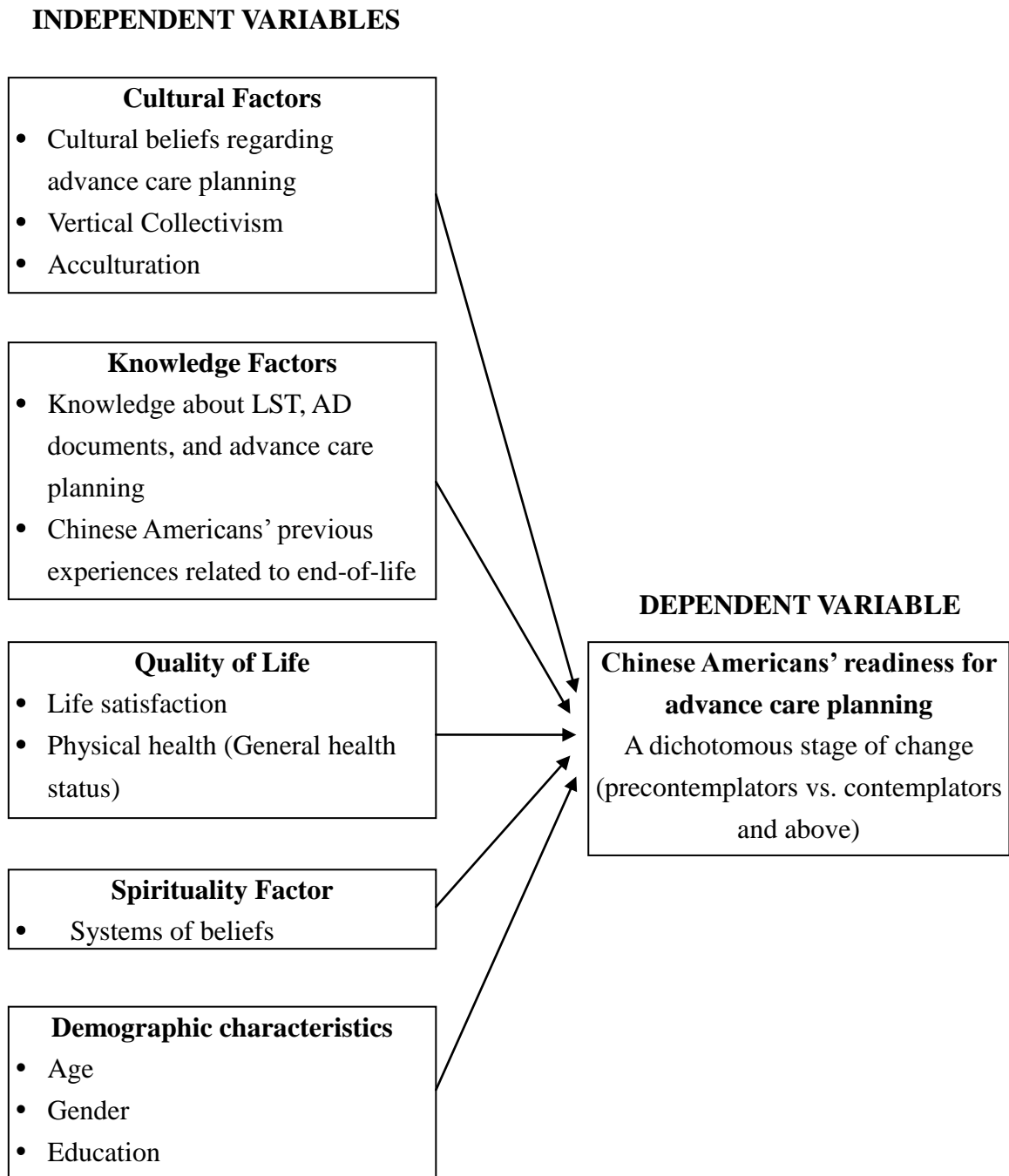


Figure 3. Independent variables and the outcome of the dichotomous stage of readiness for advance care planning in the binary logistic regression analysis

TABLE XXXXXII
CORRELATION MATRIX OF VARIABLES SLECTED IN THE BINARY REGRESSION ANALYSIS
(n= 206, unless indicated otherwise)

	Outcome	1	2	3	4	5	6	7	8	9	10
Outcome:											
Dichotomized stage of readiness											
1. Cultural beliefs	.17*	1									
2. Vertical collectivism	-0.07	.25**	1								
3. Acculturation	.13	0.12	0.04	1							
4. Knowledge	.26**	.15*	0.04	.41**	1						
5. Previous EOL experience	.18*	0.02	0.03	.18**	.25**	1					
6. Life satisfaction	0.03	.15*	0.01	.15*	.14*	-0.03	1				
7. Physical health	-0.09	0.02	0.14	.21*	.13	-.14	.36**	1			
8. System of beliefs	0.02	0.01	.27**	-0.07	0.03	0.04	0.13	-0.05	1		
9. Age	.16**	-.07	.02	-.24**	-.11	.13	-.03	-.45**	-0.01	1	
10. Gender ^a	.13	.13	.06	-0.12	-.05	.00	-.13	-.16*	0.10	-.01	1
11. Education ^b	.09	-.04	-.05	.51**	.28**	.11	.25**	.25**	-.18*	-.20**	-.37**

a. n= 203, b. n= 205

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

* Correlation is significant at the 0.05 level (2-tailed)

1. **The logistic binary regression model**

To perform a binary regression analysis, a total of 11 independent variables were selected (Figure 2) from the 24 proposed factors in the conceptual model; they were: 1) significant correlates of the outcome from preceding bivariate analyses (Table 52), 2) less problematic in terms of multicollinearity with other independents, and 3) rated important by subjects in the in-depth interviews to influence their decisions to complete advance directives. Three data-driven regression procedures were performed which were useful for the exploratory purpose of this study (standard enter LR, step-wise forward selection and backward elimination methods). Only the best regression results, a 5-predictor regression model from the backward elimination, were reported in the following section.

2. **Results from the intercept-only regression model**

A total of 202 valid cases (1.9% missing) were included in the logistic regression analysis, where precontemplators were coded 0 (as reference) and subject located at contemplation and/or stages above were coded 1. Among the 11 independent variables, only “gender” was categorical (females = 0). In the intercept-only model, the initial -2 Log Likelihood Chi-square was calculated at 244.02. Considering constant only, the predicted odds of being contemplators (and/or stages above) over precontemplators was $\text{Exp}(b_0) = e^{-.885}$ ($\text{df} = 1, p = 0.413 < .001$ (59 non-precontemplators / 143 precontemplators)). This result was suggestive that if predicting all Chinese Americans as “precontemplators,” without considering any factors, the correct probability would be as high as 70.8%.

The Rao’s efficient scores (obtained in the intercept-only model) served as important criteria for subsequent variable inclusion and/or exclusion in the following step-wise regression analyses. According to the Rao’s scores, factors were ranked in terms of their significant influences on the predictive odds. While including factors of high Rao’s efficient to the binary regression model, -2LL Chi-square would significantly drop to further increase our overall predictability. In other words,

variables with significant p-values ($p < .001$) in this study, such as overall knowledge, cultural beliefs, age, acculturation, and gender (being males) had more potential to explain the dependent variable, rather than vertical collectivism, physical health, life-satisfaction, and spirituality.

3. **Results from the best model (a step-wise backward elimination analysis)**

Starting with 11 independent variables entered, a total of seven steps were performed in the backward elimination logistic regression analysis. One particular variable would be dropped from the model at each step using Rao's efficient score as the backward elimination criterion. This procedure continued until no remaining predictor variables had a Rao's score statistic significance of .05 or higher (leading to an acceptance of the null hypothesis when coefficients were zero). As seen in Table 53, the first variable dropped from the 11-factor model was physical health, followed by system of beliefs, acculturation, vertical collectivism, life-satisfaction, and previous EOL related experience. This order also has indicated the ranked importance of factors contributing to explain the variance in the outcome: the later dropped, the more predictive.

All seven backward elimination models were insignificant in Hosmer and Lemeshow tests, suggesting a linear relationship and an overall good-fit of a binary logistic regression analysis (Table 54). Results from the Omnibus tests of model coefficients also confirmed a best model of five predictors: it had the lowest Chi-squares (35.564, $df = 5$, $p < .001$) and -2 Log Likelihood Chi-squares (208.453), the lowest Akaike Information Criterion (AIC), and the lowest Bayesian Information Criterion (BIC). Finally, the Nagelkerke R-square (Pseudo R^2) showed that these five predictors have explained about 23% of the total variance in the prediction of Chinese Americans' readiness for advance care planning.

TABLE XXXXXIII
VARIABLES ELIMINATED FROM THE MODELS

			Rao's	df	Sig.
			Score		
Step 2(a)	Variables	Physical health	.005	1	.945
	Overall Statistics		.005	1	.945
Step 3(b)	Variables	Physical health	.007	1	.934
		System of beliefs	.012	1	.914
	Overall Statistics		.016	2	.992
Step 4(c)	Variables	Acculturation	.122	1	.727
		Physical health	.005	1	.944
		System of beliefs	.007	1	.932
	Overall Statistics		.138	3	.987
Step 5(d)	Variables	Vertical collectivism	.112	1	.738
		Acculturation	.098	1	.754
		Physical health	.015	1	.901
		System of beliefs	.000	1	.999
	Overall Statistics		.251	4	.993
Step 6(e)	Variables	Vertical collectivism	.151	1	.698
		Acculturation	.072	1	.789
		Life-satisfaction	.367	1	.545
		Physical health	.128	1	.720
		System of beliefs	.006	1	.937
	Overall Statistics		.614	5	.987
Step 7(f)	Variables	Vertical collectivism	.145	1	.703
		Acculturation	.156	1	.693
		Previous EOL experience	1.044	1	.307
		Life satisfaction	.498	1	.480
		Physical health	.265	1	.607
		System of beliefs	.009	1	.926

Logistic regression coefficients (B), Wald statistic, degree of freedom, the significance of individual logistic regression coefficients, and the odds ratio (exponential) for each of the predictors are presented in Table 55. Employing a .05 criterion of significance, the final 5 predictors included: 1) knowledge related to advance care planning, 2) age, 3) gender, 4) education, and 5) cultural beliefs, in the order of their significance to increase the readiness predictability (Table 55). The logistic regression equation can be illustrated as:

$$\text{Ln (odds of being contemplators or above)} = -10.348 + .154 \text{ knowledge} + (-1.121) \text{ gender (male= 1)} + 0.402 \text{ levels of education} + 0.058 \text{ cultural belief scores} + 0.062 \text{ age}$$

TABLE XXXXXIV
STATISTICS OF THE HOSMER AND LEMESHOW TESTS AND MODEL SUMMARY OF
SEVEN STEPS IN THE BACKWARD REGRESSION ANALYSIS

Hosmer and Lemeshow				Model Summary			Omnibus Tests of Model		
Test							Coefficients		
Step	Chi-square	df	Sig.	-2 Log likelihood	Cox & Snell R-Square	Nagelkerke R- Square	Chi-square	df	Sig.
1	3.374	8	.909	206.795(a)	.168	.240	37.222 (b)	11	.000
2	3.372	8	.909	206.800(a)	.168	.240	37.217 (b)	10	.000
3	2.741	8	.950	206.812(a)	.168	.240	37.206 (b)	9	.000
4	2.096	8	.978	206.933(a)	.168	.239	37.084 (b)	8	.000
5	2.646	8	.955	207.045(a)	.167	.239	36.972 (b)	7	.000
6	4.308	8	.828	207.410(a)	.166	.236	36.607 (b)	6	.000
7	10.963	8	.204	208.453(a)	.161	.230	35.564 (b)	5	.000

a. Estimation terminated at iteration number 5 because parameter estimates changed by less than .001.

b. A negative Chi-squares value indicates that the Chi-squares value has decreased from the previous step.

TABLE XXXXXV
SUMMARY OF LOGISTIC BINARY REGRESSION ANALYSIS FOR VARIABLES PREDICTING
CHINESE AMERICANS' READINESS FOR ADVANCE CARE PLANNING

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
Constant	-10.348	2.501	17.126	1	.000	.000
1. Knowledge about advance care planning	.154	.044	12.174	1	.000	1.166
2. Age	.062	.018	11.274	1	.001	1.064
3. Gender (male)	-1.121	.425	6.941	1	.008	.326
4. Education	.402	.193	4.330	1	.037	1.495
5. Cultural beliefs	.058	.030	3.586	1	.048	1.059

When holding all other variables constant, Chinese Americans who were more knowledgeable related to advance care planning, older in their age, female, higher educated, and less traditional in terms of cultural beliefs would have better readiness for advance care planning; specifically, knowledge and education might have the most influence on stage of readiness. As predicted from this model, with a one point increase on the 16-point knowledge scale and one level up (of the 9-level highest education status), the odds of being a contemplator would increase by a multiplicative factor

of 1.17 and 1.5. Such effects from the other three predictors were relatively smaller compared to that of knowledge and levels of education—with one point increase on the year (of age) and one score increase on the cultural belief scale (possible score ranging from 13 to 72), the odds of being a non-precontemplator just slightly increased by a multiplicative factor of 1.06 each. Being males also slightly decreased the odds of advancing the stage of readiness by a multiplicative factor of .326. In other words, Chinese American females actually had a better chance to transit from the precontemplation stage to an advanced stage of readiness.

When all 11 factors were entered into the regression model (Table 56), the predictability of Chinese Americans in an advanced stage of readiness was the highest (76.7%), which was 5.9% higher than the intercept-only model (predictability= 70.8%). Using only five predictors, the suggested regression model also offered an acceptable predictability (73.3%), and sensitivity and specificity could be calculated at 30.5% (18/41+18) and 90.9% (130/130+13), respectively.

TABLE XXXXXVI
CLASSIFICATION TABLE OF THE ELEVEN- AND FIVE-PREDICTOR MODEL

Observed		Predicted		
		Precontemplators	Contemplators and above	Correct
Step 1	Precontemplators	134	9	93.7%
11 predictors	Contemplators and above	38	21	35.6%
	Overall Percentage			76.7%
Step7	Precontemplators	130	13	90.9%
5 predictors	Contemplators and above	41	18	30.5%
	Overall Percentage			73.3%

a. The cut value is at the level of .50

To conclude the regression result, a five-predictor model was suggested from the logistic binary regression analysis, using the method of stepwise backward elimination. Among the many cultural factors, vertical collectivism and acculturation have shown little influence, and only “cultural beliefs” was positive on the prediction of readiness ($p = .048$). Regarding the knowledge factors, overall knowledge related to advance care planning was found to be an important predictor for Chinese Americans to advance in their stage of readiness. Previous EOL experience, being the last factor dropped from the best model, was not conclusive to significantly influence stages of readiness. Any changes of life-satisfaction, physical health, and system of beliefs ($p < .05$) were not related to the occurring odds of Chinese Americans’ advanced stage of readiness. Last, among the three variables of demographical characteristics, the results revealed that an increase of age and education and a decrease of the gender code (from male to female) would significantly increase the predictability of a behavioral change for Chinese Americans to transit to the stage of contemplation.

C. Chinese Americans' Preferred Intervention Strategies In An Intervention Program of

Advance Care Planning

TABLE XXXXXVII
INTERVENTION STRATEGIES PREFERRED IN THE ADVANCE CARE PLANNING
INTERVENTION PROGRAM (n= 204)

Questions		Count	Percentage
1.	Please tell us would you be interested in such a program? ^a		
	Yes	157	77%
	No	47	23%
	Missing value	1	< 1%
2.	How would you prefer this program to be offered? ^a		
	Individually (one-on-one)	24	11%
	In a small group (less than 10 people)	144	70%
	In a large group (more than 10 people)	36	18%
	Missing value	2	< 1%
3.	How long would you prefer each session to last? ^b		
	No more than 1 hour	96	46.6%
	No more than 2 hours	83	40.4%
	Four hours (with a break in between)	9	4.4%
	An entire day	2	< 1%
	(more than 4 hours with breaks in between)		
	Other; none of the above	8	4%
	Missing value	6	3.9%
4.	How often would you be willing to come? ^c		
	Once a month	74	36%
	Every week	53	25.7%
	Every other week	31	15%
	Just once	17	8.3%
	Just twice	2	< 1%
	Every 3 months	2	< 1%
	Every 6 months	2	< 1%
	Don't care	2	< 1%
	Missing value	12	5.8%

a= 204, b= 200, c= 194

1. **Willingness of participation, the preferred group format, learning methods, session lengths and frequency**

Only 23% reported having no interests in the advance care planning intervention, but the majority of the survey subjects were simply too busy and had no time at this point for any health related programs. In general, this type of intervention was preferred being offered in a small group; such a format was highly expected for a productive, in-depth death and dying discussion. Each session, either monthly (36%) or weekly (26%), should take no longer than one to two hours.

2. **Persons Chinese Americans preferred to participate with in the advance care planning intervention**

To most Chinese respondents, with whom to participate in such an intervention seemed to be less of a concern (Table 58); some still preferred to participate with close family members (13%) or with acquaintances of similar backgrounds.

TABLE XXXXXVIII
PERSONS CHINESE AMERICANS PREFERRED TO PARTICIPATE WITH IN THE ADVANCE
CARE PLANNING PROGRAM (n = 200)

Options	Count	Responses	Percentage of cases
No preference	94	34.8%	47%
Strangers only	61	22.6%	30.5%
People I know of the same gender	50	18.5%	25%
Family members only	26	9.6%	13%
People I know and with similar ages	14	5.2%	7%
Nobody; self-learning	11	4.1%	5.5%
As long as I know who they are	6	2.2%	3%
Other	8	3.0%	4%
Missing	6		2.9%

3. **Learning activities and contents Chinese Americans preferred in the advance care planning intervention**

In terms of intervention program activities, the majority of Chinese subjects preferred listening to audiotapes/CDs (64%)” and a group discussion (54%), but watching videotapes/DVD

during the intervention was reportedly unattractive (1.5%). Only one fourth were interested in reading written materials (Table 59).

TABLE XXXXXIX
LEARNING ACTIVITIES CHINESE AMERICANS PREFERRED IN THE ADVANCE CARE
PLANNING PROGRAM (n = 197)

Options	Count	Responses	Percentage of cases
Audiotapes/CD	127	27%	64.5%
Group discussion	106	22.6%	53.8%
Lecture	75	16%	38.1%
Work on the computer	85	18.1%	43.1%
Read written materials	49	10.4%	25%
Videotapes/DVD	3	0.6^	1.5%
Other/None of the above	25	5.3%	12.7%

4. **Learning site/location Chinese Americans preferred in the advance care planning intervention**

A very high percentage (82%) chose their own church for such an intervention program to be held, followed by the community library (24.7%) and a health care facility (19.6%)(Table 60). In fact, about half also chose their own (or other's) houses or had no location preference, as long as the site was comfortable, quiet, and convenient to access.

TABLE XXXXXX
LEARNING SITES CHINESE AMERICANS PREFERRED IN THE ADVANCE CARE
PLANNING PROGRAM (n = 194)

Options	Count	Responses	Percentage of cases
In my church	159	56.8%	82%
In the community library	48	17.1%	24.7%
In a healthcare facility (such as hospitals or nursing homes)	38	13.6%	19.6%
In a nearby school	17	6.1%	8.8%
Other/None of the above	18	6.4%	9.3%
Missing	12		5.8%

5. **Suggestions of factors that influence Chinese Americans' willingness to participate in the advance care planning intervention**

a. **Facilitators**

Among the 105 possible responses (Table 61)(n= 101), the major facilitator was noticeably an intervention carefully designed, attractive, and resourceful in Chinese subjects' desire. In fact, more than half of the written responses were subjects' personal advice and expectations toward an advance care planning program.

TABLE XXXXXI
ADVANCE CARE PLANNING PROGRAM FACILITATORS (n= 101)

Opinions	Count	Percentage of Responses
Desired intervention characteristics	54	51.4%
Concerns about availability	24	22.9%
Participants' physical condition	11	10.5%
No comments	8	7.6%
Other	8	7.6%

Such a desirable intervention was generally described as a good lecture or seminar including a complete course agenda, an introduction about speakers' background and expertise, learning objectives, and any upcoming events. Accordingly, participation willingness would increase if the program site was close to their residence, transportation was arranged in advance, or the program was conveniently held in their local community church. The program was expected to be free of charge or inexpensive, with a friendly atmosphere, a comfortable learning environment, a feeling of mutual trust between the lecturers and participants, a respect for privacy, in a relaxing pace with no pressure of homework or forced speaking in the public. Most importantly, the program itself should include state-of-the-art information that covered advance care planning in legal, medical, and financial aspect. The lecturer or designer of this program curriculum was expected to be lawyers, physicians, or healthcare providers with expertise who were good at teaching and currently practicing in the clinical field. Many suggested analyzing real cases to avoid the program being excessively theoretical or too academic.

The second reported facilitator (22.9%) was related to a self-perceived availability, commonly described as: “when I have extra time,” “when I am not busy” or “when the time allows.” In other words, subjects’ willingness would increase if having “free (or extra) time” for a health program. For example, more than ten subjects believed they would participate “after they retire.”

The third reported facilitator (10.5%) was about Chinese Americans’ physical condition, self-perceived to be appropriate for initiating advance care planning. Many believed that their interest would increase after they became “older” or “sicker.” Some even wrote they would definitely participate in this intervention program if they were diagnosed a terminal illness or in the process to establish their wills.

b. Inhibitors

A total of 85 possible inhibitors, fewer than the facilitators, were summarized (n= 78) (Table 62); because of a lack of understanding about advance care planning, more than 62% of the survey respondents chose to leave this open-ended question unanswered. A total 18 participants (21.4% of the responses) wrote “no comments,” “no idea,” or “no advice” since they were clueless about such an intervention. The major reason reported to hinder subjects’ willingness of participation was an unwanted, pointless, or abysmal intervention program (56%). Qualitative descriptions of such an undesired or “unworthy-to-go” intervention were exactly the other extreme of characteristics mentioned in the above section (the major facilitator). Most admitted that their continuing participation was determined by the success of the first meeting—if the program seemed to be unattractive (such as unpractical, unorganized, poorly planned with no agenda introduced, or appallingly taught by unprofessional lecturers), they would participate no more.

Inhibitors of an uncomfortable environment and unfriendly atmosphere were exemplified in various situations: when their opinions were being negatively judged or commented by others, privacy was deprived in public, and death and dying was miserably depicted during the intervention, etc.

“Solicitation” was also largely mentioned as an unwanted intervention characteristic to decrease participation willingness (if this program is “trying to sell things to me,” “solely profit-earning,” or “business oriented”). Poor access to the program site (transportation inconvenience) was one of the major inhibitors frequently listed by elderly subjects who did not drive.

TABLE XXXXXXII
ADVANCE CARE PLANNING PROGRAM INHIBITORS (n= 78)

Opinions	Count	Percentage of Responses
Undesired intervention characteristics	47	56%
No comments	18	21.4%
Unavailability	13	15.5%
Participants’ physical condition	7	7%

The second and third reported inhibitors, once again, were about participants’ unavailability (15.5%) and a self-perceived physical condition (7%). Chinese Americans’ participation willingness would decrease if they perceived “no time” or “physically unaffordable” for a health intervention program. Interestingly participants’ opinions varied about what a physical condition was considered suitable for advance care planning: reportedly, “being physically and mentally healthy” would inhibit their participation, because such a planning was unnecessary at this point. However, a poor health status was also described as a situational inhibitor (“when mishaps/accidents happened,” “when I have difficulties moving around,” or “if I became too sick”).

6. Qualitative results: Interview subjects’ preferences in the intervention

a. Interview subjects’ willingness in participating in an intervention of advance care planning

Results from the in-depth interviews have corresponded to the survey result (Table 63): considering this planning important and meaningful, the majority had a desire to know more about advance care planning, were pleased to learn new information, and even had a heart to further use the information to educate families and friends. About 11% were indecisive about this health care option and they needed time to contemplate and gather more information before making any commitments or

efforts. Last, about 18% believed that such an intervention was not their priority, including two actioners. Some commented they preferred self-learning instead of participating in an educational program, because this type of decision-making was personal and it was unnecessary to be involved with a group workshop.

TABLE XXXXXXIII

INTERVIEW SUBJECTS' INTERESTS IN AN INTERVENTION PROGRAM OF ADVANCE CARE PLANNING

Interview subjects' interests	Reasons and concerns (n)
A total of 71.4% (n= 20) subjects were interested in participating in an advance care planning intervention program	<ul style="list-style-type: none"> • 11 were interested in learning new information • 7 realized the importance of advanced EOL decisions • 3 would like to educate families and friends • - 3 would like to know how others make their EOL decisions
10.7% (n= 3) would like to know more before deciding whether to participate or not	<ul style="list-style-type: none"> • 1 was interested in the topic but participating in an intervention was not the priority • - 2 still had questions and would like to know more before making the decision
18% (n= 5) were not interested in such an intervention program	<ul style="list-style-type: none"> • 4 concerned about (wasting) time • 2 preferred self-learning and no interests in a workshop • 4 lacked of stamina for such activities • 2 have completed advance directives already • 3 needed rides • - 4 no need and not a priority now

b. Interview subjects' preferred group size in an intervention of advance care planning

A one-on-one, traditional tutoring session was the least favored (n= 17): this “heart-to-heart talk” would be great for personal consultation but this type of learning was time-consuming and intimidating. A small group (suggested less than 6 persons) was considered appropriate for this sensitive and unfamiliar topic. Many expressed their interests in sharing and listening to others' previous EOL experiences and rationales for specific LST decisions, and through in-depth discussions, more ideas could be brainstormed among participants and one could be inspired to make better self EOL decisions. Another possible benefit of a small group was to encourage shy and unconfident Chinese women to speaking up, which was normally less possible in a big group setting. The big group session, generally recommended for 10 to 20 participants, was favored by those (32%) who were only interested in basic, introductory education of advance care planning. Some interviewees

also suggested the researcher to break the big group into small groups afterwards, so that participants could freely choose whether to continue participating in the in-depth discussions

TABLE XXXXXXIV
INTERVIEW SUBJECTS' PREFERENCE IN AN INTERVENTION PROGRAM OF ADVANCE CARE PLANNING

Preferred group size	Reasons and concerns
Most were interested in a small group (size < 6 persons)	<ul style="list-style-type: none"> • 20 said communications and discussions were best in a small group • Two shared that a small group was more encouraging for unconfident, shy Chinese women
A big group (10-20 persons) and an one-on-one session might be needed but not as attractive	<ul style="list-style-type: none"> • Four commented a small group was suitable for this topic due to its sensitive nature in EOL issues • Eight said a big group was great for an info session for basic introduction • Three had little commitment in a big group • Six suggested that a big group can later break into small groups • Three felt a one-on-one session was good for personal consultation but might waste time • Four thought no need to be one-on-one, too much pressure

c. **Interview subjects' preferred attendants' characteristics in an intervention of advance care planning**

TABLE XXXXXXV
INTERVIEW SUBJECTS' PREFERRED ATTENDANTS IN AN INTERVENTION PROGRAM OF ADVANCE CARE PLANNING

Preferred attendants	Reasons and concerns
Most (47%) had no preferences with whom to participate in the intervention	<ul style="list-style-type: none"> • Thirteen had no preference • Six preferred spouses • Five preferred similar background such as gender, age, education levels, etc
About 20% preferred to be with spouses (not children) or of similar backgrounds	<ul style="list-style-type: none"> • Four would like to self-learn at home

According to most interview subjects, gender, age, educational levels, or countries of origins of other participants have made no differences to them. Such life-long learning could be with anyone, not necessary with family members or people they already knew. Still, about one fifth would like to learn about advance care planning with their spouses, but 14.2% of them believed their families were not ready yet for this topic. They also did not expect to participate with adult children, since the younger generation might not be interested in this topic and had their own priorities in life.

Several (18%) preferred other intervention attendants of similar backgrounds. Their assumption was that such discussions and sharing would be much easier and more meaningful with people who

were at similar ages, educational levels, had comparable previous experiences and values than with those young people who might be naïve about EOL situations. Some specifically wanted to choose compatible discussion partners in order to avoid time being wasted on answering “stupid questions” or “debating my values.”

d. Preferred learning methods in an advance care planning intervention

While many interview subjects were relatively unknowledgeable in this area, nearly half of them could not suggest learning methods or program contents appropriate for this intervention. They simply wanted to follow program directors’ (or lecturers) syllabus and expected the most common learning strategies to be used in this intervention, for example, a series of conventional lectures with visual aids (slides) or audio aids in the classroom settings. More than 70% of the interview subjects, however, looked forward to well-guided group discussions and personal sharing in the program. Agreed was that an intervention program should be beyond reading written materials, which was the most suitable method for self-learning at their own convenience. Utilizing Internet or computers was not highly preferred, mostly because of elderly subjects’ learning disability (due to aging and limited attention span) and computer unavailability.

TABLE XXXXXXVI
INTERVIEW SUBJECTS’ PREFERENCES IN AN INTERVENTION PROGRAM OF ADVANCE CARE PLANNING

Preferred learning methods	Reasons and concerns
Group discussions, lectures, and reading written materials were generally preferred	<ul style="list-style-type: none"> • Twenty preferred group discussions • Twelve would follow whatever guidance from the lecturers • Seven would like to have written/reading materials at their convenience

e. Subjects’ preferred lengths, frequency, and location in an intervention of advance care planning

A short session/meeting no longer than two hours was preferred (Table 67): four hours (even with a break in between) was too long for the elderly, not to mention of an entire day. A monthly or bi-weekly session/class was most acceptable, and some believed one session/meeting

would be sufficient for healthy seniors to learn all about advance care planning. Similar to the survey result, though most had no preferences about the location, a large percentage (78.5%) said their community church would be a convenient public setting, in particular for those who required rides.

TABLE XXXXXXVII
INTERVIEW SUBJECTS' PREFERENCES IN AN INTERVENTION PROGRAM OF ADVANCE
CARE PLANNING

Preferred frequency and location	Reasons and concerns (n)
Most had no preference; a short (length) monthly class or once for all (frequency) was generally recommended	<ul style="list-style-type: none"> • Thirteen believed anything longer than 2 hours was too much • Seven said a weekly class was a big commitment • Four said once is enough • Five concerned about rides, age, and stamina • Five had no experience so no preference
Location was not a big concern as long as rides were available	<ul style="list-style-type: none"> • Sixteen had no preference • Twenty-two said "In my own church!"

f. **Facilitators and inhibitors of the advance care planning program**

In general, facilitators elderly subjects described in the interviews were not majorly different from survey subjects' written responses in the survey, except that interviewees gave more details and anticipation for such an intervention program. Desired program characteristics were summarized in three categories: staffs/educators, program contents, and facilitations and transportation support (Table 68). Similarly, inhibitors described by interview subjects were similar to survey subjects' responses: undesired program characteristics and their self-perceived health status (decreased stamina) would decrease their willingness of participation. As anticipated, one of the biggest inhibitors commonly brought up (40%, n= 11, >72 yrs), was related to transportation inaccessibility. Their interest was comparatively less an issue when going through the troubles to arrange rides to the intervention.

TABLE XXXXXXVIII
INTERVIEW SUBJECTS' EXPECTATIONS IN AN INTERVENTION PROGRAM OF
ADVANCE CARE PLANNING

Categories	Things subjects' wished to be included in the intervention program
Speakers & educators	<ul style="list-style-type: none"> • Bilingual health care providers who were professional and entertaining as educators and promoters • Clinically experienced consultants (doctors and nurses) • Assistance from translators (not necessary the educator)
Program topics and contents	<ul style="list-style-type: none"> • A useful, meaningful, and interesting topic in each session • Clear learning objectives and good teaching strategies • Unintimidating, desensitized, subtle yet attractive contents • Commonly seen symptoms or signs at the EOL (ex. cancer) • Sharing of real EOL cases • The most updated advance care planning information in Chinese (translation included) • Only the basics of advance care planning (such as the purpose and benefits of advance care planning, and legal documents needed to be completed in advance, etc) • A possible personalized and one-on-one consultation • The most important terminologies be explained • Practical and legal issues on how to make EOL decisions • Legally valid advance directive forms be included • Guidance and practices on how to fill out advance directives
Facilitations & transportation support	<ul style="list-style-type: none"> • Telephone follow-ups to avoid procrastination • Comfortable and cozy settings to facilitate learning • Rides be provided or carpool be arranged

7. Qualitative results: Open advice interview subjects provided to increase Chinese

Americans' readiness for advance care planning

The majority of interview subjects (85.7%) have provided direct or implied advices on how to increase Chinese Americans' readiness for advance care planning (and the related intervention program). Only four (16.6%) relatively traditional and old women (mean age= 84.5 years), considering themselves low educated and unfamiliar with this topic, did not offer any suggestions.

a. Desensitizing the death and dying taboo and targeting the religious community

In order for Chinese-ethnic Americans to achieve successful EOL planning, approximately 80% immediately reaffirmed the importance of breaking through the well-known cultural taboo of death. Although death matters have been less tabooed among Chinese immigrants in the States,

reluctance and avoidance of mentioning death remained the biggest inhibitor of advance care planning, in particular for extremely traditional Chinese. The first step to increase readiness was desensitization by encouraging frank discussions about death, such as terminal illnesses, EOL treatments, and the grief of losing beloved families. This health care option was suggested to be skillfully and steadily introduced to Chinese-ethnic Americans in order to gradually eliminate their unease, uncomfortable, and bad-luck feelings.

In addition, advance care planning was recommended to target Chinese Americans within the religious community (particularly Christians in their local churches). Accessible and convenient community churches could be utilized as program sites as well. According to those interviewees who have converted to Christianity and undergone a process of Americanization, they became more receptive, open-minded, and less fearful in discussing death matters. Compared with their overseas counterparts who believed in traditional religions of Buddhism or Taoism, they would be better candidates to initiate a planning for EOL treatment and care.

b. Promoting and educating Chinese Americans to increase advance care planning awareness and knowledge

Nearly 92% believed that education was the ultimate solution to increase Chinese Americans' readiness for advance care planning. Almost every subject towards the end of his/her interview stressed and restated the importance of a well-planned educational program; only when Chinese had correct understandings about LST and ADs, they would not be driven away by presuming difficulties, troubles, and/or procrastinations. Multiple suggestions have been provided on how advanced EOL decision-making should be edified regarding the cultural contents, lecturers/instructors, teaching strategies, and channels; these advices were somewhat similar to what they have described previously. Advance care planning education was recommended to be promoted among those healthy Chinese between 50- to 60-year-old, for they were about to encounter EOL

decision-making for themselves or for their parents who could be very traditional, low-acculturated, or have never heard about advance care planning.

c. **Providing bilingual information for Chinese Americans diverse in their English proficiency**

About 60%, regardless of their widely differed English competency, have brought up the significance of bilingual information in the advance care planning intervention. In fact, many subjects fluent in English still preferred translated (Chinese) health related information, not to mention the majority of Chinese Americans, as English illiterates, would have difficulties being exposed or accessing to health information written only in English. In order to make this relatively new idea known, accessible, and comprehensible to the general Chinese American population, bilingual materials about a) the basics of advance care planning and b) how to access to up-to-date resources from the mainstream society were critically essential and should be prepared in the intervention program.

d. **Breaking through a feeling of no urgency and procrastination for advance care planning**

Last, a state of mind was believed to seriously inhibit Chinese Americans' readiness and motivation for advanced EOL planning—as stated previously, those relatively young and healthy subjects (34%) admitted they procrastinated due to a feeling of no urgency. Actioners and maintainers (16%) have regarded this feeling “unpractical,” “mere excuses,” and “human inertia” which brought no benefits for one's EOL planning. However, subjects who were comparatively more EOL-experienced and knowledgeable about advance care planning (25%) passively believed that little could be done to truly change this state of mind: the intervention program would not make young and healthy Chinese Americans prioritize their EOL planning, unless they have perceived a severity of deteriorated health or a necessity to change. For example, only after seeing enough life tragedies, personally encountering a life-threatening situation, being aged, or currently facing a need to make

self or family's EOL decisions, Chinese Americans might be presumably facilitated to initiate their own advance care planning.

Although no ultimate useful solutions were concluded from the interview subjects to breakthrough a feeling of no urgency (and procrastinations), some (22%) suggested bringing a sense of reality and urgency in the intervention program, by re-emphasizing the inevitable fact of death and stressing the importance and benefits of advanced EOL planning: 1) contact and educate Chinese clients at the right time while they were in the midst of EOL decision-making, 2) show real EOL cases and miserable consequences of unnecessary EOL treatments, 3) offer hypothetical scenarios for participants to discuss LST options, 4) emphasize (in particular financial) burdens left to the children if without any planning, and 5) provide legal advance directive forms with a timeline for procrastinators to complete.

8. Qualitative results: General feedbacks interview subjects had for this study

As interview subjects were giving a last opportunity to share what they considered the most important after participating in this study, their comments were summarized in three categories (Table 69). More specific reflective feedbacks were given about the interview rather than the survey (Table 70) and nearly 90% have highly rated their in-depth interviews ("good," "casual with no pressure," "comfortable," "enjoyable," "able to share and say whatever I liked," "meaningful," and "resourceful"). All of them welcomed the opportunity to review personal values and LST preferences with a healthcare provider. About 80 % also complimented the researcher's attitude and interview skills, which this approach and personal characteristic would play an important role when promoting sensitive EOL education among traditional Chinese Americans. A general enthusiasm was observed to support this research study; not only have subjects shown an interest to participate in the follow-ups, but they also have expressed culturally specific gratefulness and appreciation in return to the interviewer's company and teaching.

TABLE XXXXXXIX**INTERVIEW SUBJECTS' GENERAL FEEDBACKS AND EVALUATION ABOUT THE STUDY**

Categories	Summarized comments
Reiterating the meaningfulness and importance of advance care planning	<ul style="list-style-type: none"> • Twenty-two re-emphasized the significance and benefits of initiating advance care planning learned from this study
Re-accentuating a need of a dignified death with no sufferings (most would like to forgo no unnecessary and aggressive LST)	<ul style="list-style-type: none"> • Sixteen re-affirmed their LST values • Six gave additional sharing about previous EOL experiences which have shaped their LST values
Giving more advice for future intervention programs	<ul style="list-style-type: none"> • Twenty-six again cautioned the difficulty of promoting advance care planning among Chinese Americans, as it could be culturally less receptive • Eighteen stressed what they thought very important to be included in an advance care planning program

TABLE XXXXXXXX**INTERVIEW SUBJECTS' REFLECTIVE FEEDBACKS ABOUT THIS STUDY**

Categories	Summarized comments
Feedbacks about the survey	<ul style="list-style-type: none"> • Sixteen thought the survey was resourceful • Twenty-one said survey questions have motivated them to think about their own • Five felt the survey questions were easy to follow but too long (time-consuming) • Three felt some Chinese translations of ADs and advance care planning (in the survey) were confusing and misleading
Feedbacks about the interview	<ul style="list-style-type: none"> • Twenty-six would like to further support this study and any follow-up studies • Twenty-five have positively rated the in-depth interviews • Twenty-two complimented the interview's attitude and skills • Nineteen thought the interview questions were well-designed and meaningful • Twelve among the 16 first learners felt they gained more in the interview than survey • Eight thought the questions were deep and profound, and thus required more time to digest and make connections • Eight have not talked so much for a long time but enjoyed a health provider's visit • Seven said the interview (no bad luck) was a good reminder for them to plan for their inevitable, upcoming death • Five loved a follow-up interview for it provided them an opportunity to clarify some survey answers • Five wished a legally valid Chinese ADs could be provided during their interview

Although it was not the researcher's original intention to change subjects' readiness for advance care planning, nearly 94% agreed their experience of an in-depth interview about EOL decision-making has inevitably increased their awareness, a sense of self-control, knowledge,

intention and motivations to initiate LST discussions with significant others (Table 71); noticeable behavioral changes were found especially among first learners at relatively low stages of change.

TABLE XXXXXXXXI
INTERVIEW SUBJECTS' AWARENESS AND RECOGNITION OF THEIR
READINESS CHANGE DURING THE INTERVIEWS

Subjects' stage of change	Change of readiness for advance care planning	N	Feedbacks & actions to take in the near future
Precontemplators and contemplators	An increase of advance care planning awareness	9	<ul style="list-style-type: none"> • Eight first learned and realized the importance of advanced LST planning • Five felt EOL decision-making becoming real • Four sensed a need to state again in their (pending) wills what they preferred at the EOL • Two used to feel awkward about this topic but now realized the importance and started thinking about it • Two still felt no urgent need but have taken this issue more seriously than before
	An increase of knowledge	11	<ul style="list-style-type: none"> • Seven reported their knowledge about LST and ADs in this area has increased • Four were motivated to learn more and search more info
	An increase of endorsement (pros)	8	<ul style="list-style-type: none"> • Eight agreed that the more they thought about it, the better idea advance care planning was • Seven agreed with almost all pros in the survey • Six advance care planning would lead to a less suffering EOL • Eight wanted to initiate EOL discussions with families
	Increased intention to behavioral changes	13	<ul style="list-style-type: none"> • Two planned to share EOL values with their children soon • Three were willing to make advanced LST decisions immediately (complete ADs) • Two would like to finalize their living trusts (with living wills) soon
Actioners	An increase of readiness to progress to maintenance	3	<ul style="list-style-type: none"> • Two would like to educate families and friends about advance care planning • Three was motivated to learn even more • Two would like to update or revise their existing advance directives
Maintainers		2	<ul style="list-style-type: none"> • Two would like to maintain good EOL communication with families • Two would keep updating their ADs

V. DISCUSSION

This mixed-method study has described Chinese Americans' readiness for advance care planning, examined the effects of socio-demographical factors on their stage of readiness, and discovered useful intervention strategies preferred by this cultural group regarding advance care planning. The work presented in this thesis mainly focused on cultural, knowledge, quality of life, spiritual and demographical issues that possibly precluded or facilitated Chinese Americans' advance care planning, and both expected and unexpected differences were found between Chinese American precontemplators and non-precontemplators. In this chapter, the most prominent findings that address the research questions are briefly presented, with a discussion of implications for practice and recommendations for future research.

A. **Specific Aim 1: To Describe Chinese Americans' Readiness for Advance Care Planning by Using both In-Depth and Quantitative Measures**

1. **Stages of readiness for advance care planning**

About 68% of our participants were classified as precontemplators-believers, meaning they intended to initiate advance care planning. Most felt it was necessary and were enthusiastic to obtain additional information for future EOL treatment and care, but were unclear about the most appropriate time to do so. Comments from older interview precontemplators supported the survey result regarding subjects' generally good intentions but indecisiveness about timing.

Only 11% were at the contemplation and preparation stages: willing to execute their ADs within the next 6 months and 30 days, respectively. The usage of ADs was 17.5%, lower than the nation's norm. Only 5% were at the highest "maintenance" stage of readiness. Subjects' communication about EOL decision-making was in general subtle and passive; even among those who completed their advance directives, only 39% shared their preferences with others.

2. **Decisional balance for advance care planning**

Advance care planning was viewed as a good idea. Most of our participants were learning of advance care planning for the first time, but in general they favored and believed in it. They tended to agree more with the benefits and disagree less with the concerns about advance care planning. For example, most Chinese American subjects widely recognized the significance of making EOL wishes known to others in advance, and many disbelieved that bad things would happen after initiating advance care planning. Decisional balance was moderately and positively correlated with the stage of readiness—subjects with better readiness favored advance care planning more. When progressing through stages, subjects' endorsements in the decisional balance increased, while their concerns decreased.

a. **Endorsement for advance care planning**

Generally, it was agreed by our generally older interview subjects that early preparation is always good. Benefits included: to ensure patient autonomy; protect human dignity; increase sense of self-control; alleviate possible sufferings at the EOL; facilitate a good death according to one's desires; help communicate EOL wishes with loved ones; and minimize family

decision-making, caring, and economic burdens.

b. **Concerns about advance care planning**

The survey results showed that (1) the autonomous nature of advance care planning might not be in keeping with a family model of joint decision-making and (2) troubles and complexities possibly related to such planning were the biggest concerns. In the interview data, major inhibitors of readiness included: (1) a lack of knowledge or misunderstandings leading to advance care planning being negatively perceived; (2) a sense of no urgency and/or procrastination; (3) difficulties of facing or initiating talk of death topics, in particular with adult children; and (4) a possible unwillingness to make a commitment about future EOL situations.

3. **Self-efficacy for advance care planning**

The survey findings indicated a sound level of confidence when making EOL decisions; most believed that they would not be influenced by their significant others. However, joint decision-making within the family was a cultural custom and a personal EOL preference. The concept of DOPA and family/spouse surrogate was strongly endorsed by the majority of older interview subjects. Self-efficacy was not a significant correlate of either the ordinal or dichotomous stages of readiness, and it was weakly correlated with decisional balance--the more confident one was, the more one favored advance care planning. The interview data supported that older actioners and maintainers have shown better endorsement and self-efficacy than precontemplators and contemplators. The majority of precontemplators felt that their families were unclear about their wishes and had no interest in serving as surrogates, which might have adversely affected their

readiness for advance care planning. Discouraging behaviors were –reported by interview subjects that their family members may inhibit their EOL communication or even interfere with AD implementation. Older interview subjects indicated that it was difficult to convince their whole family of their wishes within the dynamics of EOL discussion.

B. Specific Aim 2: To Examine the Effects of Cultural Factors, Knowledge of Advance Care Planning, Spirituality, Quality of Life and Demographic Characteristics on Chinese Americans' Readiness for Advance Care Planning

1. **Cultural factors**

a. **Cultural beliefs regarding EOL decisions**

Chinese beliefs regarding EOL decisions were suggested as a predictor of the stage of readiness in the regression analysis. Cultural beliefs were moderately correlated with decisional balance; those who were less traditional were more likely to favor advance care planning. Beliefs selected in the quantitative measure were commonly seen among Chinese Americans, but these beliefs were deemphasized in Western society, and many did not rate them as always true. Surprisingly, cultural beliefs were not significantly related to acculturation. Subjects who believed in “bad luck” were relatively traditional, since most said it was superstitious to believe that discussing death or participating in this study would invite unexpected death. The traditional death taboo was commonly stated as a concern that would inhibit Chinese Americans from advance care planning. In the semi-structured interviews, older subjects’ overall attitude toward discussing death and dying was shown to be quite positive and open, unexpectedly; those who were less bothered by the topic of death

had fewer difficulties in initiating/continuing death discussions with families. Beliefs about a good death, seeing the last face, and death planning were culturally unique but unrelated to readiness for advance care planning. The cultural expectation of filial piety was explicated as Chinese children's duty to make treatment and care decisions about their parents' EOL. A death curse was often implied if mentioning EOL planning in front of parents, which implied failure to observe filial piety. Together with male paternalism, seeing the last face, and non-disclosure of medical bad news, filial piety had a significant impact on the AD completion and stages of readiness. Male paternalism was still practiced in these Chinese immigrant families, but family heads were given little power to make the final EOL decisions. Most subjects had a nuclear family in the States, and family members had great influence in Chinese patients' EOL decision-making. Spouses were subjects' most preferred family surrogates, followed by adult children.

b. **English proficiency for advance care planning**

Most participants reported sound English proficiency, though some had a strong language barrier. Chinese Americans preferred receiving bilingual information, even for those who were highly educated and English-proficient. Results from older subjects' interviews supported that information-isolation in the States and a lack of English proficiency might have impaired their access to learning about advance care planning and possibly hindered their readiness for advance care planning. Chinese Americans' preferred language in the written health information was a good predictor of their English proficiency. English proficiency was positively related to acculturation, knowledge, life satisfaction, education and physical health. Those who were older, poorer, less

educated, and unemployed relied on Chinese more. English proficiency as a factor was significantly and weakly correlated with stages of readiness, but not decisional balance and self-efficacy, for advance care planning. In the regression result, its predictability for readiness was only suggestive and was not selected by the best 5-predictor model.

c. **Individualism and collectivism orientations**

Chinese Americans were generally more collectivistic and less individualistic, and this tendency was more obvious among subjects who strongly believed in traditional beliefs. The interview data showed that when making EOL treatment decisions, a cultural expectation was to consider interdependence and family harmony and integrity, but individual independence and self-control were prominent in particular among the highly educated and immigrants who highly valued self-reliance, similar to European Americans. Individualism and collectivism orientations, however, did not seem to be significantly related to readiness outcomes.

d. **Levels of acculturation**

On the whole, subjects identified themselves mostly as Chinese rather than bicultural Chinese Americans. Acculturation was moderately correlated with English proficiency, levels of education, and knowledge about advance care planning; it could be best predicted by the chosen reading and written language since the better the English, the higher the level of acculturation. Acculturation was found to be unrelated to any cultural beliefs and individualism and collectivism orientations, unlike what was anticipated. In the in-depth interviews, highly acculturated Chinese Americans were found to still hold certain traditional beliefs, such as the traditional values of filial

piety and a preferred model of family-centered EOL decision-making. Younger, better educated, richer, and Christian-believing participants had a better level of acculturation and knowledge about advance care planning. Acculturation, however, was not a strong correlate of readiness for advance care planning.

2. **Knowledge factors**

a. **Knowledge about life-sustaining treatment**

Life-sustaining treatment (LST) was a more familiar term to subjects than was AD documents or advance care planning, but there existed misunderstandings and incorrect definitions about the purpose, example, and timing of LST. Older interview subjects with more LST knowledge were more prepared and more interested in advance care planning. Subjects who were more knowledgeable about LST did not necessarily know better about various types of ADs. LST knowledge was irrelevant to AD completions. From both the survey and interview data, public media have played an important role in shaping Chinese Americans' attitudes and awareness about LST decisions.

b. **Knowledge about advance directive documents**

Only < 3% of our participants reported knowing ADs very well, but most were unfamiliar with ADs, living wills, or DOPAs. The self-report level of AD knowledge about living wills might be overestimated, since living trusts and wills were mistaken as living wills. AD knowledge was significantly correlated with AD completions. From the interview data, a subgroup of older Chinese subjects seemed to be disadvantaged in accessing AD information in the mainstream

society, such as illiterate immigrants, the socially isolated or those limited in English. In the in-depth interviews, Chinese subjects' AD knowledge was found to quickly and systematically increase. However, merely knowing about the AD terminology is insufficient; for Chinese Americans to become advance care planning maintainers, an increase is required in overall advance care planning knowledge.

c. **Knowledge about the advance care planning process**

A summated understanding about LST, types of ADs, and advance care planning was shown to be the best indicator of overall knowledge, rather than any single knowledge items or subscale scores. Overall knowledge about advance care planning was suggested in the binary regression as the major predictor for readiness, but it was not correlated with decisional balance and self-efficacy. Chinese immigrants reported receiving little information regarding advance care planning, either in English nor in Chinese; approximately 90% did not know about advance care planning as a continuous communication process of making advance EOL decisions. Knowledge about advance care planning was significantly related to English proficiency, acculturation, EOL experience, and socioeconomic status (income and education). The majority of survey and interview subjects lacked knowledge in this area; they provided insufficient or improper understanding about advance care planning. The terminology and phrases were reported as vague and poorly translated in Chinese. American primary care providers, even Chinese-ethnic physicians, were unequipped with sufficient advance care planning knowledge and would not proactively mention advance care planning to their healthy clients. Many of our participants believed that their family members were

unknowledgeable about advance care planning as well, and so were unprepared to serve as their surrogates for EOL decisions. Interview subjects agreed that lack of awareness led to low readiness. However, the basic education included in the in-depth interviews increased not only their knowledge but also their intention and readiness to complete ADs and improve EOL communication with their loved ones.

d. **Previous experiences related to life-threatening circumstances of self, close family member's EOL illness, and care-giving to a terminally ill family**

Survey subjects generally were inexperienced regarding EOL issues. Family members' illnesses were most commonly reported, but only a few had participated in discussions related to EOL treatment and care. Surprisingly, both the survey and interview data failed to show significant correlations between EOL-related experience and readiness variables, irrespective of the types of experiences. The interview subset was chosen to be rich in EOL-related experiences, but difficulties were found for them to relate EOL experience to their own readiness for advance care planning. Life-threatening circumstances only facilitated a re-evaluation of life priorities and death attitudes, not engagement in advance care planning. It was clear from the interview data that key to low readiness was unawareness and insufficient knowledge, not experiences. EOL discussions were much easier between spouses than between parents and children. Previous surrogates reported being unprepared and unequipped for such a role, since they lacked any sense of what their dying family member might want, having not had constructive EOL communication with their deceased parents. Previous experiences as family surrogates did not increase their knowledge of advance care planning, and even

among those who were aware of the option, procrastination came into play to decrease their own readiness.

3. **Quality of life factors**

a. **Life satisfaction**

Subjects' overall and four subscale scores of life satisfaction were not significantly related to their AD completions, stage of readiness, endorsement and concerns, and self-efficacy for advance care planning. In both quantitative and qualitative results, life satisfaction as a QOL factor was not significantly associated with readiness outcome variables. Life satisfaction was moderately correlated with general status, including physical and mental health and the socioeconomic status (education and income). Older Chinese interview subjects who highly rated their life satisfaction in the family domain seemed to have comparatively low self-efficacy for their advance care planning; they were more likely to be influenced by significant others.

b. **General health status**

The Chinese American sample was generally poorer in their overall health compared with the 1998 healthy U.S. norms; in particular, in the group aged 55-74, subjects were physically healthier yet mentally poorer than their counterparts. Neither PCS nor MCS were significantly correlated with AD completion, readiness, decisional balance, or self-efficacy for advance care planning. The interview data support the relatively weak survey findings that mentally healthier subjects endorsed advance care planning ($r = -.25, p < .001$) rather than being concerned about it ($r = -.18, p < .05$). Older subjects who self-described as being peaceful and joyful (not depressed) and

socially interactive were likely to initiate advance care planning. Both physical and mental health were moderately to highly correlated with the overall life satisfaction and particularly the health and functioning subscales. Younger, employed, better-educated and richer subjects were associated with better physical health.

4. **Spiritual factors**

a. **Spirituality: system of beliefs**

To Chinese American subjects, spiritual beliefs and practices were more important than perceived social support, and most Christian subjects agreed that their religion brought them a sense of hope and peace of mind. Subjects' religious needs and emphasis seemed to be placed on intrinsic rather than extrinsic spirituality. None of the subjects' overall or subscale spirituality was associated with AD completions, stage of readiness, endorsement and concerns, or self-efficacy for advance care planning.

b. **Self-perceived religiosity**

Most subjects were regular attendants of religious activities (more than twice a week) and perceived themselves as moderately to highly pious. Self-perceived religiosity was moderately correlated with spirituality, yet it was not associated with AD completions, stage of readiness, and endorsement and concerns. The more frequent participation in religious activities, the less self-efficacy for advance care planning, showing a possible influence of the religious community in subjects' EOL decision-making. However, the interview data did not strongly support this finding. Christians were found to perceive themselves as more religious than other religion believers, and this

was supported by the interview data that former Taoist and Buddhist believers were little influenced by their family religions.

5. **Demographic factors**

a. **Age and parent-alive status**

Age was very weakly correlated with the stage of readiness; older subjects tended to be more ready for advance care planning, but age was not a correlate of AD completions, decisional balance and self-efficacy for advance care planning. Surprisingly, age was not related to cultural beliefs, acculturation, knowledge and previous EOL experience, and any spiritual factors, but was weakly associated with English proficiency. Once older interview subjects were introduced to and educated about the concept, they were interested in initiating advance care planning because they already had some sort of death planning. Age was moderately correlated with physical health but not mental health and life satisfaction. The number of parents alive was positively and highly correlated with age, and only 15% had both parents alive. The number of parents alive was unrelated to any readiness outcome variables for advance care planning.

b. **Gender**

In the final binary regression model, being female was predictive to increase the odds of advance care planning, but in the correlation results there was no specific gender difference in subjects' readiness outcomes. Gender was not associated with knowledge, previous experiences, QOL and spiritual factors, but it was weakly related to English proficiency and physical health; males generally were better in their English and physical health. In the interview data, older Chinese women

emphasized more the importance of future EOL care and how their preferences could be communicated during the advance care planning process with their loved ones, whereas men's focus was primarily centered on the decisions of AD completions and functional and LST outcomes. Older women were more open and positive in their intention to learn about advance care planning; they anticipated benefits from advance care planning, endorsed this health promotion option, and seemed to be psychologically prepared for death.

c. **Highest education and annual household income**

A considerable number of subjects were highly educated: 67% were master's-prepared and one-third had an annual income higher than \$100,000 USD. The result of the logistic regression was suggestive that Chinese Americans' level of education was an important factor in predicting their readiness for advance care planning. Education and income were moderately correlated with each other, but neither of them was associated with the readiness variables. Subjects with better SES were moderately and positively related to better English proficiency and acculturation, and weakly and positively related to knowledge, satisfaction, and physical health. SES was significantly correlated with overall and each individual knowledge category for advance care planning.

d. **Marital and life-partner status**

Most participants (77%) were in a marriage or lived with a life partner. This variable was unrelated to any readiness outcome variables for advance care planning.

e. **Employment**

Less than half of the sample was currently employed. This variable was unrelated to any readiness outcome variables for advance care planning.

f. **Religion in which one was raised**

Approximately half of our participants were raised in a family of Chinese traditional religions. In the correlation results, this variable was unrelated to any readiness outcome variables for advance care planning. Beliefs and practice of atheism and Chinese traditional religions have been shown to negatively influence readiness for advance care planning; folklore religions have commonly brought about an avoidance and fear of death or the afterlife.

g. **Current religion**

Most participants were Christians and regular churchgoers. The interview data supported the weak correlation between Christianity and decisional balance; Chinese Christian believers tended to favor advance care planning. This variable was unrelated to any readiness outcome variables for advance care planning. Older Christian interview subjects were comparatively more hopeful and less fearful than non-Christians when discussing EOL matters. Christian beliefs have clearly shaped subjects' values and optimized their death and dying attitudes, but this was not a direct facilitator to increase readiness.

h. **Religion change**

More than half of our participants had changed their religion, and the majority had converted to Protestant Christians after immigrating to the United States. In the correlation results, this variable was unrelated to any readiness outcome variables for advance care planning.

C. **Specific Aim 3: To Discover Strategies that Chinese Americans would Prefer to Use in Advance Care Planning Interventions**

Since Chinese family surrogates' consideration are as imperative as patients' EOL preferences, a key strategy was to assess the stage of readiness of the whole family unit, such as identifying spouses' intentions and preparation for EOL planning. Chinese Americans recognize this cultural barrier, and more than 70% of the subjects suggested that breaking the cultural taboo of (discussing) death was the key to successful advance care planning. However, very few provided constructive opinions or actual strategies on how to overcome such taboos. Information and insight into concerns, difficulties and strategies to overcome these that Chinese American subjects preferred are outlined below.

1. **What is Chinese Americans' willingness to participate in advance care planning programs?**

A major result of this study is Chinese American precontemplators' noticeable enthusiasm in learning about advance care planning. Both quantitative and qualitative results were promising: nearly 80% were interested in the intervention programs when first approached. Findings related to willingness to participate also showed that Chinese precontemplators who highly believed in the benefits of early planning and perceived the necessity of completing their AD were highly motivated for further learning. This suggests that the Chinese American population holds promise for overcoming barriers to participating in advance care planning.

2. **What are the group format, learning methods and activities, session lengths and frequency, person to participate with, and site/location preferred by Chinese Americans?**

The group format, learning method, session and activities characteristics that Chinese Americans desire in intervention programs are and reasons for these preferences are presented in the previous chapter. What needs to be stressed again from the findings is the implied significance of a meaningful and timely intervention program which is in Chinese American subjects' words "worthy to participate." The results clearly indicate that Chinese Americans mostly are concerned about a conflict of family schedule and burdens imposed to other family members, particularly adult children. In addition, since advance care planning is not an urgent matter as prioritized by most Chinese precontemplators, their commitment to engaging in the intervention programs and preferred learning strategies rests largely on the availability of free time, transportation, and physical stamina. These concerns explain why their most favored intervention structure is an introductory education session with concise bilingual written materials. Many also preferred to have case studies constructively discussed in a small group guided by experienced lecturers for no longer than two hours at their church right after Sunday services. Although most do not mind with whom they participate in the intervention, a preference to discuss and learn with people of similar background reveals Chinese Americans' fundamental concern: to effectively and efficiently initiate advance care planning without interfering in existing family schedules or bothering their family members.

3. **What are useful strategies to promote advance care planning programs?**

While a great number of older subjects enthusiastically shared detailed intervention characteristics they believed would be useful, attractive, and practical, the best facilitator of behavioral change was obviously a well-planned and structured educational program. On the other hand, inhibitors were anticipated, including undesired intervention characteristics, situational

unavailability related to time, and physical condition not allowing for intervention programs. All these results imply that the key to behavioral change is a well-designed informative intervention program. Our suggestions for the strategies are similar to a nationally acclaimed program “Respecting Choices” (Westley & Briggs, 2004). Future interventions would be better designed to include: (a) educational materials and resources that may effectively and efficiently increase Chinese Americans’ overall knowledge; (b) realistic guidance to enhance the ongoing death-related communication in Chinese families; (c) practical tools for health care providers, such as a list of probing questions to elicit Chinese clients’ LST values and cultural beliefs; and (d) scripts and decision algorithms to help remind health care providers of the whole family’s EOL goals. In addition, we believe traditional cognitive and emotional strategies of presenting case studies and clinical scenarios are useful when encouraging Chinese Americans considering the negative outcomes of procrastination and following through to ponder what might happen in future if no EOL decisions are made. Health care providers are advised to provide their Chinese clients opportunities to openly describe death taboos, fears of losing their loved ones, or any other common concerns, such as being a burden to their family.

Most Chinese Americans’ limited knowledge about advance care planning was reflected in their near-to-the-bottom stage of readiness. Discovering strategies to purposively raise this population’s level of awareness and knowledge is crucial. Existing education about this topic is scarce. A major implication of this study was to explore education-based interventions suitable for the Chinese American population to bring basic awareness and increase knowledge on this topic. This goal was similar to what has been suggested in a recent study (Sudore et al., 2008). Another community-wide education program (Hammes & Briggs, 2000) proved successful by applying multifaceted and

stage-wise approaches to help a large sample of general population local residents not knowledgeable about this topic to understand better and take steps to initiate advance care planning. A research review (Miles et al., 1996) suggested that a combination of face-to-face education with written material, classes, or videotapes worked best to increase participants' AD completion. We believe that Chinese Americans can also benefit from such structured and introductory educational programs.

In this study, the standard education along with the in-depth interview was quite effective in increasing participants' awareness about advance care planning. This introductory session motivated more than 60% the qualitative sample to make a behavioral change. To our surprise, a few precontemplators after learning the basics about advance care planning even became ready to complete their ADs, finalize their living wills, leave written medical wills/directives to families, or discuss EOL matters not only with spouses but also with adult children and family doctors.

Subjects' positive learning experience and the collaborative relationship with the researcher have implied that older Chinese American immigrants may work with their health care providers to advance their knowledge and optimize their attitudes in a short time to affect stages of readiness for advance care planning. By implementing meaningful conversations and providing personalized education, efforts of "constructive interviews" may transform advance care planning from "a document-driven, decision-focused event to one that emphasizes a relational, patient-centered process" (Hammes & Briggs, 2000, p. 348)." We expect such educational endeavors to increase physicians' and family surrogates' knowledge of patient preferences as well (Briggs & Colvin, 2002).

Last, we learned from both the survey and interviews that the public media play an important role in shaping Chinese American society's attitudes and increasing their awareness of EOL decision-making. Further market research will be valuable when designing intervention programs to understand what types of information might trigger Chinese Americans' intention for advance care planning. In the in-depth interviews, older Chinese generally expressed that they did not want to be coerced and often needed no advice. Therefore, interventions can be framed in well-phrased questions which would leave them time to ponder the answers (Zimmerman, Olsen, & Bosworth, 2000).

D. Findings Relate to Previous Research about Stages of Readiness

1. How psychologically and behaviorally prepared are Chinese Americans for advance care planning?

Most of our Chinese American subjects were precontemplators-believers (68%) who were willing to initiate advance care planning yet unclear about the most appropriate time to do so. Only 11% were prepared to execute their ADs within the next 6 months or sooner, and the current usage of ADs (17.5%) was below the national norm. Importantly, findings from this study supported our hypothesis that Chinese Americans in general are not prepared for advance care planning. Both quantitative and qualitative data indicated that as many as 70% of the sample not only had not engaged in planning for EOL treatment and care, but also were indecisive about the most appropriate time to do so.

Though our sample was relatively highly acculturated, educated, and affluent, the prevalence of those who had advance directive documents (ADs) was 17.5%, below the average AD rate of 25%-30% in the chronically ill in the general population (Wilkinson, Wenger, & Shugarman, 2007) and much lower than the norm of non-terminally ill patients (40%) from a recent systematic review ($n = 3,206$) (Patel, Sinuff, & Cook, 2004). Such limited AD usage supported a generally low stage of readiness for advance care planning, despite that there are no accurate statistics on AD percentages for the whole Chinese American population in the greater Chicago area or the United States. In fact, the overall stage of readiness for advance care planning in the Chinese American population might be even lower, because in the qualitative interviews some older subjects (later found to misunderstand the terminology) wrongfully claimed that they had completed their ADs. Practical guidelines should be developed to meet the needs of the large number of Chinese American precontemplators who are uncertain about how and when to initiate advance care planning.

The stage of readiness was assessed multi-dimensionally to include meaningful information about subjects' psychological willingness and self-perceived necessity for advance care planning. Our findings related to advance care planning intention indicated that many Chinese Americans are in fact psychologically prepared to immediately execute their ADs and initiate EOL conversations with family members. In other TTM studies of physical activity and smoking cessation intervention, precontemplators were usually ignored or excluded from the interventions in order to increase the success of intervention programs. However, our study findings suggest that it is important to strategically target those Chinese Americans because they have great potential to quickly transition

from the precontemplation stage to the action stage. For those people with good intention for advance care planning, basic education sessions might be sufficient for changing their behavior, even without complicated, stage-tailored intervention, as suggested by our findings that many of our participants were open to advance care planning but just did not know much about it.

2. **How do Chinese Americans generally communicate their EOL treatment and care preference?**

Chinese Americans' communication regarding EOL treatment and care is mostly subtle and passive; within the family setting; and only 5% have made advance care planning decisions and shared their EOL preferences with others. Working from an earlier effective approach to improving EOL care (Sudore & Fried, 2010), this study centered on the communication component of advance care planning, rather than the narrower objective of AD completions. In the past two decades, the effort of promoting ADs only achieved modest effects in the primary care settings (Fagerlin & Schneider, 2004; Perkins, 2007; Ramsarrop, Reid, & Adelman, 2007), and a number of intervention studies that simply aimed for completion of ADs failed to improve patient EOL communication or ensure that patients received EOL care consistent with their preferences (L. Briggs, 2004; Singer, Martin, & Lavery, 1998; Wilkinson, et al., 2007).

While patients and family surrogates have been encouraged to participate with health care providers to contemplate and articulate EOL goals with loved ones, our findings suggest that most Chinese Americans have limited EOL communication in both quantity and quality. Not only are matters related to death and dying rarely brought up among families and friends, but also many

commonly lacked the necessary knowledge and skills for discussing specific LST options and EOL care preferences. Even among actioners and maintainers who completed their ADs, such passive communication patterns were evident. This finding implied a need for education in the intervention programs to address insufficient and ineffective EOL communication among Chinese Americans.

3. **What do Chinese Americans like about advance care planning?**

Advance care planning was believed to be a good idea by our participants. Advance care planning would help ensure patient autonomy; protect human dignity; increase sense of self-control; alleviate possible sufferings at the EOL; facilitate a good death in line with one's desires; help communicate EOL wishes with loved ones; and minimize the family's decision-making, caring, and economic burdens.

More than 80% of our Chinese subjects intuitively believed that advance care planning should be done. This is in contrast to the cultural reluctance frequently reported in the Western literature. Not only was advance care planning not viewed as something ominous, but even those who first heard about this idea through contact with this study were highly motivated to pursue additional information. Such a promising result highlights the significance of providing necessary knowledge and the potential of promoting advance care planning in this cultural group.

Major facilitators for Chinese subjects to endorse and favor advance care planning were identified that were consistent with the literature (Foti & Hanrahan-Boshes, 2010; Wilkinson, et al., 2007). However, among these pros/benefits of advance care planning, a cultural order was evident; constructive and candid communication was rated the most critical and valuable component regarding

EOL treatment and care. Information from the interview subjects also supported the hypothesis that the greatest motivation for Chinese-ethnic subjects to initiate advance care planning was to take the burden off the rest of the family: if EOL wishes can be discussed to reach a consensus among loved ones, it leads to a decrease of potential family conflicts and ethical dilemmas. The well-recognized individualistic objectives to prevent meaningless life-elongation, end suffering, and preserve patient autonomy were not major spurs when contemplating EOL planning for our participants. However, this is not to say Chinese Americans completely disagree with these pros. Clearly, there exists a cultural desire to avoid being a burden to family members, which is the top central value to support and favor advance care planning.

Findings related to advance care planning endorsement implied the importance to reach out to the large group of Chinese precontemplators who have great potential to endorse this health care option. When promoting advance care planning in a Chinese-ethnic population, public awareness about the advance care planning pros and advantages should be prioritized (Sudore & Fried, 2010). Positive outcomes and benefits could be strategically highlighted by presenting a maintainer who has already successfully initiated advance care planning and showcasing how he/she is now better able to maintain EOL-related communication with loved ones. Most importantly, the significance of decreasing multifaceted family burdens needs to be stressed by real case examples in the intervention program.

4. **What are Chinese Americans' concerns about advance care planning?**

Major reported inhibitors are: (1) a lack of awareness or inadequate knowledge; (2) procrastination due to no sense of urgency; (3) an unwillingness to make a commitment due to uncertainty about future EOL situations; (4) the autonomous nature of advance care planning that potentially contradicts family decision-making; and (5) troubles and complexities related to advance care planning, including the difficulties of initiating talk of death topics, in particular with adult children.

The Chinese subjects in this study differed in their concerns and barriers to initiating advance care planning, yet a number of shared hindrances were generally consistent with advance care planning obstacles recently reported among predominantly Caucasian Americans ("Barriers to advance care planning," 2010; Butterworth, 2003; Fried, Bullock, Lannone, & O'Leary, 2009; Moskop, 2004). First, the greatest barrier was clearly the basic lack of awareness among the majority of Chinese American precontemplators. In both our quantitative and qualitative data, a lack of awareness or insufficient knowledge was agreed to be a fundamental drawback, leading to poor communication and inadequate (or no) advance care planning. Special educational efforts are required to effectively engage under-informed or uninformed Chinese Americans. Particularly, relatively knowledgeable actioners and maintainers suggest that precontemplators who are disadvantaged should be targeted first, such as those who are handicapped in English, unable to access health-related information, and incorrect or insufficient in their understanding of ADs. More details about insufficient knowledge and the readiness for advance care planning are presented elsewhere herein.

Secondly, humans' procrastinating nature, a common barrier to advance care planning (Ali, 1999; Gordon & Shade, 1999; Wilkinson, et al., 2007), is a critical factor delaying Chinese Americans' progression through stages of readiness. Future EOL uncertainties also come into play to aggravate avoidance and procrastination. Almost all precontemplators, being stable in their health and functioning status, had no urgent need to initiate advance care planning. Even actioners and maintainers "dragged their feet" and "stayed away" from EOL decision-making for several years. The striking result that cancer survivors ($n = 4$) in the in-depth interviews considered themselves not candidates for this health option explains how much Chinese Americans believe advance care planning is only for the terminally ill. Future intervention needs to break the myth that advance care planning is unpractical or hypothetical for the healthy population and also address concerns that advance treatment and care plans might not reflect the actual medical, emotional, or social context in future EOL circumstances (Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006; Halpern & Arnold, 2008; Sudore et al., 2008).

Our Chinese American participants were not hesitant to plan for death, and most of these community-dwelling subjects with chronic illnesses reported often thinking about their health and possible life-threatening events. This result was different from their older predominantly Caucasian counterparts ($n = 63$) in a similar recent study (Fried, et al., 2009). However, thoughts and plans related to death rarely motivated Chinese Americans to further plan for EOL treatment and care. The reason again goes back to the barrier of insufficient awareness and knowledge. In both our quantitative and qualitative results, compared to more knowledgeable actioners and maintainers,

unaware or less knowledgeable precontemplators exhibited a greater tendency to avoid advance care planning. While an important implication is to increase and update procrastinators' knowledge, EOL scenarios could be strategically included in the interventions for them to ponder various uncertain and hypothetical ("what if") situations.

Thirdly, the autonomous nature of advance care planning seems to raise a cultural concern since family harmony and family recognition are highly valued in Chinese culture. Quite a lot of Chinese American precontemplators questioned whether such planning rooted in American individualistic values might not be adapted to a preferable family model of joint EOL decision-making for Chinese Americans. In addition, because many subjects at the preliminary stage of readiness experienced difficulties with their families initiating talk of death topics, particularly with their adult children, many older Chinese Americans avoided advance care planning for the sake of maintaining family harmony. More issues related to the cultural avoidance of death and potential awkwardness and discomfort during EOL discussions are discussed elsewhere herein.

The Chinese emphasis on family harmony and a general fear of being a burden to families/adult children fundamentally contributed to other advance care planning concerns. A number of immigrants mentioned as explicit barriers the intricacy of AD execution, information inaccessibility, and limited English proficiency. However, what inhibits their readiness for advance care planning may not be solely language or health access problems. Advance care planning materials written in English might have compromised Chinese Americans' motivation and comprehension of such information. Our subjects agreed that what they want to avoid whenever possible was in fact troubles or hassles

involving other family members, such as requesting time from adult children for a translation or transportation favor. This also explains why a majority prefer the intervention being held right after their Sunday services in the local churches; not because they like the church settings, but because this is the most convenient for family schedules.

Lastly, despite “loss of hope” being reported as a major advance care planning obstacle (Calvin & Eriksen, 2006) as to why many nurses and physicians are reluctant to initiate EOL topic discussion (Norlander & McSteen, 2000), our result shows this is less of a concern for Chinese Americans already contemplating advance care planning. In quantitative and qualitative data, the statement, “AD completions would adversely affect patients’ treatment and shorten life” was not highly agreed with, showing that ADs were not considered ominous among our Chinese subjects. Like subjects in earlier studies, they understood that there might be worse states than death (Lockhart, Ditto, Danks, Coppola, & Smucker, 2001) if no planning was in place (Robert A Pearlman, William G. Cole, Donald L. Patrick, Helene E. Starks, & Kevin C. Cain, 1995). This result implies that health care providers should not avoid this topic and need to proactively approach their Chinese clients.

In the main, Chinese Americans tend to trust that physicians would never purposely maltreat patients, as family surrogates would never knowingly disregard their loved ones’ best interests. To date, no known studies have investigated the influence of “a sense of hope” or “losing hope” on Chinese Americans’ readiness. In order to better understand how patients and family surrogates perceive hope throughout the process of EOL decision-making, qualitative methods would be useful in future studies to identify such behavioral patterns.

The significance of decisional balance in relation to the stage of readiness has varied greatly in the TTM literature (J. O. Prochaska, Velicer, & DiClemente, 1988) and largely depended on how readiness was measured (Robert A Pearlman, et al., 1995). In studies of physical activity (Marcus & Owen, 1992; Pinto, H, BH, J, & MG, 2001) and substance abuse (Share, McCrady, & Epstein, 2004), decisional balance was found to be a mediator of readiness. Since no previous efforts have been made to identify the mediating role of decisional balance in research of advance care planning, this study was the first effort to understand its influence on Chinese Americans' readiness in both dichotomous and categorical scales. In line with results from prior studies, a higher level of readiness regarding advance care planning was only moderately associated ($\rho = -.43$ and $-.40$, $p < .001$) with more pros and fewer cons. A possible explanation might be that in this study, Chinese subjects across stages of readiness had similar decisional balance and little variation in favoring this planning.

5. **How do Chinese Americans rate their self-efficacy regarding advance care planning?**

Although more than half of our subjects were confident about their self-control in EOL decision-making, their family's influence remained noticeable. Joint family decision-making is a preferred cultural custom. The concept of DOPA and family/spouse surrogate is strongly endorsed. The majority felt their families were unclear about their EOL wishes and had no interest at this point in serving as surrogates. Unsupportive families might inhibit AD implementation and EOL communication, but to most Chinese, the family dynamics were difficult to change. In this study, the influence of self-efficacy on the readiness for advance care planning was critically important due to the great emphasis of family opinions in Chinese collectivistic cultural beliefs.

Since Chinese immigrants are significantly oriented toward external control beliefs, including the power of others, luck, and fate (Crain, 1997), self-efficacy over advance care planning was originally anticipated to be low among subjects who had not yet completed their ADs ($n = 170$), and they were expected to require approvals or verbal consents from significant others (Braun & Nicoles, 1997; Chen, 1996). However, the self-efficacy results were surprising in that most Chinese Americans in this sample were actually quite confident about their control regarding AD completions: about two-thirds of precontemplators' decision in regards to whether to execute AD documents were little influenced by important family members. Approval from family members was only preferred among one fifth of the total sample.

Regarding the cultural custom of male paternalism, support from both quantitative and qualitative data showed that there was increasing endorsement of patient autonomy among Chinese patients and their families. Most subjects strongly desired to have self-control over their own EOL planning, and male paternalism did not seem to be commonly practiced in Chinese Americans' EOL decision-making. In other words, we have reason to believe that Chinese Americans' self-efficacy, their confidence in relation to EOL decisions, is not as limited as has been portrayed in Western literature.

On the other hand, Chinese Americans' self-efficacy regarding EOL treatment and care communication remained strongly shaped by the collectivistic ideals of social hierarchy, responsibility, and family harmony. Precontemplators recognized that their ongoing communication was strongly influenced by important family members; this explains why half of the subjects preferred to discuss

with their loved ones before initiating advance care planning and why a family DOPA was preferred by more than 80% of the subjects. For the most part, our Chinese American subjects would like their spouses, not their adult children, to make joint EOL decisions and serve as their future surrogates when incapacitated. The fact that no subjects required approval from adult children before initiating advance care planning indicates that the cultural custom of the eldest sons holding absolute power in parents' EOL decisions was not in practice, contrasting with what has been commonly reported in the earlier literature (Char, et al., 1996; Der-McLeod, 1995; Guo, 1995).

This study also confirms that unsupportive families' discouraging behaviors regarding EOL conversations directly inhibited precontemplators' readiness for advance care planning. In order to facilitate stage transitions, an important intervention implication is to introduce this concept and guide family EOL communication so as to decrease difficulties and increase family support. More details about the family influence are discussed elsewhere herein.

In this study, only a small group of the sample had completed ADs or communicated their EOL preferences with their families. One strength of this study was to specifically request those older subjects who were in advanced stages of readiness to describe and offer emotional and cognitive strategies they had used to successfully increase confidence and overcome communication challenges. For example, strategies to ice-break awkward moments and conquer frustrating responses as a way to manifest self-efficacy (Fried, et al., 2009) have important applications for health care providers who work with precontemplators with unsupportive families. It is worth noting that the relatively high level of confidence revealed in this study might only reflect norms in a similar population as our

sample. More research is necessary to further explore the interaction between self-efficacy and readiness, in particular among Chinese American precontemplators of low SES.

6. **What is the relationship between self-efficacy and stages of readiness for advance care planning?**

Self-efficacy is not a significant correlate of either the ordinal or dichotomous stages of readiness. In the qualitative data, self-efficacy and the stage of readiness seem to be positively and closely related. Similar to the construct of decisional balance, self-efficacy was also a mediator of the readiness stage (J. Prochaska & Velicer, 1997). It was found to be a positive correlate of readiness in TTM studies of dietary and nutritional education (Contento, 2010; Noia & Prochaska, 2010) and physical activity (Marcus & Owen, 1992). When the TTM was applied in addictive behaviors, situational temptations enticed individuals to engage in a problem behavior and thus decreased their readiness for change. However, in this study, no such temptations were pertinent in the nature of EOL decision-making. On the contrary, the context might positively facilitate individuals' motivational readiness for advance care planning, such as significant others' full support for patients' self-control. Unfortunately, no previous research efforts have been made to investigate the mediating role of self-efficacy and its influence on advance care planning in this population, and this study is the first to investigate such a relationship among community-residing Chinese American precontemplators.

Although the survey results revealed no significant correlations between self-efficacy and readiness in either the ordinal or dichotomous scales, this result may be influenced by (a) the limited number of cases in both contemplation and preparation stages and (b) the little variation of

self-efficacy among the vast group of precontemplators. It is worth noting that in this study, actioners and maintainers at the advanced stages of readiness were excluded from the correlation test. While more than 90% completing a self-efficacy measure were precontemplators who highly preferred family's input in advance care planning, their self-efficacy scores clearly are skewed due to little variation. Their common close-to-constant level of self-efficacy may explain the low correlation between self-efficacy and stages of readiness.

On the other hand, in the qualitative data, older subjects' motivational readiness was positively related to the amount of perceived self-efficacy, which follows the TTM principles. This tendency is obvious across the six stages, including actioners and maintainers ($n = 36$) at the most advanced stages: subjects with higher readiness were more likely to have higher self-control and better support from family members. This is because the qualitative sampling purposely selected interviewees at various stages of readiness, and their self-efficacy data were segmented and compared with each other. Moreover, subjects' differing attitudes and expectations toward physicians' roles in EOL decision-making reflected their various levels of confidence regarding advance care planning. Similarly, a positive correlation was noticeable between self-efficacy and readiness in the in-depth interviews. All these qualitative findings imply that Chinese Americans' self-efficacy, sense of self-control, and expectations toward physicians may be positively and closely related to stages of readiness for advance care planning. Additional mixed-method studies are necessary in order to examine the mediating role and correlations between these two TTM constructs.

E. **Sampling Issues in This Mixed-Method Study**

Because the understanding of Chinese Americans' readiness for advance care planning is in its infancy, a cost-effective and time-efficient sampling technique was preferable to gain insight into the phenomenon of interest. A non-probability sample conveniently accessible in the target churches was therefore proposed to include only self-identified Chinese American volunteers residing in the greater Chicago area. Thus, motivational readiness for advance care planning was assessed primarily among highly educated, acculturated, and affluent first-generation immigrants who have mostly converted from traditional Chinese folklore religions to Presbyterian Christianity.

Since many Chinese American immigrants have regularly participated in church activities, and local Chinese-speaking community churches are important social settings, the attempt to use a purposive church sample was advantageous for this study. The primary advantages were that it permitted the researcher to: establish the existence of problem areas regarding advance care planning, identify and target potential candidates for interventions, and provide insights for future research directions in this cultural group. Both quantitative and qualitative results indicated that first-generation Chinese immigrants are receptive to advance care planning, and churches provide an established group setting for conducting this research, as well as for subsequent work to develop and deliver interventions promoting advance care planning. Future studies may include Chinese Americans of heterogeneous characteristics from a variety of settings in order to broaden the understanding of their stages of readiness for advance care planning.

On the other hand, a convenience sample inevitably involves sampling bias (Polit & Beck, 2004). Because not all eligible Chinese Americans in the population have an equal chance to be included in

this study, the external validity, the generalizeable inference, is limited due to the use of Christian churches for recruitment. In this study sample, the majority of highly educated, acculturated, and affluent Chinese Christians (mostly from Taiwanese and Hong Kong) might have actively supported a point of view regarding their motivational readiness for advance care planning, which may not be similar to other groups. We recognize that Chinese Americans who believe in other religions, non Chinese-speaking church-goers, those of low SES, immigrants who were raised in Mainland China, and self-identified atheists or communists have not been proportionally included in our sample. These other groups may be at a lower stage of readiness and with lower level of confidence to initiate EOL conversations within Chinese immigrant families.

F. **Conclusion**

Employing a cross-sectional mixed-method design, this study demonstrated how a trans-theoretical model can be applied to quantitatively and qualitatively characterize Chinese Americans' behavioral change regarding advance care planning. Major outcomes of this study include: (1) categorizations and dense descriptions of the stage of readiness, decisional balance, and self-efficacy; (2) identification of socio-cultural, knowledge, quality of life, spiritual, and demographical factors significantly contributing to engagement in such planning; and (3) explorations of preferable strategies to enhance Chinese Americans' future participation in intervention programs. Although the majority of the Chinese American population may be precontemplators with a lack of basic awareness of advance care planning, our results are optimistic and suggestive that they are highly motivated, prepared, and capable of executing ADs and communicating their EOL treatment

and care preferences with loved ones. In addition, findings from this relatively homogeneous sample suggest significant determinants of readiness, including factors of knowledge, gender (female), levels of education, cultural beliefs, and age, respectively. To serve the large diverse group of Chinese Americans, insights have been provided for health care providers to incorporate the TTM principles and develop a cultural intervention program. However, before intervention studies can be conducted and tested for this cultural group, in light of the paucity of literature, it is essential to have prospective and comprehensive research to determine the fit of the TTM as a theoretical framework for such behavioral change and explore additional determinants of the readiness in other heterogeneous Chinese American groups.

APPENDICES

APPENDIX A

RECRUITMENT SCRIPT AT CHURCH FOR PARTICIPATION IN RESEARCH
“Planning for Treatment and Care at the End-of-Life”
A Study of Chinese Americans’ Readiness for Advance Care Planning
University of Illinois at Chicago

Good afternoon, ladies and gentlemen. You must be very curious why I am here today at your church. My name is Yi-fang Yvonne Hsiung and I am a nursing doctoral candidate of University of Illinois at Chicago. I am also the Primary Investigator of a study of Chinese Americans’ readiness for advance care planning, “Planning for Treatment and Care at the End-of-Life.” I sincerely hope you can stay a little bit longer than you usual do and stop by the church fellowship room to participate my study. Now I am going to explain this study in more details. Please interrupt me and raise your hands if you have any questions.

The purpose of my study is to have a better understanding of Chinese Americans’ readiness toward advance care planning. It will hopefully improve our quality of health care. This study, guided by my two advisors, Professors Carol Ferrans and Karen Kavanaugh, has been approved by University of Illinois at Chicago. Now I am going to announce the inclusion criteria of this study. If you are a Chinese American who is age 45 and older, understand (traditional) Chinese, and reside within Chicago metropolitan area, I sincerely encourage you to take part in this study. You only need to fill out a questionnaire no longer than 45 minutes. In the fellowship room, I have prepared snacks and drinks to appreciate your participation in filling out this questionnaire. I strongly encourage you to complete the questionnaire here at the church, but you also have the freedom to fill out the questionnaire in your convenience time. I have prepared addressed, stamped envelopes for you to mail your answers directly back to me. Questionnaire asks about your immigration history, cultural and religious beliefs, and a variety of things about your healthcare in America, such as your past illness experiences, and personal feelings about medical treatments and advance care planning. The primary risk for this study is related to the sensitive nature of a death and dying topic, and it is possible that you may experience some emotional discomfort when answering the questionnaire. However, this is anticipated to be mild according to our previous experience. After you complete the questionnaire, if you are age 65 and older, speak fluent (traditional) Chinese, and reside within Chicago metropolitan area, please consider taking part in the interview part of this study. I will make an appointment with you for one interview (about 1-2 hours), and you can decide where the interview takes place.

Other details of this study are as follows: About 150 Chinese Americans (aged 45 and above) from four community churches will participate in the study. Your participation in this study is voluntary. You do not have to answer any questions that you do not want to, and you can stop at any time without consequences of any kind. Although I will ask you to sign the consent forms for the questionnaire and interview, your decision to participate or not will NOT result in any penalty, and will NOT affect your current or future medical care. I also will make every effort to keep the things you write on the questionnaire confidential and private. No one at the church will know what you have written. The final report will summarize the findings for the whole group of people who participate, so that no one will be able to tell who took part or what you wrote by looking at the report. The findings of the study will be published so that they can be of help to others. You can be sent a summary of the findings when the study is finished, if you would like. You will be not be given money for taking part in the study. Although there is no direct benefit to you for taking part in the study, I hope the information learned from you will benefit other Chinese Americans in the future.

To ask questions about the study, please contact me at University of Illinois at Chicago at (847) 727-2345 or write an email to yhsiun1@uic.edu. Thank you again for considering participation for this study. Please stop by the fellowship room and help me with this study. I appreciate your time in advance.

APPENDIX A (continued)

RECRUITMENT SCRIPT FOR PARTICIPATION IN RESEARCH

征召研究參與者講稿內容

“Planning for Treatment and Care at the End-of-Life”

A Study of Chinese Americans' Readiness for Advance Care Planning

研究題目：美籍華人對預定護理計畫的預備度及意願

University of Illinois at Chicago 伊利諾大學芝加哥分校

各位先生、女士午安。您一定很好奇為什麼我今天來到貴教會。我是伊利諾大學芝加哥分校護理系博士候選人熊誼芳(Yvonne Hsiung)，同時也是「美籍華人對預定護理計畫的意願」這項研究的研究主持人。我誠摯地希望您稍後留步團契室來參與這個研究。現在我將為您詳細地解釋這項研究，並歡迎各位發問。

我的研究的主旨在於了解美籍華人對預定護理計畫的意願，藉此希望可以增進我們美籍華人的醫療護理品質。此研究由卡洛費倫絲(Carol Ferrans)博士與凱倫卡凡娜(Karen Kavanaugh)博士共同指導，並且已經通過伊利諾大學芝加哥分校的研究許可。

現在我將公佈這項研究的條件：若您是年齡在四十五歲以上、懂(繁體)中文，並居住在大芝加哥地區美籍華人，我誠心地鼓勵您協助填寫一份約四十五分鐘的問卷。在團契室我備有茶點答謝您參與這個研究並填寫這份問卷。我鼓勵您盡量在教會完成問卷，但也準備了回郵信封給您直接寄還給我。問卷問題包括您的移民經歷，文化和信仰觀念，以及您在美國的醫療護理情形……等等。要知道這個研究的主要危險性僅在於「臨終及死亡」對華人而言，是個較敏感的話題。也許您在回答有關這方面的問題時，心情上會感到不舒服。但以我們之前的研究經驗得知，只有少數人可能感到輕微地不舒服。填寫問卷之後，若您是年齡在六十五歲以上，(華語)中文流利，並居住在大芝加哥地區的美籍華人，我再誠心地邀請您撥冗參與這項研究的面談部份，我將與您約定面談一次(約一至二小時)，並且您可以決定面談地點。

其他研究詳細內容如下：大約有一百五十位到二百位來自四個大芝加哥社區教會的美籍華人將會參與這個研究。您的參與是義務性質，若您不想回答某些問題，您可以隨時無條件終止問卷調查及面談。雖然我會要求您填寫「參與研究同意書」但是不論您填寫問卷或參加面談與否，將不會有任何處罰或影響到您目前及未來的醫療照護。我也將全力確保您的隱私和機密，最後的研究結果也將以團體的名義來發表公布。特別教會中也不會有任何人知道您是否參與研究，以及在研究中問答了什麼。研究成果將會公開發表做為幫助他人之用。若您有興趣的話，我們可以在研究結束之後寄一份摘要給您。您參與研究及填寫這份問卷將沒有任何金錢酬勞。雖然您的參與並沒有實質的直接利益，但是我誠摯地希望您的參與，使得本研究的成果在將來能造福更多的美籍華人，並幫助改善華人在美國的醫療護理及其它方面的服務。

若有各樣疑問，您可以隨時連絡我在伊利諾大學的電話(847)727-2345，或寫信到我的電子信箱 yhsiun1@uic.edu。

再一次謝謝您的時間！請留步團契室參與這個研究。

APPENDIX B

QUANTITATIVE SURVEY

Date: _____

Church: _____

Subject Number: _____

Investigator's note: _____

APPENDIX B (continued)

Planning for treatment and care at the end-of-life among Chinese Americans

Yvonne Hsiung & Carol E. Ferrans, 2006

University of Illinois at Chicago

CHINESE CULTURAL BELIEFS RELATED TO ADVANCE CARE PLANNING SCALE

People hold different cultural beliefs. We are interested in your opinions about traditional Chinese cultural beliefs and medical treatment decisions. Please answer the following questions in **YOUR PERSONAL VIEW** and mark (✓) the most appropriate answer.

	Always true	Quite true	A little bit true	Never true
1. Accumulating good deeds in the present life will lead to a better next life.				
2. I need to save my family's face (not embarrassing them).				
3. I should talk to my family before making any medical decisions.				
4. Keeping harmony in the family means not fighting with each other over treatment decisions.				
5. Filial piety is to respect parents' wishes to die.				
6. Filial piety is to keep dying parents alive as long as possible.				
7. Family head (Father or Big Brother) should make the final treatment decision.				
8. Not telling terminal patients their medical condition is for their own good.				

APPENDIX B (continued)

	Always true	Quite true	A little bit true	Never true
9. Doctors should make the final treatment decisions because they know better.				
10. Questioning doctors' professional suggestions for treatment is rude and inappropriate.				
11. Talking about death and dying brings bad luck.				
12. Mentioning death and dying in front of elderly people is rude and disrespectful.				
13. Treatments should be used to keep a dying family alive so that other family members can have some time to come and say goodbye.				

14. Please tell us in your own words what "a good death" means to you?

***** (Go to next page) *****

APPENDIX B (continued)

CHINESE AMERICANS' ENGLISH PROFICIENCY FOR ADVANCE CARE PLANNING

	Always true	Quite true	A little bit true	Never true
15. I have problems using English in daily life.				
16. If my doctor does not speak Chinese, I need someone to help me translate.				

17. In which language do you prefer when receiving healthcare information? Why? (please check ~ the box and write your reasons)	<input type="checkbox"/> English only, because _____	<input type="checkbox"/> English with Chinese translation, because _____	<input type="checkbox"/> Chinese only, because _____.	<input type="checkbox"/> No preference
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APPENDIX B (continued)

CHINESE AMERICANS' PREVIOUS END-OF-LIFE EXPERIENCES SCALE

The following questions ask about your **healthcare experiences** you have had before. Please mark (√) the most appropriate answer.

	Yes	No
18. I have had a life-threatening illness or accident.		
19. One of my very close family members has had life-threatening illness or accident.		
20. I have been a patient in the intensive care unit (ICU).		
21. One of my very close family members has stayed in ICU.		
22. I have taken care of a dying family member.		
23. I have participated in discussions regarding life-sustaining treatment for a very close family member.		

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APPENDIX B (continued)

CHINESE AMERICANS' KNOWLEDGE FOR ADVANCE CARE PLANNING SCALE

Please answer the following questions based on **your own understanding**. Please mark (✓) the most appropriate answer.

	Yes	No
24. BEFORE TODAY, have you heard this English term “life-sustaining treatment”		
25. BEFORE today, have you heard this Chinese term “維生治療?”		

26. Please tell us in your own words what a “life-sustaining treatment” is (you can use examples if you want to).

27. Where did you learn this term? (please mark ✓ or write your answers)	<input type="checkbox"/> Media (i.e. TV, newspapers, magazines, etc)	<input type="checkbox"/> Healthcare provider (i.e. doctors and nurses)	<input type="checkbox"/> Family and friends	<input type="checkbox"/> Others_____
28. How much do you think you understand “life-sustaining treatment (維生治療)? (Please mark ✓ or write your answers.)	<input type="checkbox"/> Very much	<input type="checkbox"/> Moderate amount	<input type="checkbox"/> A little	<input type="checkbox"/> Not at all

APPENDIX B (continued)

BEFORE TODAY, have you heard the following English terms?

			Yes	No
29. I have heard the English term "Advance Directives."				
30. I have heard the English term "Living Wills."				
31. I have heard the English term "Durable Power of Attorneys"				
32. How much do you think you understand Advance Directives?	<input type="checkbox"/> Very much	<input type="checkbox"/> Moderate amount	<input type="checkbox"/> A little	<input type="checkbox"/> Not at all

Not everyone has heard about advance care planning. "Advance Care Planning" is a process that you discuss with others and make life-sustaining treatment decisions in advance before you are too ill to speak for yourself (with no hope of recovery). Please answer the following questions and mark (✓) the most appropriate answer.

			Yes	No
33. BEFORE today, have you heard this English term "advance care planning"				
34. BEFORE today, have you heard this term in Chinese "預定治療護理計劃?"				
35. Where did you learn this term? (please mark ✓ or write your answers)	<input type="checkbox"/> media (i.e. TV, newspapers, magazines, etc)	<input type="checkbox"/> Healthcare provider (i.e. doctors and nurses)	<input type="checkbox"/> Family and friends	<input type="checkbox"/> Others_____
36. How much do you think you understand this term?	<input type="checkbox"/> Very much	<input type="checkbox"/> Moderate amount	<input type="checkbox"/> A little	<input type="checkbox"/> Not at all

37. Can you please tell us in your own words what "Advance care planning" is to you (you can use examples if you want to).

APPENDIX B (continued)

STAGE OF CHANGE FOR CHINESE AMERICANS' ADVANCE CARE PLANNING SCALE

38. Are you willing to start planning for your future life-sustaining treatment and possible care at the EOL?	<input type="checkbox"/> Yes, soon (within the next 6 months)	<input type="checkbox"/> Yes, but later (at least 6 months from now)	<input type="checkbox"/> Yes, but I do not know what time is the best time for me	<input type="checkbox"/> I don't know. if I want to know more	<input type="checkbox"/> No, I don't need to know more
39. Do you want to know more about "Advance care planning?"	<input type="checkbox"/> Yes, soon (within the next 6 months)	<input type="checkbox"/> Yes, but later (at least 6 months from now)	<input type="checkbox"/> Yes, but I do not know what time is the best time for me	<input type="checkbox"/> I don't know if I want to know more	<input type="checkbox"/> No, I don't need to know more
40. In your opinion, do you think necessary now to plan for your future life-sustaining treatment?	<input type="checkbox"/> Yes, I think so.	<input type="checkbox"/> I don't know if it is necessary.		<input type="checkbox"/> No, I don't think so.	

(Question 58, 59, 60 and 61 are also questions of this measure)

***** (Go to next page) *****

APPENDIX B (continued)

DECISIONAL BALANCE FOR CHINESE AMERICANS' ADVANCE CARE PLANNING SCALE

“Advance care planning” is a medical term, which means people can early plan for their future “life-sustaining treatment and care” before they are too ill to speak for themselves. Please tell us how much you think the following statements are true and mark (✓) the most appropriate answer.

	Always true	Quite true	A little bit true	Never true
41. Advance care planning can give me some time to prepare for a good death.				
42. Advance care planning may save money for my family by reducing medical expenses.				
43. Advance care planning may help me die the way I want.				
44. Advance care planning may decrease my family's burden at the end of my life.				
45. Advance care planning may help my doctor know my wishes for the end of my life.				
46. Advance care planning may help my family know my wishes for the end of my life.				
47. Advance care planning may possibly shorten my life.				
48. Advance care planning is against my religious beliefs.				
49. Advance care planning is not good because I should not make this decision alone.				

APPENDIX B (continued)

	Always true	Quite true	A little bit true	Never true
50. Advance care planning sounds troublesome				
51. Advance care planning is not necessary because the doctors will know the right thing to do at the end of my life.				
52. Advance care planning is bad luck and bad things may happen afterwards.				
53. Advance care planning uncomfortable because I need to think about my own death and dying.				
54. Advance care planning is not good because The family relationship may change afterwards.				
55. Advance care planning is not good and I do not want to commit to anything.				

56. Overall, do you think “advance care planning” (early planning for your future life-sustaining treatment and care at the end of life) is a good or bad idea?	<input type="checkbox"/> A good idea	<input type="checkbox"/> A bad idea	<input type="checkbox"/> I don't know
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57. Can you please tell us the reasons why you think it is a good (or bad) idea?

***** (Go to next page)*****

APPENDIX B (continued)

STAGE OF CHANGE FOR CHINESE AMERICANS' ADVANCE CARE PLANNING SCALE

For many people one outcome of the "Advance care planning" is to sign a legal document called "Advance Directives (or living wills)". Please answer the following questions and mark (✓) the most appropriate answer.

58. Have you signed an advance directive?	<input type="checkbox"/> Yes, I signed it more than 6 months ago	<input type="checkbox"/> Yes, I signed it less than 6 months ago	<input type="checkbox"/> No, I have never signed one
---	--	--	--

If your answer is **YES**, please answer the following 2 question (#61 and #62):

	Yes	No
59. If you have signed an advance directive, have you told people that you have completed an advance directive?		
60. If you have signed an advance directive, do you still talk to people about your decisions in your advance directive?		

If your answer is **No**, please answer the following 3 questions (#63, #64, and #65):

61. If you have not signed an advance directive, are you able to sign one today? (We are just interested in your opinion and will not ask you sign one today)	<input type="checkbox"/> Yes	<input type="checkbox"/> I do not know	<input type="checkbox"/> No
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APPENDIX B (continued)

SELF-EFFICACY FOR CHINESE AMERICANS' ADVANCE CARE PLANNING SCALE

62. Do you need to get someone's approval to sign an advance directive document?	<input type="checkbox"/> Yes, I need to get approval from _____	<input type="checkbox"/> Maybe, I need to get approval from _____	<input type="checkbox"/> No need to obtain anyone's approval
63. I prefer discussing with others before signing this document about my future life-sustaining treatment.	<input type="checkbox"/> Yes, I need to discuss with _____, because _____	<input type="checkbox"/> I don't know	<input type="checkbox"/> No, I don't need to discuss with anyone. I can make the decision myself.

***** (Go to next page) *****

APPENDIX B (continued)

DEMOGRAPHICAL QUESTIONS

Last, we have several questions regarding your personal information. Please select the answer that best fits your situation.

64. What is your age on your last birthday?					_____ year-old						
65. What is your gender?					<input type="checkbox"/> Male				<input type="checkbox"/> Female		
66. What is your marital status?		<input type="checkbox"/> Single/Never married		<input type="checkbox"/> Married Partnered	<input type="checkbox"/> Widowed		<input type="checkbox"/> Divorced Separated		Other _____		
67. How many parents are still alive?					<input type="checkbox"/> 2		<input type="checkbox"/> 1		<input type="checkbox"/> 0		
68. What is your highest level of education you have completed?	<input type="checkbox"/> Doctoral degree	<input type="checkbox"/> Master's degree	<input type="checkbox"/> Bachelor's degree	<input type="checkbox"/> College Technical school	<input type="checkbox"/> Senior High school	<input type="checkbox"/> Junior High school	<input type="checkbox"/> Elementary school	<input type="checkbox"/> Some education but no diploma	<input type="checkbox"/> None	<input type="checkbox"/> Other _____	
69. What is your employment status?	<input type="checkbox"/> Disabled		<input type="checkbox"/> Retired		<input type="checkbox"/> Employed		<input type="checkbox"/> Housewives		<input type="checkbox"/> Unemployed		<input type="checkbox"/> Other _____

70. Considering all your income from employment and from all other sources for everyone in your household, which best describes your annual income?	<input type="checkbox"/> \$100,000 or more (USD)	<input type="checkbox"/> \$75,000 to \$99,999	<input type="checkbox"/> \$50,000 to \$74,999	<input type="checkbox"/> \$35,000 to \$49,999	<input type="checkbox"/> \$25,000 to \$34,999	<input type="checkbox"/> \$15,000 to \$24,999	<input type="checkbox"/> \$10,000 to \$14,999	<input type="checkbox"/> \$5,000 to \$9,999	<input type="checkbox"/> Less than \$5,000 (USD)
71. In what religion were you raised in your family?	<input type="checkbox"/> Atheist	<input type="checkbox"/> Buddhist	<input type="checkbox"/> Taoist Taiwanese tradition	<input type="checkbox"/> Muslim	<input type="checkbox"/> Catholic Christian	<input type="checkbox"/> No preference	<input type="checkbox"/> Other		
72. What is your current religious preference?	<input type="checkbox"/> Atheist	<input type="checkbox"/> Buddhist	<input type="checkbox"/> Taoist Taiwanese tradition	<input type="checkbox"/> Muslim	<input type="checkbox"/> Catholic Christian	<input type="checkbox"/> No preference	<input type="checkbox"/> Other		
73. Has your religion changed after you come to the United States?					<input type="checkbox"/> Yes		<input type="checkbox"/> No		

APPENDIX B (continued)

CHINESE AMERICANS' SELF-RATED RELIGIOSITY

74. How often do you participate in your religious activities?	<input type="checkbox"/> More than twice a week	<input type="checkbox"/> Weekly	<input type="checkbox"/> Two to three times a month	<input type="checkbox"/> Monthly	<input type="checkbox"/> Annually	<input type="checkbox"/> Never
75. How religious are you compared to other people in your religion?	<input type="checkbox"/> Very religious	<input type="checkbox"/> Quite religious	<input type="checkbox"/> Moderately religious	<input type="checkbox"/> A little bit religious	<input type="checkbox"/> Not religious at all	

APPENDIX B (continued)

PREFERRED INTERVENTION STRATEGIES FOR ADVANCE CARE PLANNING

Yvonne Hsiung & Carol E. Ferrans, 2006

University of Illinois at Chicago

At the end of life, when people are dying (with no hope of recovery), there are decisions that need to be made about what medical treatments should be given or not given. "Advance Care Planning" is making this type of treatment decisions in advance before you are too ill to speak for yourself. We would like your help in developing such a advance care planning program for Chinese Americans.

1. First of all, please tell us would you (or members of your family) be interested in such a program?

☐ Yes

☐ No

There are different ways that programs like this can be offered. Please let us know which would work best for you?

2. How would you prefer this program to be offered?

☐ In a small group (less than 10 people)

☐ In a large group (more than 10 people)

☐ Individually (one-on-one)

APPENDIX B (continued)

3. Who would you prefer to participate with you in this program? (Please mark **ALL** that apply)

- ☐ No preference
- ☐ Self-learning at home
- ☐ Strangers only
- ☐ People I know
- ☐ People I know of my gender
- ☐ People I know and with similar ages
- ☐ Only my family members
- ☐ Other_____

4. Which of the following activities would you prefer in the program? (Please mark **ALL** that apply)

- ☐ Group discussion
- ☐ Lecture
- ☐ Written materials
- ☐ Videotapes/DVD
- ☐ Audiotapes/CD
- ☐ Work on the computer
- ☐ Other_____

5. How long would you prefer each session to last?

- ☐ No more than 1 hour
- ☐ No more than 2 hours
- ☐ 4 hours with a break in between
- ☐ An entire day (more than 4 hours) with breaks in between
- ☐ None of the above_____

APPENDIX B (continued)

6. How often would you be willing to come?

- ☐ Every week
- ☐ Every other week
- ☐ Once a month
- ☐ Other _____

7. Where should the program be? (Please check **ALL** that apply)

- ☐ In my church
- ☐ In the library
- ☐ In a school
- ☐ In a hospital setting
- ☐ Other _____.

8. What would make you **WANT** to come to this kind of program?

9. What would make you **NOT** want to come?

Thank you for your participation! Please continue to fill out the rest of the questions.

APPENDIX B (continued)

PLANNING FOR TREATMENT AND CARE AT THE END-OF-LIFE AMONG CHINESE AMERICANS

計劃您未來的維生治療及護理照顧 (美籍華人對預定護理計畫的意願調查)

Yvonne Hsiung 熊誼芳 & Carol Ferrans 卡洛費倫絲 西元 2007 年 University of Illinois at Chicago 伊利諾大學芝加哥分校

每個人的文化信仰都不相同。我們想了解您對於 傳統中華文化信仰 和 醫療護理決定 有什麼想法。

請針對以下的敘述，按照您自己本身同意(或不同意)的程度，在適當的格子中打勾 (~)。

	Always true 總是非常同意	Quite true 相當地同意	A little bit true 稍微有點同意	Never true 完全不同意
1. 在今世多積功德，多做善事就能夠擁有更好的來生				
2. 我必須保留家人的面子（不讓他們覺得丟臉）。				
3. 在做任何有關醫療方面的決定前，我必須要跟家人商量。				
4. 保持家庭和諧就是不在醫療決定上與家人起爭執。				
5. 孝道的一種表現是尊重父母想結束生命的意願。				

***** (請繼續下頁) *****

	Always true 總是非常同意	Quite true 相當地同意	A little bit true 稍微有點同意	Never true 完全不同意
6. 孝道的另一種表現，是能夠讓病重臨終的父母活得更久一點。				
7. 家族的男性家長（父親或長兄）應該有權做最後的醫療決定。				
8. 不告訴臨終病人他們的病情，是為了他(她)們著想。				
9. 醫師應該作最後的醫療決定，因為他們懂得比較多。				
10. 質疑醫師對治療的專業判斷是不恰當且無禮的。				
11. 討論死亡和臨終之類的事不大吉利。				
12. 在老年人面前談論死亡和臨終之類的事，是不尊敬他們且無禮的。				
13. 為了能夠讓其它的親人有機會向臨終的家人道別，用醫療延續他(她)的生命是有必要的。				

14. 請告訴我們「好死（善終）」對您來說是什麼。

***** (請繼續下頁) *****

APPENDIX B (continued)

以下的問題是有關您的**英語能力及醫療資訊取得**，請告訴我們您的答案，並在適當的格子中打勾（☐）。

	Always true 總是非常同意	Quite true 相當地同意	A little bit true 稍微有點同意	Never true 完全不同意
15. 我的英文不夠應付日常生活。				
16. 若是我的醫師不會說中文，我需要有人替我翻譯英文。				
17. 您偏好哪種語言的醫療健康資訊？為什麼？(請在一個適當的格子中打勾 <input type="checkbox"/> 並告訴我們您的答案)	<input type="checkbox"/> 英文 因為： _____ _____	<input type="checkbox"/> 英文且附上中文翻譯 因為： _____ _____	<input type="checkbox"/> 中文 因為： _____ _____	<input type="checkbox"/> 無偏好 因為： _____ _____

***** (請繼續下頁) *****

APPENDIX B (continued)

以下的問題是有關您及家人**過去的醫療經驗**，請告訴我們您的答案，並在適當的格子中打勾（☐）。

	Yes (是/曾經)	No (否/不曾)
18. 我曾經罹患致命的疾病或遭遇重大意外。		
19. 我的至親之一曾經患致命的疾病或遭遇重大意外。		
20. 我曾是加護病房病患。		
21. 我的至親之一也曾是住在加護病房的病患。		
22. 我曾經照顧過瀕死臨終的家人。		
23. 我曾參與討論是否決定用醫療延續臨終家人生命。		

***** (請繼續下頁) *****

APPENDIX B (continued)

在美國的醫療系統當中，臨終的病人（也就是沒有治癒希望時）常需要討論決定給予或不給予哪些治療。

“預定護理計劃”是人民在美國的一種治療抉擇權----在病人過分病重而不能夠表達和決定護理安排之前，他們可以事先考慮和決定他們將來想要的治療和護理，為確保自己在這方面的選擇能得到家人及醫師的尊重。在美國並沒有太多華人知道或是聽過“預定護理計劃”及相關的資訊。

我們想多了解您的想法，下列問題是有關您對這方面的了解，請告訴我們您的答案，並在適當的格子中打勾（✓）。

請在適當的格子中打勾（✓）	Yes 是/有	No 否/沒有
24. 在今天之前，您是否有聽說過這個英文字詞 “Life-Sustaining Treatment”?		
25. 在今天之前，您是否有聽說過這個中文字詞 「維生治療」?		

26. 以您自己的話，請告訴我們您對「維生治療」（Life-sustaining Treatment）的了解（若您想舉例也可以）。

***** (請繼續下頁) *****

APPENDIX B (continued)

27. 您是在哪裡第一次聽到或學到「維生治療」(Life-sustaining Treatment) 這個字詞的?	<input type="checkbox"/> 媒體 (如電視報章雜誌等)	<input type="checkbox"/> 醫療機構 及醫護人員	<input type="checkbox"/> 家人及朋友	<input type="checkbox"/> 其他 (請填寫在哪裡聽到學到的) _____
28. 再來請問您對「維生治療」(Life-sustaining Treatment) 這個字詞的了解有多少?	<input type="checkbox"/> 非常地了解	<input type="checkbox"/> 中等程度的了解	<input type="checkbox"/> 了解一點點	<input type="checkbox"/> 完全不了解
請在適當的格子中打勾 (~)			Yes 是/有	No 否/沒有
29. 在今天之前，您是否有聽說過這個英文字詞 “Advance Directives”?				
30. 在今天之前，您是否有聽說過這個英文字詞 “Living Wills”?				
31. 在今天之前，您是否有聽說過這個英文字詞 “Durable Power of Attorneys”?				
32. 請問您對 Advance Directives 「預立醫囑」這個字詞的了解有多少?	<input type="checkbox"/> 非常地了解	<input type="checkbox"/> 中等程度的了解	<input type="checkbox"/> 了解一點點	<input type="checkbox"/> 完全不了解

***** (請繼續下頁) *****

APPENDIX B (continued)

到目前為止並沒有很多人聽說過「預定護理計畫」。如同之前提過的，在美國的醫療系統當中，臨終的病人（也就是沒有治癒希望時）常需要討論決定給予或不給予哪些治療。“預定護理計畫”是人民在美國的一種治療抉擇權--在病人過分病重而不能夠表達和決定護理安排之前，他們可以事先考慮和決定他們將來想要的治療和護理，為確保自己在這方面的選擇，能得到家人及醫師的尊重。

請回答以下問題，並在適當的格子中打勾（✓）及填寫您的答案。			Yes 是/有	No 否/沒有
33. 在今天之前，您是否有聽說過“Advance Care Planning”這個英文字詞？				
34. 在今天之前，您是否有聽說過「預定護理計畫」這個中文字詞？“				
35. 您是在哪裡聽到或學到「預定護理計畫」“Advance Care Planning”這個字詞的？	<input type="checkbox"/> 媒體 (如電視報章雜誌等)	<input type="checkbox"/> 醫療機構 及醫 護人員	<input type="checkbox"/> 家人及朋友	<input type="checkbox"/> 其他 (請填寫 在哪裡學到的) _____
36. 請問您對 Advance Care Planning 「預定護理計畫」這個字詞的了解有多少？	<input type="checkbox"/> 非常地了解	<input type="checkbox"/> 中等程度的了 解	<input type="checkbox"/> 了解一點點	<input type="checkbox"/> 完全不了解

37. 以您自己的話，請告訴我們您對 Advance Care Planning 「預定護理計畫」的了解（若您想舉例也可以）。

***** (請繼續下頁) *****

APPENDIX B (continued)

38. 您是否願意開始計劃您未來臨終之時的維生治療及護理照顧？	<input type="checkbox"/> 願意，越快越好（最好六個月內）	<input type="checkbox"/> 願意，但晚一點（至少六個月之後）	<input type="checkbox"/> 願意，但我不知道什麼時候開始計劃最好	<input type="checkbox"/> 我不知道是否有需要	<input type="checkbox"/> 不願意，我認為我沒有需要
39. 您願意不願意知道更多有關預定護理計劃的資訊呢？	<input type="checkbox"/> 願意，越快越好（最好六個月內）	<input type="checkbox"/> 願意，但晚一點（至少六個月之後）	<input type="checkbox"/> 願意，但我不知道什麼時候開始最好	<input type="checkbox"/> 我不知道是否有需要	<input type="checkbox"/> 不願意，我認為沒有需要
40. 您認為現在有無必要開始計劃未來臨終之時的維生治療及護理照顧呢？	<input type="checkbox"/> 我認為有必要		<input type="checkbox"/> 我不知道是否有必要	<input type="checkbox"/> 我認為沒有必要	

***** (請繼續下頁) *****

APPENDIX B (continued)

您覺得“預先”擬訂治療護理計劃(在臨終病重而不能夠表達之前)，是否是個好主意呢？我們列出了一些想法，想聽聽您的意見，請依照您本身對以下的敘述同意或不同意的程度，在適當的格子中打勾（✓）。

	Always true 總是非常同意	Quite true 相當地同意	A little bit true 稍微有點同意	Never true 完全不同意
41. 我因此有時間準備善終事宜。				
42. 我因此可以為家人節省下不必要的醫療花費。				
43. 我可以選擇用我想要的方式離開這個世界。				
44. 在我臨終時能可以減少家人的負擔。				
45. 我的醫師因此可以事先了解我臨終時的醫療意願。				
46. 我的家人因此可以事先了解我臨終時的醫療意願。				
47. 我的壽命可能因此縮短（活的可能沒原來長）。				
48. 這和我的宗教信仰相互抵觸。				

***** (請繼續下頁) *****

APPENDIX B (continued)

	Always true 總是非常同意	Quite true 相當地同意	A little bit true 稍微有點同意	Never true 完全不同意
49. 我原不該獨自做醫療決定。				
50. 我還得簽署法律文件。				
51. 反正醫生到時會知道如何為我臨終時做醫療決定				
52. 討論這些不太吉利而且觸霉頭。				
53. 想到自己的臨終和死亡總讓人覺得不舒服。				
54. 家人關係可能因著有「預定護理計畫」有所改變。				
55. 我不想先作任何決定或作任何承諾。				

56. 總括來說，您認為「預定護理計畫」(事先計劃您未來臨終的維生治療及護理照顧) 是不是個好主意呢？	<input type="checkbox"/> 是個好主意	<input type="checkbox"/> 是個爛主意	<input type="checkbox"/> 我不知道
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57. 請告訴我們您認為「預定護理計畫」是個好主意 (或是個爛主意)的想法或理由。

***** (請繼續下頁) *****

對許多人來說「預定護理計畫」的最終目的是填寫「醫療授權書」(Advance Directives) 或「生前預囑」(Living Wills) 的法律文件。請回答以下問題，並在適當的格子中打勾 (✓) 及填寫您的答案。

58. 請問您已經簽署「醫療授權書」(Advance Directives) 或「生前預囑」(Living Wills)了嗎？	<input type="checkbox"/> 是的，比六個月還更早以前	<input type="checkbox"/> 是的，還不到六個月	<input type="checkbox"/> 沒有，我還沒有簽署
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若您 **已經簽署**「醫療授權書」或「生前預囑」請回答以下兩個問題 (#59 & #60):

59. 您有沒有告訴過別人，您已經簽署「醫療授權書」或「生前預囑」這件事？	<input type="checkbox"/> 有告訴過別人	<input type="checkbox"/> 沒有告訴過別人
60. 您仍持續地和他人溝通那些您簽署在「醫療授權書」或「生前預囑」上的治療及護理決定嗎？	<input type="checkbox"/> 是的，我仍持續地和他人溝通我的維生治療及護理照顧決定	<input type="checkbox"/> 沒有，我沒有再和他人溝通我的維生治療及護理照顧決定

若您 **尚未簽署**「醫療授權書」或「生前預囑」請回答以下三個問題(#61, #62, & #63):

61. 若您尚未簽署「醫療授權書」或「生前預囑」，您今天是否能夠決定簽署呢？(我們只想了解您的意願，今天不會要求您簽署)	<input type="checkbox"/> 可以	<input type="checkbox"/> 不行	<input type="checkbox"/> 我不知道
62. 您需要得到別人同意才能簽署「醫療授權書」或「生前預囑」嗎？	<input type="checkbox"/> 是的，我需要得到別人同意	<input type="checkbox"/> 沒有，我不需要得到別人同意	<input type="checkbox"/> 我不知道
63. 您需要和別人討論才能簽署「醫療授權書」或「生前預囑」嗎？	<input type="checkbox"/> 是的，我需要和_____討論	<input type="checkbox"/> 沒有，我不需要和別人討論	<input type="checkbox"/> 我不知道該不該和別人討論

***** (請繼續下頁個人資料部份) *****

最後，我們有一些關於您 **個人資料** 的問題，請依照您目前的情況回答，並在適當的格子中打勾（☐）及填寫您的答案。

64. 您上次生日是幾歲？						_____歲					
65. 您的性別是？						<input type="checkbox"/> 男			<input type="checkbox"/> 女		
66. 您目前的婚姻狀況？		<input type="checkbox"/> 未婚/單身		<input type="checkbox"/> 已婚/有固定伴侶		<input type="checkbox"/> 喪偶		<input type="checkbox"/> 離婚/分居		<input type="checkbox"/> 其他 _____ _____	
67. 您的父母親還健在嗎？						<input type="checkbox"/> 兩位都健在		<input type="checkbox"/> 一位尚健在		<input type="checkbox"/> 都不在世上	
68. 您的最高學歷	<input type="checkbox"/> 博士	<input type="checkbox"/> 碩士	<input type="checkbox"/> 大學	<input type="checkbox"/> 大專院校	<input type="checkbox"/> 高中	<input type="checkbox"/> 初中	<input type="checkbox"/> 小學	<input type="checkbox"/> 受一些教育但無文憑	<input type="checkbox"/> 未受教育	其他 _____ _____	
69. 您目前的工作情況？	<input type="checkbox"/> 身心傷殘		<input type="checkbox"/> 退休		<input type="checkbox"/> 受雇		<input type="checkbox"/> 家管		<input type="checkbox"/> 無工作		<input type="checkbox"/> 其他 _____ _____
70. 您一年的家庭總收入有多少？(包括您全家人上班收入及其他經濟來源)	<input type="checkbox"/> 超過 \$100,000 美元	<input type="checkbox"/> \$75,000 ~ \$99,999 美元	<input type="checkbox"/> \$50,000 ~ \$74,999 美元	<input type="checkbox"/> \$35,000 ~ \$49,999 美元	<input type="checkbox"/> \$25,000 ~ \$34,999 美元	<input type="checkbox"/> \$15,000 ~ \$24,999 美元	<input type="checkbox"/> \$10,000 ~ \$14,999 美元	<input type="checkbox"/> \$5,000 ~ 9,999 美元	<input type="checkbox"/> 少於 \$5,000 美元		

71. 請問您是在何種家庭宗教信仰下成長的?	<input type="checkbox"/> 無神論	<input type="checkbox"/> 佛教	<input type="checkbox"/> 道教及民間信仰	<input type="checkbox"/> 回教	<input type="checkbox"/> 天主教或基督教	<input type="checkbox"/> 無特殊信仰	<input type="checkbox"/> 其他 _____
72. 請問您目前的宗教信仰是?	<input type="checkbox"/> 無神論	<input type="checkbox"/> 佛教	<input type="checkbox"/> 道教及民間信仰	<input type="checkbox"/> 回教	<input type="checkbox"/> 天主教或基督教	<input type="checkbox"/> 無特殊信仰	<input type="checkbox"/> 其他 _____
73. 您的信仰在來美國之後有改變嗎?	<input type="checkbox"/> 有				<input type="checkbox"/> 沒有		

74. 您參與宗教活動頻繁的程度?	<input type="checkbox"/> 每週超過一次	<input type="checkbox"/> 每週一次	<input type="checkbox"/> 一個月一次	<input type="checkbox"/> 一年一度	<input type="checkbox"/> 從未參加
75. 和其它的信徒相比，您認為您信仰虔誠嗎?	<input type="checkbox"/> 非常虔誠	<input type="checkbox"/> 蠻虔誠的	<input type="checkbox"/> 中等虔誠	<input type="checkbox"/> 只有一點虔誠	<input type="checkbox"/> 一點也不

***** (請繼續以下有關華人屬意的預定護理計畫課程) *****

APPENDIX B (continued)

Chinese Americans' Preferred Intervention strategies for advance care planning 華人屬意的預定護理計畫課程

Yvonne Hsiung 熊誼芳 & Carol Ferrans 卡洛費倫絲 2006 年

伊利諾大學芝加哥分校

美國的醫療系統當中，臨終的病人（也就是沒有治癒希望時）常需要討論決定給予或不給予哪些治療。“預定護理計畫”是人民在美國的一種治療抉擇權--在病人過分病重而不能夠表達和決定護理安排之前，他們可以事先考慮和決定他們將來想要的治療和護理，為確保自己在這方面的選擇能得到家人及醫師為的尊重。我們希望藉由您的幫助來發展出一套**適合美籍華人的「預定護理計畫」**課程。

下列有一些不同的**課程規畫**，請告訴我們那一種比較適合您，您比較喜歡。請選出您較喜好的安排，在適當的格子中打勾（☐）或填寫您的答案。

1. 首先，請告訴我們您或您的家人是否可能對這個課程有興趣？	<input type="checkbox"/> 是/有	<input type="checkbox"/> 否/沒有
2. 您覺得最適當的課程人數(只選一項最適當的)	<input type="checkbox"/> 單獨(一對一)	<input type="checkbox"/> 小班制 (少於十人) <input type="checkbox"/> 大班制 (多於十人)

3. 你希望誰與你一起參與像這樣的課程？(可複選 所有您喜好的安排)

- | | |
|---------------------------------------|---|
| <input type="checkbox"/> 無偏好 | <input type="checkbox"/> 只想和認識且差不多年齡的朋友一起參與 |
| <input type="checkbox"/> 不和誰，在家自我學習 | <input type="checkbox"/> 只想和家人一起參與 |
| <input type="checkbox"/> 最好和不認識的人一起參與 | <input type="checkbox"/> 只想和認識的人且同性別的朋友一起參與 |
| <input type="checkbox"/> 只想和認識的人一起參與 | <input type="checkbox"/> 其他 _____ |

APPENDIX B (continued)

4. 您認為課程中有下列那些內容較有趣? (可複選 所有您喜好的安排)

- | | |
|-------------------------------|-----------------------------------|
| <input type="checkbox"/> 團體討論 | <input type="checkbox"/> 聽錄音帶或 CD |
| <input type="checkbox"/> 講座 | <input type="checkbox"/> 電腦上機 |
| <input type="checkbox"/> 閱讀資料 | <input type="checkbox"/> 其他_____ |
| <input type="checkbox"/> 觀賞影片 | |

5. 您認為課程設計以每節課時間多長較適宜? (只選一項您最認為最適當的)

- | | |
|--|--------------------------------------|
| <input type="checkbox"/> 不超過一小時 | |
| <input type="checkbox"/> 不超過二小時 | |
| <input type="checkbox"/> 四小時但中間有下課 | |
| <input type="checkbox"/> 全天(超過四小時)但中間有下課 | <input type="checkbox"/> 都不是 其他_____ |

6. 您願意多久來上一次課? (只選一項您最認為最適當的)

- | |
|------------------------------------|
| <input type="checkbox"/> 每週一次 |
| <input type="checkbox"/> 每二週(隔週)一次 |
| <input type="checkbox"/> 每月一次 |
| <input type="checkbox"/> 其他 _____ |

APPENDIX B (continued)

7. 您認為課程地點在哪裏較適宜? (可複選 所有您喜好的安排)
- ☐ 就在自己教會內
- ☐ 在社區圖書館內
- ☐ 在學校內
- ☐ 在醫療相關機構內
- ☐ 其他 _____
8. 請建議我們，在什麼條件或情況下會使您更想要參加像這樣的課程 (有關計劃您未來維生治療及護理照顧的課程)?
- _____
9. 請建議我們，那些條件或情況反而會使您不想參加像這樣的課程(有關計劃您未來維生治療及護理照顧的課程)?
- _____
- _____

Thank you for your participation! 非常感謝您對本研究的參與及支持!

APPENDIX B (continued)

TRIANDIS & GELFAND**INDIVIDUALISM AND COLLECTIVISM SCALE**

I would now like to give a brief set of statements and ask you to answer each of them For each statement, please let me know if you strongly disagree, somewhat disagree, or neither agree nor disagree with each, somewhat agree, strongly agree. Please remember, there is no right or wrong answers, just your opinions about each.					
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
1. I'd rather depend on myself than others.					
2. I rely on my self most of the time; I rarely rely on others.					
3. I often do "my own things"					
4. My personal identity, independent of others is very important to me.					
5. It is important that I do my job.					
6. Winning is everything					
7. Competition is the law of nature					
8. When another person does better than I do, I get tense and aroused					
9. If a coworker gets a prize, I would feel proud.					
10. The well-being of my coworkers is important to me					

APPENDIX B (continued)
TRIANDIS & GELFAND
INDIVIDUALISM AND COLLECTIVISM SCALE (continued)

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
11. To me, pleasure is spending time with others					
12. I feel good when I cooperate with others					
13. Parents and children must stay together					
14. It is my duty to take care of my family, even when I have to sacrifice what I want					
15. Family members should stick together, no matter what sacrifices are required					
16. It is important to me that I respect the decisions made by my groups					

Chinese American's Readiness for Advance Care Planning-UIC
Survey Instrument: Triandis_Gelfand's IC scale
English, version #2, June 17, 2007

APPENDIX B (continued)

TRIANDIS & GELFAND INDIVIDUALISM AND COLLECTIVISM SCALE**個人主義與集體主義量表**

現在我將給您一份簡短的問卷並請您回答每一題。下列是有關個人主義與集體主義的一些敘述，請針對以下的敘述，按照您自己本身同意(或不同意)的程度，在適當的格子中打勾 (✓)。這些回答純粹只是您的個人意見，並沒有一定的標準答案。

	非常 同意	有些 同意	沒有同意 也不反對	不太 同意	非常地 不同意
1. 我選擇依靠自己不依靠他人。					
2. 大部份時候我依靠自己，很少依靠他人。					
3. 我常常是「自己作自己的事」。					
4. 我的個人認同(不同於他人) 對我很重要。					
5. 能作自己想作的對我很重要。					
6. 獲勝就是一切。					
7. 競爭是自然的法則。					
8. 當有其它人做得比我好時，我就神經繃緊心理激動起來。					
9. 若是我的同事得獎賞，我也覺得驕傲。					
10. 我的同事的健康對我很重要。					
11. 對我來說，花時間和別人在一起是一種喜悅					
12. 我覺得和別人合作的感覺很棒。					
13. 父母和孩子必須儘量待在一起。					
14. 照顧父母是我的責任，即便是要我犧牲我想要的東西。					
15. 家人應該在一起，無論付上什麼代價。					
16. 對我來說，我尊重我的群體所做的決定是很重要的。					

APPENDIX B (continued)

SUINN-LEW ASIAN SELF-IDENTITY ACCULTURATION SCALE (SL-ASIA)

The questions which follow are for the purpose of collecting information about your historical background as well as more recent behaviors which may be related to your cultural identity. **Choose the one answer** which best describes you.

1. What language can you speak?
 1. Asian only (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
 2. Mostly Asian, some English
 3. Asian and English about equally well (bilingual)
 4. Mostly English, some Asian
 5. Only English
2. What language do you prefer?
 1. Asian only (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
 2. Mostly Asian, some English
 3. Asian and English about equally well (bilingual)
 4. Mostly English, some Asian
 5. Only English
3. How do you identify yourself?
 1. Oriental
 2. Asian
 3. Asian-American
 4. Chinese-American, Japanese-American, Korean-American, etc.
 5. American
4. Which identification does (did) your mother use?
 1. Oriental
 2. Asian
 3. Asian-American
 4. Chinese-American, Japanese-American, Korean-American, etc.
 5. American
5. Which identification does (did) your father use?
 1. Oriental
 2. Asian
 3. Asian-American
 4. Chinese-American, Japanese-American, Korean-American, etc.
 5. American

APPENDIX B (continued)

6. What was the ethnic origin of the friends and peers you had, as a child up to age 6?
 1. Almost exclusively Asians, Asian-Americans, Orientals
 2. Mostly Asians, Asian-Americans, Orientals
 3. About equally Asian groups and Anglo groups
 4. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
 5. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
7. What was the ethnic origin of the friends and peers you had, as a child from 6 to 18?
 1. Almost exclusively Asians, Asian-Americans, Orientals
 2. Mostly Asians, Asian-Americans, Orientals
 3. About equally Asian groups and Anglo groups
 4. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
 5. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
8. Whom do you now associate with in the community?
 1. Almost exclusively Asians, Asian-Americans, Orientals
 2. Mostly Asians, Asian-Americans, Orientals
 3. About equally Asian groups and Anglo groups
 4. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
 5. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
9. If you could pick, whom would you prefer to associate with in the community?
 1. Almost exclusively Asians, Asian-Americans, Orientals
 2. Mostly Asians, Asian-Americans, Orientals
 3. About equally Asian groups and Anglo groups
 4. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
 5. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
10. What is your music preference?
 1. Only Asian music (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
 2. Mostly Asian
 3. Equally Asian and English
 4. Mostly English
 5. English only
11. What is your movie preference?
 1. Asian-language movies only
 2. Asian-language movies mostly
 3. Equally Asian/English English-language movies
 4. Mostly English-language movies only
 5. English-language movies only
12. What generation are you? (circle the generation that best applies to you:)

1st Generation = I was born in Asia or country other than U.S.

2nd Generation = I was born in U.S., either parent was born in Asia or country other than U.S.

3rd Generation = I was born in U.S., both parents were born in U.S., and all grandparents born in Asia or country other than U.S.

4th Generation = I was born in U.S., both parents were born in U.S., and at least one grandparent born in Asia or country other than U.S. and one grandparent born in U.S.

5th Generation = I was born in U.S., both parents were born in U.S., and all grandparents also born in U.S.; Don't know what generation best fits since I lack some information.

13. Where were you raised?

1. In Asia only
2. Mostly in Asia, some in U.S.
3. Equally in Asia and U.S.
4. Mostly in U.S., some in Asia
5. In U.S. only

14. What contact have you had with Asia?

1. Raised one year or more in Asia
2. Lived for less than one year in Asia
3. Occasional visits to Asia
4. Occasional communications (letters, phone calls, etc.) with people in Asia
5. No exposure or communications with people in Asia

15. What is your food preference at home?

1. Exclusively Asian food
2. Mostly Asian food, some American
3. About equally Asian and American
4. Mostly American food
5. Exclusively American food

16. What is your food preference in restaurants?

1. Exclusively Asian food
2. Mostly Asian food, some American
3. About equally Asian and American
4. Mostly American food
5. Exclusively American food

17. Do you

1. Read only an Asian language?
2. Read an Asian language better than English?
3. Read both Asian and English equally well?
4. Read English better than an Asian language?
5. Read only English?

APPENDIX B (continued)

18. Do you
 1. Write only an Asian language?
 2. Write an Asian language better than English?
 3. Write both Asian and English equally well?
 4. Write English better than an Asian language?
 5. Write only English?
19. If you consider yourself a member of the Asian group (Oriental, Asian, Asian-American, Chinese-American, etc., whatever term you prefer), how much pride do you have in this group?
 1. Extremely proud
 2. Moderately proud
 3. Little pride
 4. No pride but do not feel negative toward group
 5. No pride but do feel negative toward group
20. How would you rate yourself?
 1. Very Asian
 2. Mostly Asian
 3. Bicultural
 4. Mostly Westernized
 5. Very Westernized
21. Do you participate in Asian occasions, holidays, traditions, etc.?
 1. Nearly all
 2. Most of them
 3. Some of them
 4. A few of them
 5. None at all

THE SUINN-LEW ASIA SELF-IDENTITY ACCULTURATION SCALE

亞裔自我認同-文化淺移默化量表

以下是一些有關您生長背景及文化認同的問題。請您每題只選擇一個最適當的答案，並在格子中打勾（ <input type="checkbox"/> ）。					
1. 您會哪一種語言？	<input type="checkbox"/> 只有中文	<input type="checkbox"/> 大部份中文一些英文	<input type="checkbox"/> 中文和英文一樣好(雙語)	<input type="checkbox"/> 大部份英文一些中文	<input type="checkbox"/> 只有英文
2. 您較喜歡用哪一種語言？	<input type="checkbox"/> 只有中文	<input type="checkbox"/> 大部份中文一些英文	<input type="checkbox"/> 中文和英文一樣好(雙語)	<input type="checkbox"/> 大部份英文一些中文	<input type="checkbox"/> 只有英文
3. 您如何認同自己？	<input type="checkbox"/> 東方人	<input type="checkbox"/> 亞洲人	<input type="checkbox"/> 亞裔美國人	<input type="checkbox"/> 華裔美國人	<input type="checkbox"/> 美國人
4. 您母親如何認同她自己？	<input type="checkbox"/> 東方人	<input type="checkbox"/> 亞洲人	<input type="checkbox"/> 亞裔美國人	<input type="checkbox"/> 華裔美國人	<input type="checkbox"/> 美國人
5. 您父親如何認同它自己？	<input type="checkbox"/> 東方人	<input type="checkbox"/> 亞洲人	<input type="checkbox"/> 亞裔美國人	<input type="checkbox"/> 華裔美國人	<input type="checkbox"/> 美國人
6. 六歲以前，您的朋友同伴是什麼種族的？	<input type="checkbox"/> 完全是東方人亞洲人(華人)或 亞裔美國人	<input type="checkbox"/> 大部份是東方人、亞洲人(華人)、或亞裔美國人	<input type="checkbox"/> 一半是亞洲人(華人)或亞裔美國人、一半是歐裔人	<input type="checkbox"/> 大部份是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人	<input type="checkbox"/> 完全是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人
7. 從六歲到十八歲，您的朋友同伴是什麼種族的？	<input type="checkbox"/> 完全是東方人亞洲人(華人)或 亞裔美國人	<input type="checkbox"/> 大部份是東方人、亞洲人(華人)、或亞裔美國人	<input type="checkbox"/> 一半是亞洲人(華人)或亞裔美國人、一半是歐裔人	<input type="checkbox"/> 大部份是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人	<input type="checkbox"/> 完全是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人
8. 目前您社交圈的朋友同伴是什麼種族的？	<input type="checkbox"/> 完全是東方人亞洲人(華人)或 亞裔美國人	<input type="checkbox"/> 大部份是東方人、亞洲人(華人)、或 亞裔美國人	<input type="checkbox"/> 一半是亞洲人(華人)或亞裔美國人、一半是歐裔人	<input type="checkbox"/> 大部份是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人	<input type="checkbox"/> 完全是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人

9. 如果可以選擇，您想要在社區中和什麼種族的人交往？	<input type="checkbox"/> 完全是東方人亞洲人(華人)或亞裔美國人	<input type="checkbox"/> 大部份是東方人、亞洲人(華人)、或亞裔美國人	<input type="checkbox"/> 一半是亞洲人(華人)或亞裔美國人、一半是歐裔人	<input type="checkbox"/> 大部份是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人	<input type="checkbox"/> 完全是歐裔、非裔(黑人)、拉丁裔或其他非亞裔(美國)人	
10. 您喜歡哪一種音樂？	<input type="checkbox"/> 只有聽亞洲(華人)音樂	<input type="checkbox"/> 亞洲(華人)音樂為主、也喜歡一些英文音樂	<input type="checkbox"/> 亞洲(華人)和英文音樂一樣喜歡	<input type="checkbox"/> 英文音樂為主、也喜歡一些亞洲(華人)音樂	<input type="checkbox"/> 只有聽英文音樂	
11. 您較喜歡哪一種電影？	<input type="checkbox"/> 只看亞洲(華語)電影	<input type="checkbox"/> 大部份以亞洲(華語)電影為主、也喜歡一些英語電影	<input type="checkbox"/> 亞洲(華語)電影和英語電影一樣喜歡	<input type="checkbox"/> 大部份以英語電影為主、也喜歡一些亞洲(華語)電影	<input type="checkbox"/> 只看英語電影	
12. 您屬於美國的第幾代？	<input type="checkbox"/> 第一代：我出生在亞洲(華人區)或其他非美國地方	<input type="checkbox"/> 第二代：我出生在美國、父母出生在亞洲(華人區)或其他非美國地方	<input type="checkbox"/> 第三代：我和父母都出生在美國、祖父母出生在亞洲(華人區)或其他非美國地方	<input type="checkbox"/> 第四代：我和父母都出生在美國、祖父母有一人出生在美國、有一人出生在亞洲(華人區)或其他非美國地方	<input type="checkbox"/> 第五代：我和父母、祖父母都出生在美國	<input type="checkbox"/> 我不知道我是第幾代
13. 您在哪裡長大？	<input type="checkbox"/> 只有在亞洲(華人區)		<input type="checkbox"/> 大部份時間在亞洲(華人)、一些時間在美國	<input type="checkbox"/> 在亞洲(華人)和在美國時間一樣長	<input type="checkbox"/> 大部份時間在美國、一些時間在亞洲(華人)	<input type="checkbox"/> 只有在美國
14. 您和亞洲(華人區)有過什麼接觸？	<input type="checkbox"/> 至少有一年在亞洲(華人區)成長	<input type="checkbox"/> 在亞洲(華人區)居住時間不到一年	<input type="checkbox"/> 偶爾拜訪亞洲(華人區)	<input type="checkbox"/> 偶爾用信件電話聯絡在亞洲(華人區)的人	<input type="checkbox"/> 沒有和亞洲(華人區)有過什麼接觸	

APPENDIX B (continued)

15. 在家裡您喜歡哪一種食物?	<input type="checkbox"/> 完全是亞洲人(華人)食物	<input type="checkbox"/> 主要是亞洲人(華人)食物、也喜歡吃一些美國食物	<input type="checkbox"/> 一半亞洲人(華人)食物、一半美國食物	<input type="checkbox"/> 大部份以美國食物為主、也喜歡吃一些亞洲人(華人)食物	<input type="checkbox"/> 完全是美國食物
16. 在餐廳裡您喜歡哪一種食物?	<input type="checkbox"/> 完全是亞洲人(華人)食物	<input type="checkbox"/> 主要是亞洲人(華人)食物、也喜歡吃一些美國食物	<input type="checkbox"/> 一半亞洲人(華人)食物、一半美國食物	<input type="checkbox"/> 大部份以美國食物為主、也喜歡吃一些亞洲人(華人)食物	<input type="checkbox"/> 完全是美國食物
17. 您會讀哪一種語言?	<input type="checkbox"/> 只會讀中文	<input type="checkbox"/> 中文讀得比英文好	<input type="checkbox"/> 中文和英文讀得一樣好(雙語)	<input type="checkbox"/> 英文讀得比中文好	<input type="checkbox"/> 只會讀英文
18. 您會寫哪一種語言?	<input type="checkbox"/> 只會寫中文	<input type="checkbox"/> 中文寫得比英文好	<input type="checkbox"/> 中文和英文寫得一樣好(雙語)	<input type="checkbox"/> 英文寫得比中文好	<input type="checkbox"/> 只會寫英文
19. 您對自己所認同的族裔(華人、亞裔美國人或美國人都好)...	<input type="checkbox"/> 非常驕傲	<input type="checkbox"/> 中等程度的驕傲	<input type="checkbox"/> 一點點驕傲	<input type="checkbox"/> 沒有驕傲也沒有反感	<input type="checkbox"/> 沒有驕傲甚至有負面的感覺
20. 您如何評價您自己?	<input type="checkbox"/> 非常中國(華人)化	<input type="checkbox"/> 大部份時候相當中國(華人)化	<input type="checkbox"/> 具雙重文化	<input type="checkbox"/> 大部份時候相當西化(美國文化)了	<input type="checkbox"/> 非常西化(美國文化)
21. 您參與亞洲(華人)慶典傳統節日嗎?	<input type="checkbox"/> 幾乎全參與	<input type="checkbox"/> 大部份參與	<input type="checkbox"/> 與一些	<input type="checkbox"/> 只參與少部份	<input type="checkbox"/> 從不參與

APPENDIX B (continued)

Ferrans and Powers QUALITY OF LIFE INDEX[®] GENERIC VERSION – III

PART 1. For each of the following, please choose the answer that best describes how satisfied you are with that area of your life.

Please mark your answer by circling the number.

There are no right or wrong answers.

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Carol Estwing Ferrans and Marjorie J. Powers

	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
HOW SATISFIED ARE YOU WITH:						
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3	4	5	6
5. Your ability to take care of yourself without help?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your chances of living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
16. Your ability to take care of family responsibilities?	1	2	3	4	5	6
17. How useful you are to others?	1	2	3	4	5	6
18. The amount of worries in your life?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. How well you can take care of your financial needs?	1	2	3	4	5	6
25. The things you do for fun?	1	2	3	4	5	6
26. Your chances for a happy future?	1	2	3	4	5	6
27. Your peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Your achievement of personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Your life in general?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Yourself in general?	1	2	3	4	5	6

APPENDIX B (continued)

Ferrans and Powers 生活品質指標(QUALITY OF LIFE INDEX®)**一般版本 3(GENERIC VERSION – III)**

請針對下列問題，選擇您認為最適合的答案（您對自己各方面生活的滿意程度）。
請圈選代表您答案的數字，所有的答案並沒有所謂的”對”或”錯”。

您對下列各方面生活有多滿意：	非常 不滿意	中 等 程 度 的 不 滿 意	稍 微 不 滿 意	稍 微 滿 意	中 等 程 度 的 滿 意	非 常 滿 意
1. 您的健康	1	2	3	4	5	6
2. 您所獲得的健康照顧	1	2	3	4	5	6
3. 您身體上的疼痛	1	2	3	4	5	6
4. 您日常生活的精力	1	2	3	4	5	6
5. 您自我照顧的能力（無需其他幫助）	1	2	3	4	5	6
6. 您對您自己生活的掌控	1	2	3	4	5	6
7. 能夠活到‘您所想活歲數’的機會	1	2	3	4	5	6
8. 家人的健康	1	2	3	4	5	6
9. 您的孩子	1	2	3	4	5	6
10. 家庭的和諧	1	2	3	4	5	6
11. 您的性生活	1	2	3	4	5	6
12. 您的配偶、愛人、親密伴侶	1	2	3	4	5	6
13. 您的朋友	1	2	3	4	5	6
14. 家人所給予您的情緒支持	1	2	3	4	5	6
15. 他人(除家人)所給予您的情緒支持	1	2	3	4	5	6

您對下列各方面生活有多滿意：	非常 不滿意	中等 程度的 不滿意	稍微 不滿意	稍微 滿意	中等 程度的 滿意	非常 滿意
16. 您負擔家庭責任的能力	1	2	3	4	5	6
17. 您認為您自己對別人有用的程度	1	2	3	4	5	6
18. 生活中的憂慮	1	2	3	4	5	6
19. 您居住的四周環境	1	2	3	4	5	6
20. 您的房屋、公寓、或住所	1	2	3	4	5	6
21. 您的工作（若就業中）	1	2	3	4	5	6
22. 無工作（若您無就業、退休、或殘障）	1	2	3	4	5	6
23. 您的教育	1	2	3	4	5	6
24. 您自己處理財務需求的能力	1	2	3	4	5	6
25. 您的娛樂活動	1	2	3	4	5	6
26. 您有個‘快樂未來’的機會	1	2	3	4	5	6
27. 您心靈上的平安	1	2	3	4	5	6
28. 您的宗教信仰	1	2	3	4	5	6
29. 您的成就（達成個人目標）	1	2	3	4	5	6
30. 您整體的快樂	1	2	3	4	5	6
31. 您整體的生活	1	2	3	4	5	6
32. 您的外觀	1	2	3	4	5	6
33. 整體來說，您自己本身	1	2	3	4	5	6

APPENDIX B (continued)
SYSTEMS OF BELIEF INVENTORY

Below you will find number of statements describing several aspects of religious and spiritual beliefs and practices. Circle the number indicating your agreement with the following statements.

	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
1. Religion is important in my day-to-day life.				
2. Prayer or meditation has helped me cope during times of serious illness.				
3. I enjoy attending social functions held by my religious or spiritual group.				
4. I feel certain that God in some form exists.				
5. When I need suggestions on how to deal with problems, I know someone in my spiritual or religious community that I can turn to.				
6. I believe God will not give me a burden I cannot carry.				
7. I enjoy meeting or talking often with people who share my religious or spiritual beliefs.				
8. During times of illness my religious or spiritual beliefs have been strengthened.				

Chinese Americans' Readiness for Advance Care Planning-UIC
 Survey Instrument: SBI-15R
 English, version #2, June 17, 2007

APPENDIX B (continued)

SYSTEMS OF BELIEF INVENTORY (Continued)

	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
9. When I feel lonely, I rely on people who share my spiritual or religious beliefs for support.				
10. I have experienced a sense of hope as a result of my religious or spiritual beliefs.				
11. I have experienced peace of mind through my prayers and meditation.				
12. One's life and death follows a plan from God.				
13. I seek out people in my religious or spiritual community when I need help.				
14. I believe that God protects me from harm.				
15. I pray for help during bad times.				

Chinese Americans' Readiness for Advance Care Planning-UIC
 Survey Instrument: SBI-15R
 English, version #2, June 17, 2007

APPENDIX B (continued)

SYSTEMS OF BELIEF INVENTORY 信仰觀念調查表

下列是有關宗教信仰與靈修生活的一些敘述。請針對以下的敘述，按照您自己本身同意(或不同意)的程度，在適當的格子中打勾 (✓)

	非常 同意	有些 同意	沒有同 意也不 反對	不太 同意	非常地 不同意
1. 宗教對我每天的生活很重要。					
2. 禱告或冥想曾幫助我渡過病重時期。					
3. 我很享受參與我的宗教(或靈修小組)所舉辦的社交活動。					
4. 我的確感到神以某種形式存在。					
5. 當我遇到困難需要建議時，我知道我可以去找某位宗教小組的成員。					
6. 我相信神不會給我所不能負荷的重擔。					
7. 我很享受與和我有相同宗教或屬靈信仰的人們聚會或討論。					
8. 我的宗教或屬靈信仰在我病痛時變得更加堅固。					
9. 當我覺得寂寞時，我仰賴和我有相同宗教或屬靈信仰的人們的支持。					
10. 從我的宗教或屬靈信仰，我感受到盼望。					
11. 我藉由禱告和冥想得到心靈上的平靜。					
12. 人的生死是照神所計畫的。					
13. 當我需要幫助時，我尋求我的宗教或屬靈團體的協助。					
14. 我相信神能保護我免於受傷害。					
15. 我在遭於困難時會藉著禱告求助。					

APPENDIX C

CONSENT FOR SURVEY PARTICIPATION IN RESEARCH University of Illinois at Chicago
Chinese Americans' Readiness for Advance Care Planning

This is a survey consent form for taking part in a research study. You are being asked to take part in a research study among Chinese Americans about advance care planning (which is a healthcare option that facilitates medical decisions before crises). This study is being conducted by Ms. Yvonne Hsiung, Dr. Carol Ferrans, and Dr. Karen Kavanaugh, and has been approved by University of Illinois at Chicago. This study will give us a better understanding of Chinese Americans' readiness toward advance care planning and hopefully improve the quality of health care of Chinese Americans.

You are being asked to take part because you are a Chinese American who is age 45 and older, understand (traditional) Chinese, and reside within Chicago metropolitan area. If you agree to take part in the study, you will fill out a questionnaire. The questionnaire will take about 45 minutes to complete. The questions ask about your immigration history, cultural and religious beliefs, and a variety of things about your healthcare in America, such as your past illness experiences, and personal feelings about medical treatments and advance care planning.

About 200 Chinese Americans (aged 45 and above) from four community churches will participate in the study. Your participation in this study is voluntary. You do not have to answer any questions that you do not want to, and you can stop at any time without consequences of any kind. Your decision to participate or not will NOT result in any penalty, and will NOT affect your current or future medical care. We also will make every effort to keep the things you write on the questionnaire confidential and private. No one at the church will know what you have written. The final report will summarize the findings for the whole group of people who participate, so that no one will be able to tell who took part or what you wrote by looking at the report. The findings of the study will be published so that they can be of help to others. You can be sent a summary of the findings when the study is finished, if you would like.

You will be not be given money for taking part in the study. There is no direct benefit to you for taking part in the study, but we hope the information learned from this study will benefit other Chinese Americans in the future, by helping to improve health care and other services.

APPENDIX C (continued)

To ask questions about the study, please contact Ms. Yvonne Hsiung at University of Illinois at Chicago at (847) 727-2345 or write an email to yhsiun1@uic.edu. If you have questions about your rights as a research subject, you may call the Institutional Review Board (which is a group of people who review the research to protect your rights) at the University of Illinois at Chicago at (312) 996-1711. You will be given a copy of this form for your information and to keep for your records.

If you agree to take part in the study, please sign below. You can decide not to participate later, even if you sign this form.

Signature of Participant

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research study. I have been given a copy of this form.

 Printed Name

 Signature

 Date

 Signature of researcher

 Date

APPENDIX C (continued)

“Planning for Treatment and Care at the End-of-Life”
A Study of Chinese Americans’ Readiness for Advance Care Planning

研究題目：美籍華人對預定護理計畫的預備度及意願

這是一份參與學術研究的同意書(問卷調查部分)。您被邀請參與「美籍華人對預定護理計畫的意願」這項研究(「預定護理計畫(advance care planning)」是您有權利在危機發生之前，預先安排你的照護和醫療計劃)。此項研究的主旨在於了解美籍華人對預定護理計畫的意願，並且希望藉此增進美籍華人的醫療護理品質。研究主持人為伊利諾大學芝加哥分校護理系博士候選人熊誼芳(Yvonne Hsiung)，由卡洛費倫絲(Carol Ferrans)博士與凱倫卡凡娜(Karen Kavanaugh)博士共同指導，並且已經通過伊利諾大學芝加哥分校的研究許可。

您被邀請參與這項研究，因為您符合這項研究的條件：美籍華人、年齡在四十五歲以上、懂(繁體)中文，並居住在大芝加哥地區。若您同意參與這項研究，請協助填寫一份問卷，填完這份問卷預計約四十五分鐘。問卷問題將包括您的移民經歷，文化和信仰觀念，以及您在美國的醫療護理情形--例如您過去的看病經驗和您個人對醫療及預先護理的看法…等等。這個研究的主要危險性僅在於「臨終及死亡」對華人而言，是個較敏感的話題。也許您在回答有關這方面的問題時，心情上會感到不舒服。但以我們之前的研究經驗得知，只有少數人可能感到輕微地不舒服。約一百五十 二百位來自四個大芝加哥社區教會的美籍華人將會參與這個研究。您的參與屬於義務性質，若您不想回答某些問題，您可以隨時無條件終止問卷調查。不論您填寫問卷與否，將不會有任何處罰或影響到您目前及未來的醫療照護。我們將全力確保您的隱私和機密，最後的結果將以團體的名義來發表公布。特別教會中也不會有任何人知道您是否參與研究，以及在研究中問答了什麼。研究成果將會公開發表做為幫助他人之用。若您有興趣的話，我們可以在研究結束之後寄一份摘要給您。

您參與研究及填寫這份問卷將沒有任何金錢酬勞。雖然您的參與並沒有實質的直接利益，但是我們誠摯地希望您的參與，使得本研究的成果在將來能造福更多的美籍華人，並幫助改善華人在美國的醫療護理及其它方面的服務。您可以隨時連絡熊誼芳小姐在伊利諾大學的電話(847)727-2345，或寫信到電子信箱 yhsiun1@uic.edu。若您對身為參與研究者有任何疑問，可以連絡伊利諾大學的學術研究倫理委員會(這個團體的成員將保護身為參與研究者的權益)，電話是(312)996-1771。最後，我們將此份同意書的副本給您做為參考及備份。若您同意參與這項研究，請在下面簽名。即使您簽名之後，仍然可以決定終止參與本研究。非常感謝您對本研究的參與！

APPENDIX C (continued)

我已經閱讀(或由別人代為宣讀)以上的資料。我有附與權利發問，並且我的問題都已得到完滿的回答。我同意參與此項研究，並且已拿到了一份同意書的副本。

同

意人簽名

日期

同意人姓名（正楷）

研究人員簽名

日期

Chinese Americans' Readiness for Advance Care Planning
Survey Informed Consent- UIC
Chinese Version #7, June 17, 2007

APPENDIX C (continued)

INTERVIEW CONSENT FOR PARTICIPATION IN RESEARCH

Chinese Americans' Readiness for Care Planning

University of Illinois at Chicago

This is an interview consent form for taking part in a research study. You are being asked to take part in a research study among elderly Chinese Americans about advance care planning. This study is being conducted by Ms. Yvonne Hsiung, Dr. Carol Ferrans, and Dr. Karen Kavanaugh, and has been approved by University of Illinois at Chicago. This study will give us a better understanding of Chinese Americans' readiness toward advance care planning and hopefully improve the quality of health care of Chinese Americans.

You are being asked to take part because you are an elderly Chinese American (age 65 and older) who are fluent in Chinese (Mandarin) and reside within Chicago metropolitan area. If you agree to take part in the study, you will be interviewed one time for about one to two hour, in a private place you choose. The interview asks about your immigration history, cultural and religious beliefs, and a variety of things about your healthcare in America, such as your past illness experiences, and personal feelings about advance care planning.

About 20 to 30 elderly Chinese Americans (aged 65 and above) will participate in the interview part of this study. Your participation in this interview is voluntary. You do not have to answer any questions that you do not want to, and you can stop at any time. Your decision to participate or not will NOT result in any penalty, and will NOT affect your current or future medical care.

Your responses during the interview will be tape-recorded but no names or personal identifiers will be placed on these tapes. **If you feel uncomfortable during the interview (even if you don't),** you may stop the interview **at anytime** and have the tape returned to you. **In this case, your audiotape will not be used for this study.**

We will make every effort to keep the things you talk about in the interview confidential and private. No one at the church will know what you have said. The final report will summarize the findings for the whole group of people who participate, so that no one will be able to tell who took part or what you said by looking at the report. The findings of the study will be published so that they can be of help to others. You can be sent a summary of the findings when the study is finished, if you would like.

APPENDIX C (continued)

You will be not be given money for taking part in the study. There is no direct benefit to you for taking part in the study, but we hope the information learned from this study will benefit other Chinese Americans in the future, by helping to improve health care and other services.

To ask questions about the study, please contact Ms. Yvonne Hsiung at the University of Illinois at Chicago at (847) 727-2345 or write an email to yhsiun1@uic.edu. If you have questions about your rights as a research subject, you may call the Institutional Review Board (which is a group of people who review the research to protect your rights) at the University of Illinois at Chicago at (312) 996-1711. You will be given a copy of this form to keep for your records.

If you agree to take part in the study, please sign below. You can decide not to participate later, even if you sign this form.

Signature of Participant

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research study.

Signature

Date

Printed Name

Signature of Researcher

Date

APPENDIX C (continued)
 “Planning for Treatment and Care at the End-of-Life”
 A Study of Chinese Americans’ Readiness for Advance Care Planning

研究題目：美籍華人對預定護理計畫的預備度及意願

這是一份參與學術研究的同意書。您被邀請參與「美籍華人對預定護理計畫的預備度及意願」這項研究（「預定護理計畫 (advance care planning)」是您有權利在危機發生之前，預先安排你的照護和醫療計劃）。此項研究的主旨在於了解美籍華人對預定護理計畫的意願，並且希望藉此增進美籍華人的醫療護理品質。研究主持人為伊利諾大學芝加哥分校護理系博士候選人熊誼芳(Yvonne Hsiung)，由卡蘿費倫絲(Carol Ferrans)博士與凱倫卡凡娜(Karen Kavanaugh)博士共同指導，並且已經通過伊利諾大學芝加哥分校的研究許可。

您被邀請參與這項研究的面談部份，因為您符合這些條件：美籍華人、年齡在六十五歲以上，(華語)中文流利，並居住在大芝加哥地區。若您同意參與這項研究，研究人員將與您約定面談一次(一至二小時)，並且您可以決定面談地點。面談問題將包括您的移民經歷，文化和信仰觀念，以及您在美國的醫療護理情形--例如您過去的看病經驗和您個人對醫療及預先護理的看法…等等。這個研究的主要危險性僅在於「臨終及死亡」對華人而言，是個較敏感的話題。也許您在回答有關這方面的問題時，心情上會感到不舒服。但以我們之前的研究經驗得知，只有少數人可能感到輕微地不舒服。即將有約二十~三十位美籍華人長者(年齡六十五歲以上)將會參與這個研究的面談部分。您的參與屬於義務性質，若您不想回答某些問題，您可以隨時無條件終止面談，將不會有任何處罰或影響到您目前及未來的醫療照護。您在面談過程中將會被錄音，但是我們決不會在錄音帶上註記任何姓名或顯露身份的記號。若您真的在面談中覺得不舒服(即使您並不覺得不舒服)，不希望錄音記錄外流，您可以隨時無條件終止面談。我們也可以在面試之後立刻將錄音帶還給您。這樣子錄音內容就不會被記錄也不會用於這個研究。我們將盡力確保您面談內容的隱私和機密，最後的結果將會以團體的名義來發表公布。特別是教會中也不會有任何人知道您的說法。研究成果將會公開發表做為幫助他人之用，若您有興趣的話，我們可以在研究結束之後寄一份摘要給您。

您參與研究及面談將沒有任何金錢酬勞。雖然您的參與並沒有實質的直接利益，但是我們仍誠摯地希望您參與，使得本研究的成果能在將來能造福更多的美籍華人，並幫助改善華人在美國的醫療護理及其它方面的服務。您可以隨時連絡熊誼芳小姐在伊利諾大學的電話(847)727-2345，或寫信到電子信箱 yhsun1@uic.edu 若您對身為參與研究者有任何疑問，可以連絡伊利諾大學的學術研究倫理委員會(這個團體的成員將保護身為參與研究者的權益)，電話是(312)996-1771。最後，我們將此份同意書的副本給您做為參考及備份。若您同意參與這項研究，請在下面簽名。即使您簽名之後，仍然可以決定終止參與本研究。非常感謝您對本研究的參與！

APPENDIX C (continued)

我已經閱讀(或由別人代為宣讀)以上的資料。我有附與權利發問，並且我的問題都已得到完滿的回答。我同意參與此項研究，並且已拿到了一份同意書的副本。

同意人簽名

日期

(正楷)

研究人員簽名

日期

同意人姓名

Chinese Americans' Readiness for Advance Care Panning-UIC
Interview informed consent, Chinese, version#7, June 17, 2007

APPENDIX D

STAGE OF CHANGE ALGORITHM AND SCORING

The algorithm of stages of change consisted of seven self-report questions assessing Chinese Americans' intentions and current activities for advance care planning. Participants were classified into one of six discrete stage categories (Table 3).

Scoring steps:

1. Maintenance: participants who have signed the document (YES in 58) and continuously communicated with others (YES in both 59 and 60) were given a score of 6.
2. Action: participants who signed more or less than 6 months ago (checked YES in 58) but have not communicated with others (checked both NO in 59 or 60) were given a score of 5.
3. Preparation: participants who prepared for advance care planning (checked No in 58 but checked YES in 61) and considered to make a change in the next following 30 days (Yes in 38, 39 and 40) were given a score of 4
4. Contemplation: participants who have not signed any advance directives (NO in 58) but willing to make a behavioral change (YES within the next 6 months in all 38, 39, and 40) were given a score of 3. They are different from people at the preparation stage, because they were not able to sign advance directives right now (checked I DON'T KNOW or No in 61)
5. Precontemplation: ALL other participants who have not signed any advance directives (NO in 58) and were not going to make a behavioral change were in the precontemplation stage.

Among these precontemplaters, there were 2 subgroups: precontemplaters (believer but not too sure about advance care planning) and precontemplation (non-believers in advance care planning).

- a) Precontemplaters (believers) were those who checked "YES, 6 months later", Yes but don't know what time" or "I don't know" in item 38, 39, 40. They also checked NO in item 58 and any answer in item 61.
They were given a score of 2.
- b) Precontemplaters (non-believers) checked NO in 38, 39, 40 and 58 (and any other answers in 61) were given a score of 1.

Appendix E

Semi-structured Interview Guide (Version 12)
Chinese Americans' Readiness for Advance Care Planning
(Planning for advanced treatment and care and the end of life)

I. Introduction

The reason why we are having this interview is because we are interested in learning about older Chinese Americans' readiness for advance care planning. Because you are an older Chinese American and a cultural expert, we are interested in your opinions.

Not everyone has heard about "advance care planning." In America, when people are dying (with no hope of recovery), there are decisions that need to be made about what treatments should be given or not given at the EOL. "Advance Care Planning" is a healthcare option that people can make treatment decisions in advance, before they are too ill to speak for themselves.

During this interview, I will ask you a series of questions to find out how treatment decisions are made for yourself, and how you were informed and involved in this decision-making. In particular, I am interested in hearing about your readiness for participating in advance care planning. We hope information that we learn from you today may help healthcare professionals best care Chinese Americans. Please do not hesitate to ask me any questions or express any concerns you have during our conversations.

II. Acculturation and English proficiency:

First, I would like to learn more about your experiences in the States.

1. **Mr./Mrs.____, how long have you been in the United States? What was the reason you came to the States?**
2. (Questionnaire #15 & #16) In your survey, you checked that you have (or have no) problems using English in your daily life; and also you will (or not) need a translator when seeing an English-speaking doctor. **So does English a factor influence your health behavior in the States?**
3. **In your past experiences, how (where and from whom) do you usually receive healthcare information in the States? How did your ability to speak English influence how you receive health information in the States?**
4. You prefer receiving healthcare information in English (or) Chinese, because____
 (Questionnaire #17). **If I am providing you some new healthcare information, you will prefer it written in English (or Chinese), because?**

APPENDIX E (continued)

III. Knowledge & Past EOL experience

I first want to learn more about your understanding about life-sustaining treatment. I am now going to ask you questions to find out what you know about these medical terms so that we can have the same thing in mind.

1. In your survey, you answered that you have (or have not) heard about the term “life-sustaining treatment?” (#24-28). **Can you tell me what you know about “life-sustaining treatment”?** (#26 & #28) **What do you think “life-sustaining treatment” is?**
2. You marked that you learned “life-sustaining treatment” from the media (or healthcare providers, etc) (#27). **What do you remember about that?**
3. You also feel you “don’t know too much” (or know very much) about LST (#28), is that right?
4. My last question related to life-sustaining treatment is from your answers of (#18-#23). You said you have (not) had experience with end-of life treatment. **How has that made any difference in your views about planning for life-sustaining treatment? Or how does that influence the life-sustaining treatment decisions you would make for your family?**

I am now going to ask you questions about advance directives, living wills, durable power of attorney, and advance care planning. I have looked at your responses in the survey, and understand you may not have heard about all of them. In fact, advance care planning is a very new thing for older Americans. Even for many Caucasian Americans, they do not know about this and often get confused. Please do not hesitate to share what you know or ask me any questions. I would like to know your understanding so we can have the same in mind.

5. You mentioned that you have (or have not) heard about “advance directives” You have not heard about the term “durable power of attorney (give terms in both Chinese and English), and you have not heard about “living wills.” (question #29-32) **Am I correct? What do you know about these terms?**
6. Have you heard about “advance care planning? (#24- #28)?” (Only if they marked yes) then ask: **What do you know about it?**
7. **I know you have not heard about these medical terms before. But I am interested in hearing what you think “advance care planning” refers to?**

APPENDIX E (continued)

I am going to share what I know about advance care planning with you. As we have mentioned, when people are dying (with no hope of recovery), there are decisions that need to be made about what treatments should be given or not given. “Life-sustaining treatments” are often used at the EOL to lengthen terminal patients’ lives. Typically used treatments include: CPR, mechanical ventilators, and tube feedings. Advance Care Planning is a healthcare option that people can make decisions about life-sustaining treatment in advance before they are too ill to speak for themselves. The document you sign about life-sustaining treatment is called “advance directives.”

At the end of the interview, I will provide you a document that is designed for people to understand what advance care planning is. You can contact me anytime if you have questions or need more information on ACP.

IV. Readiness for Advance Care Planning (Part I: yes, advance directives signed)

- If people marked “yes” (#58), they will be asked the following 7 questions.

Mr./Mrs.____, in the forms you completed, we found that you have taken an action to complete an advance directive (or a living will). Not many Chinese Americans have heard of advance care planning and only few have signed advance directives/living wills. We really can learn a lot from you. Please share with us your understanding about advance care planning.

- 1. What motivated you to have advance directives/living wills? How did you (and your family) come to decide that you would like to plan your end-of-life treatment decisions in advance?**
- 2. (If they had prior EOL experiences) How much did your prior experiences impact on your decision to plan in advance?**
- 3. How difficult was it to make up your mind about advance care planning?**
- 4. Have you talked to other people about your wishes in your advance directives/living wills (#59 & #60)?**
- 5. What was the response from your family and friends after they heard about the decisions you made in your advanced directives?**
- 6. Did they have a strong opinion on what should be done for you? How did their responses or opinions affect your decisions?**
- 7. How have you been involved with the decision-making? (What role did you play? For example, were you an active participant? Were you ready to complete ACP at that time?**
- 8. You also answered that you want (do not want) to know more about planning for your future life-sustaining treatment and care (#39). Can you tell me why you want (do not want) to know more?**

APPENDIX E (continued)

9. You think it is “necessary (or unnecessary) to plan for your future life-sustaining treatment and care” (#40) **Can you tell me your reasons for this?**
10. You have answered a number of questions about advance care planning being a good idea or a bad idea (# 41 to #55). **Overall, do you think it is a good idea or a bad idea? (#56) What are your reasons for saying this** (also clarify their survey answers) (#57)
11. **How important is it that you make your own decision?**

IV. Readiness for Advance Care Planning (Part II: No, no advance directives signed)

- If people marked “no” (#58), meaning they have not signed an advance directive or a living will. They will be asked the following 8 questions.

Mr./Mrs.____, not many Chinese Americans have heard of advance care planning and signed advance directives/living wills, in the forms you completed. We would like to find out if you would be interested in planning life-sustaining treatment in advance.

1. In your survey, you answered that “you are willing to start planning for your future life-sustaining treatment and care at the end-of-life.” (#38) **Can you tell me your reasons for this?**
2. You also answered that you want (do not want) to know more about planning for your future life-sustaining treatment and care (#39). **Can you tell me why you want (do not want) to know more?**
3. You think it is “necessary (or unnecessary) to plan for your future life-sustaining treatment and care” (#40) **Can you tell me your reasons for this?**
4. You have answered a number of questions about advance care planning being a good idea or a bad idea (# 41 to #55). **Overall, do you think it is a good idea or a bad idea? (#56) What are your reasons for saying this** (also clarify their survey answers) (#57)
5. **Who do you think is most likely to make the final life-sustaining treatment decision for you? Is he/she the best person to make the decision? Does this situation fit well with what you would like? If not, what would be the most ideal situation at that time?**
6. If right now you need to plan your future life-sustaining treatment, **do you need to get others’ approval for your treatment decision (#62)? Can you please tell me your reasons?**
7. You answered that you prefer discussing with someone about your future life-sustaining treatment. (#63) **What role is he/she playing in this situation?**
8. **How important is it that you make your own decision?**

APPENDIX E (continued)

V. Knowledge and Readiness (only people who have demonstrated very knowledgeable and have AD signed)

Mr./Mrs.____, in the forms you completed, you are very knowledgeable about advance care planning. You are one of a small number of people who have heard of advance care planning (and advance directives/living wills), and we can learn a lot from you. I have looked at your responses in the survey, and now I would like to know more about your opinions and how these answers were selected. I appreciate everything you can share with me.

1. **Can you tell me again, in your own words, what do you know about advance care planning (#37)?**
2. **Where and how did you learn all this (#36)?** You mentioned you learned this from the media (or healthcare providers or family friends). (#35) **Specifically, do you remember what they told you about ACP?**
3. When you were asked how much you think you understand ACP (#36), you marked “a little” (or very much). **Why do you think so?**
4. **Did you feel that you understand the information when it was first presented to you? What was it about the way you were told that was helpful for you to understand ACP?**
5. You answered that you have had (or have no) end-of-life experiences before (#18-#23). (If the participant has prior EOL experience) ask: **How much of your knowledge of ACP you think is from your previous “life-threatening” experience?**
6. You also answered that you have participated EOL treatment decision-making before (#25). **What was your role in this decision-making process?**
7. **How were you able to use your knowledge to participate in the decision-making process?**

APPENDIX E (continued)

VI. Other factors

Thank you for your participation. We have talked a lot about treatment decisions. Now I would like to ask you some questions about how you feel your cultural and religious beliefs may have influenced your ACP decisions. Often times Chinese Americans have been strongly influenced by traditional Chinese beliefs.

- **Religiosity**
 1. **Mr./Mrs.____, did you change your religion preference after you came to the States?**
 2. **How would you say your current religious belief has influenced your readiness for having advance care planning? For example, is being a Presbyterian a factor so that you accept/do not accept the idea of ACP?**
 3. **How would you say Chinese traditional religions have influenced your readiness for having advance care planning? Are your EOL decisions still strongly influenced by Taoism or Folklore religion? How?**
 - **Cultural beliefs**
 1. (Look at their traditional beliefs #1-13). In your survey, you gave us your opinions on these cultural questions. **Among these culture-related questions, which one is the most important to you that you want to share with me?**
 2. **Which cultural factor has the most impact on your view of advance care planning actors? For example, you marked that “keeping your dying family alive” is very important (# 13), how does that impact on your views of advance care planning?**
 3. We heard that some Chinese people wanted to have advance care planning because they wanted to have a good death. **What does “a good death” mean to you? (#14) How does advance care planning impact on having a good death?**
 4. **What are some other reasons that would influence Chinese Americans’ readiness for advance care planning? For example, could English be one of reasons?**

VI. Intervention Development

Part of this interview is for me to learn your preference about an advance care planning program.

1. In your survey, you said you would (would not) be interested in an advance care planning program. **Why? Can you please tell me your reasons?**
2. (Go through #2-#7 preference of program activities and contents) **If I were to teach you something about advance care planning, what format would you prefer? Can you please tell what is appealing about xx you selected?**

APPENDIX E (continued)

VII. Summary and Closing questions

We are almost done. I have some last questions before we end today's interview.

- 1. What advice would you give to me in particular how to increase people's readiness for advance care planning?**
- 2. What do you think would help other elderly Chinese Americans to make advance care planning decisions?**
- 3. Is there anything else you would like to add today? What has it been like to talk to me today?**

APPENDIX E (continued)

Semi-structured Interview Guide 半結構式面談手冊（指南）
Chinese Americans' Readiness for Advance Care Planning
美籍華人對預定護理計劃之意願

I. Introduction 引言

今天我們訪談的目的，是因為我對於**年長華人對預定護理計劃之意願**這項研究題目很有興趣。因為您是華人長輩，又可說熟悉美國及中華二方面的文化，我想多了解及學習您的意見。

在美國並沒有太多人知道或是聽過「預定護理計劃」。美國的醫療系統當中，臨終的病人（也就是沒有治療希望時）常需要討論並決定給予或不給予哪些治療。「預定護理計劃」是人民在美國的一種治療抉擇權--在病人過分病重而不能夠表達之前，他們可以事先考慮和決定他們將來想要的治療和護理安排，為確保自己在這方面的選擇能得到家人及醫師的尊重。

在今天的訪問，我接下來會問您一些有關治療抉擇的問題，也就是想多了解，您平常是如何得到醫療資訊和作出您自己的醫療決定的。特別是我非常有興趣聽聽您對事先決定將來想要的治療和護理安排之意願。我希望今天從您這兒學到的，能幫助美國醫護人員更完善地來照顧華人。請不吝指教並提出任何您所關心的問題，謝謝！

II. Acculturation and English proficiency: 文化適應同化過程及英語語文能力

首先，我想知道您在美國的一些經驗。

5. _____ 先生/女士，請問您來美國多久了？為了什麼原因來美國呢？
6. 您問卷中 (#15 and #16)提到:您的英文不太夠應付日常生活。若是您的醫師不會說中文，您需要有人替您翻譯。那麼這樣子的話，您的英語程度是不是會影響到您在美國的就醫行為嗎？
7. 在您過去的經驗中您在美國平時是從哪裡得到健康醫療資訊的？(或是從誰)獲得健康醫療資訊的？您的英語程度是不是會影響到您獲得健康醫療資訊呢？
8. 您問卷中說到(#17)您偏好英文且附上中文翻譯的醫療健康資訊，因為(#17). 若是我現在提供您一些新的醫療健康資訊，是否表示您也希望這些資料是英文且附上中文翻譯的，對嗎？

III. Knowledge 知識程度 (Part I)

我現在要請教您一些有關醫療抉擇的問題，這些是大部份人在臨終抉擇必須要討論的。更重要的是，我想知道您對預定護理計劃的認識。我們已經看過您的問卷答案，現在我想更進一步了解您如何選出這些答案的。我非常感激您能和我分享。

在我們繼續談論預定護理計劃之前，首先我想知道您對一些專有名詞(例如:維生治療,預立醫囑,醫療授權書...等等)有多少了解，所以我們能有些共識。這些名詞或是用語並沒有許多人知道。事實上，預定護理計劃對大多數華人來說還是一件新鮮事，甚至很多白人也搞不清楚常常和其他東西搞混。所以請別客氣和我們分享您所知道的。

1. 我的第一個問題是，您問卷中有提到(#24-#28): 您有(沒有)聽過「維生治療」這個詞 (英文原文是“Life-sustaining Treatment”) 您提到對「維生治療」的了解是...(#26 & #28)? (有聽過的話)可以再請您以自己的話來說，告訴我什麼是「維生治療」呢? (沒有聽過的話) 您以為什麼是「維生治療」呢?
2. 您是在(#27)聽到學到這個詞的。您還記得當時他們是(醫護人員或是其他相關的人)是怎麼告訴您的？譬如說，他們解釋「維生治療」是...？

3. 您回答對「維生治療」(Life-sustaining Treatment) 這個字詞的了解程度是? (#28)。為什麼您覺得您不夠了解?
4. 最後有關「維生治療」的一個問題是，您問卷中(#18-#23)提到您曾經（不曾）有瀕臨死亡或臨終的經驗（比如說曾經照顧過瀕死的家人親屬或您本身有過醫療上的危機）。可以請您談談嗎?
5. 請問這些「危及生命」的經驗，會不會讓您對提早計劃「維生治療」的看法有所改變？或者這些「危及生命」的經驗會不會改變您對您家人親屬「維生治療」的決定？

我要繼續談論預立醫囑，醫療授權書…等等專有名詞，想知道您對這些有多少了解。這些名詞用語也並沒有許多人知道。

6. 您問卷中提到(#29-#32):您有(沒有)聽過「預定指示 或是 預立醫囑」這個專有名詞 (英文原文是 “Advance Directives”)沒有聽過「生前預囑」或是「垂危急救意願」(living wills)也沒有聽過「醫療授權書」「個人護理授權書」或是「醫療決定委任書」(Durable Power of Attorney)是嗎?
7. 您有沒有聽過「預定護理計劃」(Advance Care Planning) 這個專有名詞呢? 您對它的了解是?(#26 & #28) (若有聽過 go to #9)
8. 我了解到您也許沒有聽過「預定護理計劃」(Advance Care Planning)，但是我很有興趣聽聽您以為「預定護理計劃」是什麼東西？

就像我一開始提到的，在美國並沒有太多人知道或是聽過預定護理計劃。美國的醫療系統當中，臨終的病人（也就是沒有治癒希望時）常需要討論決定是否給予某些治療。維生治療指的是那些在末期病人臨終時，常用的一些「延長生命、但無法治癒疾病」的治療方法。典型常見的維生治療包括：心肺復甦術(CPR)、呼吸器使用、及人工管灌餵食…等。預定護理計劃是人民在美國的一種治療抉擇權--他們可以事先考慮和決定他們將來的維生治療和護理，為確保自己在過分病重而不能夠表達和決定護理安排之前，自己這方面的選擇能得到家人及醫師的尊重。而預立醫囑、醫療授權書、個人護理授權書、或是 醫療決定委任書 則是各式有關預定護理計劃所填寫的法律文件。

在訪談結束後，我有一份有關訂定預定護理計劃的資料，可以給您作參考。您有任何有關預定護理計劃的疑問也可以聯絡我。

以下七題訪問非常有預定護理計劃知識的長輩羣

_____ 先生/女士，在我們的問卷當中，發現您是少數非常非常了解預定護理計劃及預前指示的。我們真的可以向您有不少的學習。

9. 您何時以及在這裡學到這些的 (#35)? 您提到是在_____聽到學到這個詞的。特別您還記得他們是(醫護人員或是其他相關的人)怎麼告訴您的? 譬如說，他們解釋預定護理計劃是...?
10. 您回答對「預定護理計劃」(Advance Care Planning) 這個字詞的了解程度是 (#36)。為什麼您覺得您不夠了解?
11. 您覺得當時您可以了解他們提供有關「預定護理計劃」的資訊嗎? 在當時，什麼情況底下讓您覺得特別有幫助您來了解預定護理計劃?
12. 您問卷中 (#18-#23) 提到：您（不曾）曾經有瀕臨死亡或臨終的經驗嗎(比如說曾經照顧過瀕死的家人親屬或您本身有過醫療上的危機)。可以說您對預定護理計劃這麼的了解，是因為先前您（或您的家人）有過一些「危及生命」的經驗嗎？

APPENDIX E (continued)

13. 您問卷中也提到(#25)：您曾經參與是否決定用醫療延續臨終家人生命的討論。您在討論決定過程的角色是什麼？
14. 您對預定護理計劃的了解有無派上用場？您如何使用這些知識來討論臨終家人的醫療決定？

IV. Readiness for Advance Care Planning 對預定護理計劃之準備度(意願) (Part I)

- 若受訪者已經簽署「醫療授權書」(Advance Directives) 或「生前預囑」(Living Wills)(#58) 即代表他們對預定護理計劃有較好的準備度。以下七題是給 對預定護理計劃有良好的準備度並已經簽署“醫療授權書”及“生前預囑”的長輩

_____ 先生/女士，在我們的問卷當中，發現您是少數已經簽署「醫療授權書」(Advance Directives) 或「生前預囑」(Living Wills) 的長輩。事實上對大多數華人來說，並沒有許多人簽署「醫療授權書」或「生前預囑」，我們真的可以向您有不少的學習。

12. 在提到是什麼原動力使您開始採用預定護理計劃？您和您的家人是如何決定要事先安排您的治療及護理？
13. (若曾有「危及生命」的經驗)可以說您決定預先簽署醫療授權書及生前預囑，是因為先前您（或您的家人）有過一些「危及生命」的經驗嗎？
14. 要下定決心安排您自己的臨終治療及安排臨終護理(採用預定護理計劃)有多困難？
15. 您有告訴其他人您在醫療授權書及生前預囑中的治療安排嗎？(#59 & #60)
16. 家人朋友他們聽見您決定要事先安排您的治療及護理(採用預定護理計劃)，是什麼反應？
17. 他們有沒有什麼強烈的意見覺得您該怎麼作？那他們的意見有沒有影響到您的計劃和決定呢？
18. 這個決定的過程當中，您如何參與？(您扮演什麼角色？比如說您很積極計劃嗎？當時真的準備好接受預定護理計劃了嗎？)
19. 您認為現在您願意(不願意)知道更多有關預定護理計劃的資訊(#39)，可以告訴我為什麼您現在願意(不願意)知道？
20. 您認為現在有(無)必要開始計劃未來臨終之時的維生治療及護理照顧 (#40)，可以告訴我為什麼您認為有(無)必要？
21. 您在問卷中回答了一系列有關“預先”擬訂治療護理計劃是不是個好主意的問題 (# 41 to #55)。總括來說，您認為「預定護理計畫」(即事先計劃您未來臨終的維生治療及護理照顧)是不是個好主意呢？(#56) 麻煩請再告訴我，您認為「預定護理計畫」是個好主意 (或是個爛主意)的想法或理由(#57) (澄清問卷答案# 41 to #55)
22. 您自己決定您自己未來的臨終治療這件事，對您有多重要？

APPENDIX E (continued)

IV. Readiness for Advance Care Planning 對預定護理計劃之準備度(意願) (Part II)

- 若受訪者尚未簽署「醫療授權書」(Advance Directives) 或「生前預囑」(Living Wills)(#58) 則代表他們對預定護理計劃較無準備度。以下七題是給對預定護理計劃較無準備、尚未簽署“醫療授權書”及“生前預囑”的長輩

_____ 先生/女士，大多數的華人，並沒有簽署「醫療授權書」(Advance Directives) 或「生前預囑」(Living Wills)。我們想知道您是否有興趣開始考慮並事先安排您未來的臨終治療及護理(採用預定護理計劃)。

1. 在您問卷中，您說您有興趣考慮事先安排您臨終治療及護理（或沒興趣、還未準備好接受預定護理計劃）(#38)，可以分享是什麼原因您還未準備好？
2. 您認為現在您願意(不願意)知道更多有關預定護理計劃的資訊(#39)，可以告訴我為什麼您現在願意(不願意)知道？
3. 您認為現在有(無)必要開始計劃未來臨終之時的維生治療及護理照顧 (#40)，可以告訴我為什麼您認為有(無)必要？
4. 您在問卷中回答了一系列有關“預先”擬訂治療護理計劃是不是個好主意的問題 (# 41 to #55)。總括來說，您認為「預定護理計畫」(即事先計劃您未來臨終的維生治療及護理照顧) 是不是個好主意呢？(#56) 麻煩請再告訴我，您認為「預定護理計畫」是個好主意 (或是個爛主意的)的想法或理由(#57) (澄清問卷答案# 41 to #55)
5. 您病重的話，您認為誰有責任要替您的臨終治療作最後決定？(您自己？還是家人？) 您認為他是最佳作決定的人選嗎？他作決定這樣的情況是不是您心中最理想的狀況？若不是的話，什麼才是您心中最理想的狀況？
6. 若您現在可以為自己決定您未來的臨終治療，您需要得到別人同意(首肯)才能簽署「醫療授權書」決定您的治療嗎？(#62) 可以告訴我為什麼您需要得到別人同意？
7. 在您問卷中，您說您希望和別人討論來決定您未來的臨終治療。(#63) 在這個過程當中，您覺得您將扮演什麼角色？
8. 您自己決定您自己未來的臨終治療這件事，對您有多重要？

.....

Other factors 其他因素

謝謝您很有耐心，我們已經談了許多有關治療的決定。接下來我想問您一些問題是有關您的文化及宗教信仰，也許這些會影響您對預定護理計劃的意願也說不定。常常我們華人是深受傳統中華文化之影響的。

- **Religiosity 宗教觀**

1. _____ 先生/女士，您來美國之後改變了您的宗教信仰嗎？
2. 您認為您目前的宗教信仰是否會影響您對接受預定護理計劃(即事先計劃您未來臨終的維生治療及護理照顧)的意願？比如說做為一個基督徒，是否讓您比較能夠或不能夠接受預定護理計劃？
3. 中國人傳統的宗教信仰是否又會影響您對預定護理計劃的意願(即事先計劃您未來臨終的維生治療及護理照顧)？請問您的臨終治療的決定，是否仍深受道教及民間信仰的影響？如何被影響呢？

APPENDIX E (continued)

- **Cultural beliefs 文化信仰**

4. (一一澄清問卷答案#1-13)— 問卷中您回答了一系列有關華人文化的問題，您認為哪一項對您最重要？ 例如“延續瀕死家人生命”很重要，這是否影響您對預定護理計劃的意願呢？
5. 我們曾聽說有些華人預定護理計劃是為了有個善終(好死)。請問‘善終(好死)’對您而言是什麼 (#14)？預定護理計劃能夠如何幫忙您有個善終呢？

- **Other factors 其他因素**

6. 可以想到也許有其他原因會影響華人接受預定護理計劃嗎？英文也是其中一個可能影響華人預定護理計劃意願的原因嗎？

VI. Intervention Development 發展華人預定護理計劃課程

我們面談的一個目的，是向您請教對於參加 “華人預定護理計劃課程” 的意願。

1. 您在問卷中提到您對於預定護理計劃課程沒/有興趣。為什麼呢？
2. (#2-#7 對課程活動內容的意見) 可以告訴我為什麼有些選項比較好嗎？(澄清問卷答案#2-7)

VII. Summary and Closing questions 總結

面談到此差不多快可以結束了。結束之前，我有最後幾個問題。

3. 可不可提供一些建議，特別是如何能提高華人對預定護理計劃的意願？
4. 您認為怎樣能幫助其他華人長輩開始預定護理計劃？
5. 最後，您有任何想補充的嗎？
6. 今天和我面談您覺得如何？

Appendix F

Information Regarding Quality of Translation and Translator Qualification Research Project: Chinese Americans' Readiness for Advance Care Planning

To the Chairman and Members of IRB:

I would like to supply information about the Chinese language documents and qualifications regarding the informed consent translation:

1. Translation approach of the informed consent:

In the past decades, the Brislin's back-translation approach (Brislin, 1970), required by the UIC IRB, has been the most common method for instrument translation in cross-cultural research. However, this popular technique has three major disadvantages: first, it deals only with semantic equivalence; second, the source and the original language may correspond with one another for the wrong reasons; and third, the target language version may not convey the intended meaning to potential respondents even though the source may resemble the original. Therefore, the translation/back-translation approach does not provide an adequate test of the equivalence of the target and source language documents (Behling & Law, 2000).

Recently, six methods of translations have been suggested when translating an existing instrument, which include: simple direct translation, modified direct translation, translation/back-translation, parallel blind technique, random probe, and ultimate test (Guthery & Lowe, 1992). Four criteria of a useful translation technique: informativeness, source language transparency, security, practicality were considered when choosing the translation method. The suggested committee-based approach (Harkness, et al., 2003) appeared to be the most adequate approach for instrument translation. The strength of this approach is the optimal output from difference perspectives of the committee members. However, because multiple committee members involves in a series of complicated procedures, this approach is somewhat impractical.

In order to properly translate the informed consent, the PI has slightly modified Harkness' approach and combined it with Brislin's translation/back-translation method. First, a translation committee of 3 Chinese cultural and language experts who are familiar with the study population was constructed. They followed the same translation guideline to forward translate the source language (English) into the target language (Chinese).

Multiple consensus meetings then were held among the three forward translators and the PI to obtain an agree-on forward version. Last, back translation of the "agree-on forward version" was performed by another independent translator who is a bilingual Chinese American and also familiar with the study population. The original English version and the backward translation version then were compared by the PI; modifications were made to obtain a suitable Chinese version. Last, this Chinese version was reviewed by a group of 7 bilingual Chinese Americans. Informed consents were obtained even though their data will not be included in study results. In summary, a careful translation process was performed that the PI and the translator group members have jointly translated, reviewed, adjudicated, and documented the final version of the instruments, the interview guide, and the informed consent forms.

Appendix F (continued)

2. Translator Qualification

- a. Name of person performing the forward translation (English to Chinese):
Sherry Hwang, Bertha Lee, and Vivian Hsiung. All three translators were born in Taiwan. They are all bilingual with Mandarin Chinese as their native language. All of them were early educated in Taiwan and received their Master's or PhD degrees here in the States. Among them, Ms. Hsiung is a professional translator with 4 years of professional translating experience in the United States, mainly in technical and science articles translation. Ms. Hwang and Ms. Lee are not professional translators but have been working in the United States for more than 10 to 20 years. They did not receive payment for the translation work performed for this study but was appreciated by the PI.
- b. Back translation (starting with the "agree-on" Chinese version and translating it back into English):
Snow Tseng. Mr. Tseng is not a professional translator but chosen to perform this back translation because he is bilingual and familiar with the study group. He was born in the United States and had education both in Taiwan and the States. He received his PhD degree from Northwestern University and has more than 10 years of translation experience with science articles. Mr. Tseng did not receive payment for the translation work performed for this study, either.
- c. PI's translation qualification: The PI was actively involved in this translation process. The PI was born in Taiwan and bilingual with Mandarin Chinese as her native language. She has been certified as a medical interpreter and has volunteered herself in South Suburban Hospital. She has taken many courses in English grammar and composition, in which she has an average of 3.8 GPA during her graduate study. She received her Nurse MS from UIC in 2001 and is currently teaching and working as research assistant at College of Nursing, UIC.
- d. Verification of consistency: as mentioned above, multiple consensus meetings were held among the translators and the PI to obtain a suitable Chinese version of the informed consent. The final version of the Chinese language document was determined by all translators to be consistent and accurate in its meaning.

Thank you very much,

Yi-fang Yvonne Hsiung, MS, Phd candidate
College of Nursing, UIC

Appendix G
Chinese Americans' Readiness for Advance Care Planning
Individual Case Summary

Case ID: _____

0. Demographical characteristics and Survey scores

Age:
Gender:
Income:
Education:
Acculturation level:
Overall English proficiency:
Quality of Life--overall life-satisfaction:
Quality of Life--general health status:
Spirituality--Change of religion:
Spirituality--Religiosity (self-rated/SOB):
EOL experience:

I. Immigration history

Immigration time and reasons	Code 1
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II. Cultural beliefs

Values and opinions about a good death	Code 2-1
Filial Piety	Code 2-2
Familism	Code 2-3
Male paternalism	Code 2-4
Arrive to say good-bye	Code 2-5
Longevity	Code 2-6
Male paternalism	Code 2-7
Karma	Code 2-8
Death Discussion	Code 2-9
Disclosure of terminal illness	Code 2-10
Death planning	Code 2-11

APPENDIX G (continued)

III. English Proficiency

English proficiency & health-seeking behavior	Code 3-1
English & access to health information in America	Code 3-2
Isolation	Code 3-3

IV Previous EOL experience

Self EOL experience	Code 4-1
Family EOL experience	Code 4-2

V. Knowledge

Knowledge related to LST	Code 5-1
Knowledge related to ADs	Code 5-2
Knowledge related to ACP	Code 5-3

VI. Life-sustaining values and opinions

LST values and opinions	Code 7
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VII. Decision-making

Final decisions made by physicians	Code 8-1
Uncertainty about future	Code 8-2
Preferred role and self-efficacy for ACP decision-making	Code 10

VIII. Readiness for advance care planning

Endorsement of ACP (Decisional balance)	Code 9-1
Concerns about ACP (Decisional balance)	Code 9-2
Current readiness stage (Change of stage)	Code 9-3
Readiness and preference for an ACP program	Code 12
Open advice to increase readiness	Code 13-1

IX. Spirituality

Religion beliefs and practice	Code 11-1
Religiosity and ACP	Code 11-2

X. General feedback about the study

Reflective feedback	Code 13-2
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APPENDIX H: A Summary of Key Findings

A. Chinese Americans' Readiness for advance care planning

Stages of readiness	<ul style="list-style-type: none"> • About 68% were classified as precontemplators-believers; they were intended to initiate advance care planning, since most felt necessary and enthusiastic to obtain additional information for future EOL treatment and care, but unclear about the most appropriate time to do so • Comments from older interview precontemplators supported the survey result regarding subjects' generally good intention and indecisiveness about time • Only 11% were at the contemplation and preparation stages who were willing to execute their ADs within the next 6 months and 30 days, respectively • The usage of ADs was 17.5%, lower than the nation's norm • Only 5% was at the highest "maintenance" stage of readiness. Subjects' communication about EOL decision-making was in general subtle and passive; even among those who have completed their ADs, only 39% continued to share their preference with others
Decisional balance	<ul style="list-style-type: none"> • Advance care planning was intuitively viewed as a good idea • The majority of subjects were first learners of advance care planning but generally favored and believed in it; they tended to agree more with the pros and disagree less with the cons statements • Decisional balance was moderately and positively correlated with the stage of readiness—subjects with better readiness favor advance care planning more • When progressing through stages, subjects' endorsement in the decisional balance have increased and their concerns decreased • Endorsement: <ul style="list-style-type: none"> • Generally it was agreed by older interview subjects that early preparation is always good • Benefits included: to ensure patient autonomy, protect human dignity, increase a sense of self-control, alleviate possible sufferings at the EOL and thus facilitate a good death in one's desire, help communicate EOL wishes with loved ones, and minimize family decision-making, caring, and economic burdens • Concerns: <ul style="list-style-type: none"> • The survey result showed that 1) the autonomous nature of advance care planning that might not realize a family model of joint decision-making and 2) troubles and complicities that were possibly related to this planning were mostly concerned • In the interview data, major inhibitors of readiness included: 1) a lack of knowledge or misunderstandings negatively perceived by the unknowledgeable, 2) a sense of no urgency and/or procrastinations, 3) difficulties of facing or initiating death topics, in particular with adult children, 4) a possible unwillingness to make a commitment to future EOL situations

APPENDIX H (continued)

Self-efficacy	<ul style="list-style-type: none"> • The survey revealed a sound level of confidence when making EOL decisions; the majority believed they would not be influenced by their significant others • However, a joint decision-making within the family was a cultural custom and a personal EOL preference • The concept of DOPA and family/spouse surrogate was strongly endorsed by most older interview subjects • Self-efficacy was not a significant correlate of both the ordinal or dichotomous stages of readiness • Self-efficacy was weakly correlated with decisional balance; the more confident the more favor for advance care planning • The majority felt that their families were unclear about their wishes and had no interests at this point to serve as their surrogates which might have conversely affected their readiness for advance care planning • Discouraging behaviors were observed among family members to inhibit EOL communication or even interfere with AD implementations. • Older interview subjects shared it was difficult to convince their whole family in the dynamics of EOL discussion
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B. Cultural Factors

Cultural beliefs	<ul style="list-style-type: none"> • Chinese beliefs regarding EOL decisions were suggested as a predictor of the stage of readiness in the regression analysis • Cultural beliefs were moderately correlated with decisional balance; the less traditional, the more likely to favor advance care planning • Beliefs selected in the quantitative measure were commonly seen among Chinese Americans, but these beliefs were graduated deemphasized in a Western modern society and the majority did not rate them always true • Surprisingly, cultural beliefs were not significantly related to acculturation • Subjects who believed in “back luck” were relatively traditional, since most said it was superstitious to believe that discussing death or participating in this study would invite unexpected death • A traditional belief related to the death taboo was commonly viewed as a concern to inhibit Chinese Americans from advance care planning • In the semi-structured interviews, older subjects’ overall attitude toward discussing death and dying was shown to be quite positive and open, unlike one might think; those who were less bothered by a death topic had fewer difficulties in initiating/continuing death discussions with families
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	<ul style="list-style-type: none"> • Beliefs of a good death, seeing the last face, and death planning were culturally unique but unrelated to readiness for advance care planning • The cultural expectation of filial piety was explicated in Chinese children's duty to make treatment and care decisions at parents' EOL. A death curse was often implied if mentioning EOL planning in front of parents, which simply defied filial piety • Together with male paternalism, seeing the last face, and non-disclosure of medical bad news, filial piety had a significant impact on the AD completion and stages of readiness • Male paternalism was still practiced in Chinese immigrant families, but nowadays family heads were given little power to make the final EOL decisions. Most subjects had a nuclear family in the States, and family members had great influence in Chinese patients' EOL decision-making • Spouses were subjects' most preferred family surrogates, followed by adult children
English proficiency	<ul style="list-style-type: none"> • The majority of subjects reported sound English proficiency, only some had a strong language barrier • Chinese Americans preferred receiving bilingual information, even for those who were highly educated and English proficient • Result from older interview subjects supported how information-isolation in the States and a lack of English proficiency might have impacted their access and possibly hinder readiness for advance care planning • Chinese Americans' preferred language in the written health information was a good predictor of their English proficiency • English proficiency was positively related to acculturation, knowledge, life-satisfaction, education and physical health. Those who were older, poorer, less educated, and unemployed relied on Chinese more. • English proficiency as a factor was significantly and weakly correlated with stages of readiness, but not decisional balance and self-efficacy for advance care planning • In the regression result, its predictability for the readiness outcome was only suggestive and was not selected by the best 5-predictor model
Individualism and Collectivism orientations	<ul style="list-style-type: none"> • Chinese Americans were generally more collectivistic and less individual, and this tendency was more obvious among subjects who strongly believed in traditional beliefs • The interview data showed that when making EOL treatment decisions, a cultural expectation was to consider interdependence and family harmony and integrity, but individual independence and self-control were also prominent in particular among highly educated and educated immigrants who highly valued self-reliance similar to European Americans • IC orientations, however, did not seem to be significantly related to readiness outcomes

APPENDIX H (continued)

Acculturation	<ul style="list-style-type: none"> • On the whole, subjects identified themselves mostly Chinese rather than bi-cultural Chinese Americans • Acculturation was moderately correlated with English proficiency, levels of education, and knowledge for advance care planning; it could be best predicted by a chosen reading and written language since the better the English, the higher the level of acculturation • Acculturation was found unrelated to any cultural beliefs and IC orientations, unlike what was anticipated • In the in-depth interviews highly acculturated Chinese Americans remained holding certain traditional beliefs, such as the traditional value of filial piety and a preferable model of family-centered EOL decision-making • Younger educated, richer, Christian believers were related to a better level of acculturation and knowledge for advance care planning. • Acculturation however was not a strong correlate of readiness for advance care planning
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APPENDIX H (continued)

C. Knowledge Factors

Knowledge about life-sustaining treatment	<ul style="list-style-type: none"> • Life-sustaining treatment (LST) was a more familiar term to subjects compared to AD documents and advance care planning, but there existed misunderstandings and incorrect definitions about the purpose, example, and timing of LST • Older interview subjects with more LST knowledge were more prepared and interested in advance care planning • Subjects who were more knowledgeable about LST did not necessarily know better about various types of ADs • LST knowledge was irrelevant to AD completions • From both the survey and interview data, public media have played an important role in shaping Chinese American society's attitudes and public's awareness of LST decisions
Knowledge about advance directive documents	<ul style="list-style-type: none"> • Only < 3% reported knowing ADs very well, but the majority were unfamiliar with advance directives, living wills, or DOPAs • The self-report level of AD knowledge about living wills might be overestimated, since living trusts and wills were mistaken as living wills • AD knowledge was significantly correlated with AD completions • From the interview data, a subgroup of Chinese older subjects seemed to be disadvantageous in accessing AD information in the mainstream society, such as illiterate immigrants who were socially isolated and limited in English • In the in-depth interviews Chinese subjects' AD knowledge has quickly and systematically increased in a short time • Merely knowing about the AD terminology was insufficient; for Chinese Americans to become advance care planning maintainers, an increase of overall advance care planning knowledge was required
Knowledge about advance care planning	<ul style="list-style-type: none"> • A summated understanding about LST, types of ADs, and advance care planning was shown to be the best indicator of overall knowledge, rather than any single knowledge items or subscale scores • Overall knowledge about advance care planning was suggested in the binary regression as the major predictor for readiness, but it was not correlated with decisional balance and self-efficacy • Chinese immigrants reported receiving little information regarding advance care planning, neither in English nor in Chinese; approximately 90% did not know about advance care planning as a continuous communication process of making advanced EOL decisions • Knowledge about advance care planning was significantly related to English

	<p>proficiency, acculturation, EOL experience, and socio-economic status (income and education)</p> <ul style="list-style-type: none"> • The majority of survey and interview subjects lacked of knowledge in this area; they provided insufficient or improper understandings about advance care planning. • The terminology and phrase were reported very vague and poorly translated in Chinese • American primary care providers, even Chinese-ethnic physicians, were unequipped with sufficient advance care planning knowledge and would not proactively mention advance care planning to their healthy clients. Many believed their family members were unknowledgeable about advance care planning as well, so were unprepared to serve as their surrogates for EOL decisions • Interview subjects agreed that a lack of awareness led to low readiness, but the basic education included in the in-depth interviews have increased not only the knowledge but also their intention and readiness to complete ADs and improve EOL communication with their loved ones
<p>Previous experiences related to life-threatening circumstances of self, a close family members' EOL illness, and caregiving to a terminally ill family</p>	<ul style="list-style-type: none"> • Survey subjects generally were EOL inexperienced in three experience categories • Mostly reported were family members' illnesses, but only a few have participated in discussions related to EOL treatment and care • Surprisingly both the survey and interview data failed to show significant correlations between EOL related experience and readiness variables, irrespective of the types of experiences • The interview subset was chosen to be rich in EOL related experiences but difficulties were found for them to relate EOL experience to their own readiness for advance care planning, • Life-threatening circumstances only facilitated a re-evaluation of life priorities and death attitudes, not engagement in advance care planning • It was clear from the interview data that unawareness and insufficient knowledge was key to low readiness, not experiences • EOL discussions were much more easier between spouses than between parents and children • Previous surrogates reported being unprepared and unequipped for such a role, since they lacked any sense of what their dying family might have without constructive EOL communication with their deceased parents • Previous experiences as family surrogates did not increase their knowledge of advance care planning and even among those who were aware of the option, procrastination also came into play to decrease their own readiness •

APPENDIX H (continued)

D. Quality of Life

Life-satisfaction	<ul style="list-style-type: none"> - Subjects' overall and four subscale scores of life-satisfaction In both quantitative and qualitative results, life-satisfaction as a QOL factor was not significantly associated with readiness outcome variables. were not significantly related to their AD completions, stage of readiness, endorsement and concerns, and self-efficacy for advance care planning - Life-satisfaction was moderately correlated with general status including physical and mental health and the socio-economic status of education and income - Older Chinese interview subjects who highly rated their life-satisfaction in the family domain seemed to have comparatively low self-efficacy for their advance care planning; they were more likely to be influenced by significant others
General health status	<ul style="list-style-type: none"> - The Chinese American sample was generally poorer in their overall health compared with the 1998 healthy U.S. norms of no chronic condition, in particular, in the age group between 55-74, subjects were physically healthier yet mentally poorer than their counterpart - Neither PCS or MCS were significantly correlated with AD completion, readiness, decisional balance, and self-efficacy for advance care planning - The interview data support the relatively weak survey findings that mentally healthier subjects endorsed ($r = -.25, p < .001$) rather than concerned ($r = -.18, p < .05$) about advance care planning. Older subjects who self-described peaceful and joyful, not depressed, and socially interactive would like to initiate advance care planning - Both physical and mental health were moderately to highly correlated with the overall and particularly health and functioning subscale of life-satisfaction - Younger, employed, better educated and richer subjects were associated with better physical health

APPENDIX H (continued)

E. Spiritual Factors

Spirituality, the system of beliefs	<ul style="list-style-type: none"> - To Chinese American subjects, spiritual beliefs and practice were more important than perceived social support, and most Christian subjects agreed their religion has brought them a sense of hope and peace of mind - Subjects' religious needs and emphasis seemed to be placed on the intrinsic rather than extrinsic spirituality - None of subjects' overall or subscale spirituality was associated with AD completions, stage of readiness, endorsement and concerns, and self-efficacy for advance care planning
Self-perceived religiosity	<ul style="list-style-type: none"> - Most subjects were regular attendants of religious activities (more than twice a week) and perceived themselves moderately to highly pious - Self-perceived religiosity was moderately correlated with spirituality - Self-rated religiosity was not associated with AD completions, stage of readiness, and endorsement and concerns - The more frequent participation in religious activities, the less self-efficacy for advance care planning, showing a possible influence of the religious community in subjects' EOL decision-making, however, the interview data did not strongly support this finding - Christians were found to perceived themselves more religious than other religion believers and this was supported by the interview data that former Taoist and Buddhist believers were little influenced by their family religions

APPENDIX H (continued)

F. Demographical Factor

Age and parent alive status	<ul style="list-style-type: none"> - Age was very weakly correlated with the stage of readiness; older subjects tended to be related to better readiness for advance care planning, but age was not a correlate of AD completions, decisional balance and self-efficacy for advance care planning - Surprisingly, age was not related to cultural beliefs, acculturation, knowledge and previous EOL experience, and any spiritual factors, but was weakly associated with English proficiency - Once older interview subjects were introduced and educated about the concept, they were interested in initiating advance care planning because they already had some sort of death planning - Age was moderately correlated with physical health but not mental health and life-satisfaction - The number of parents alive was positively and highly correlated with age, and only 15% had both parents alive - The number of parents alive was unrelated to any readiness outcome variables for advance care planning
Gender	<ul style="list-style-type: none"> - Being a female was predictive in the final binary regression model to increase the odds of advance care planning, but in the correlation results there was no specific gender difference in subjects' readiness outcomes - Gender was not associated with knowledge, previous experiences, QOL and spiritual factors, but it was weakly related to English proficiency and physical health; males generally were better in their English and physical health - In the interview data older Chinese women emphasized more on future EOL care and how their preferences could be communicated during the advance care planning process with their loved ones, where men's focus was primarily centered on the decisions of AD completions and functional and LST outcomes - Older women were more open and positive in their intention regarding learning advance care planning; they anticipated benefits from advance care planning, endorsed this health promotion option, and seemed to be psychologically prepared for death.

APPENDIX H (continued)

Highest education and annual household income	<ul style="list-style-type: none"> - A considerable number of subjects were highly educated that 67% were Master's prepared and one thirds had an annual income higher than \$100,000USD - The result of the logistic regression was suggestive that Chinese Americans' level of education was an important factor to predict their readiness for advance care planning - Education and income were moderately correlated with each other but neither of them was associated with the readiness outcome variables - Subjects with better SES were moderately and positively related to better English proficiency and acculturation, and weakly and positively related to knowledge, satisfaction, and physical health - SES was significantly correlated with overall and all knowledge categories for advance care planning, except for the knowledge about advance care planning
Marital and life-partner status	<ul style="list-style-type: none"> - The majority 77% was in a marriage or lived with a life-partner - This variable was unrelated to any readiness outcome variables for advance care planning
Employment	<ul style="list-style-type: none"> - Less than half of the sample was currently employed - This variable was unrelated to any readiness outcome variables for advance care planning
Raised religion	<ul style="list-style-type: none"> - Approximately half were raised in a family of Chinese traditional religions - In the correlation results, this variable was unrelated to any readiness outcome variables for advance care planning - Beliefs and practice of atheism and Chinese traditional religions have negatively influenced readiness for advance care planning; folklore religions have commonly brought about an avoidance and fear of death or the afterlife
Current religion	<ul style="list-style-type: none"> - The majority of this sample were Christians and regular church-goers - The interview data supported the weak correlation between Christianity and decisional balance; Chinese Christian believers tended to favor advance care planning - This variable was unrelated to any readiness outcome variables for advance care planning - Older Christian interview subjects were comparatively more hopeful and less fearful than non-Christians when discussing EOL matters - Christian beliefs have clearly shaped subjects' values and optimized their death and dying attitudes but it was not a direct facilitator to increase readiness
Religion change	<ul style="list-style-type: none"> - More than half have changed their religion and the majority have converted to Protestant Christians after immigrating to the States - In the correlation results, this variable was unrelated to any readiness outcome variables for advance care planning

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VITA

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Hsiung, Y., Ferrans, C. (May 2007). Factors that influence Chinese Americans' readiness for advance care planning. International Network for Doctoral Education in Nursing (INDEN) Biennial Meeting, Tokyo, Japan.

Hsiung, Y., Ferrans, C. (April 2007). Chinese Americans' readiness for advance care planning. The 3rd Asian American Pacific Islander Nurses Association Annual Conference, San Francisco, CA.

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Hsiung, Y., Ferrans, C. (March 2006). Recognizing Chinese Americans' cultural needs at the end-of-life. The 2nd Asian American Pacific Islander Nurses Association Annual Conference, Chicago, IL.

Hsiung, Y., Ferrans, C. (November 2005). Cultural issues and theory application in Chinese Americans' end-of life treatment decision-making. Sigma Theta Tau International 38th Biennial Convention, Indianapolis, IN.

Hsiung, Y., Ferrans, C. (May 2005). Cultural issues and theory application in Chinese Americans' end-of-life treatment decision-making. International Council of Nurses 23rd Quadrennial Congress, Taipei, Taiwan.

Hsiung, Y., Ferrans, C. (March 2005). Cultural issues in Chinese Americans end-of-life treatment decision-making. The 1st Annual Conference of The National Coalition of Ethnic Minority Nurse Associations (NCEMNA), Washington, DC.

Hsiung, Y., Ferrans, C. (August 2004). Cultural issues in Chinese Americans' end-of-life treatment decision-making. Asian American Pacific Islander Nurses Association 1st Annual Conference, San Francisco, CA.

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1. **Hsiung ,Y.** (2011) Chinese Americans' Readiness for Advance Care Planning, University of Illinois at Chicago, IL.
2. Yang CL, Chiu TY, **Hsiung ,Y.**, Hu WY. (2011) Which Factors Have the Greatest Influence on Bereaved Families' Willingness to Execute Advance Directives in Taiwan? Cancer Nurs. 34 (2), 98-106.
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5. **Hsiung, Y.** (2001). Do-Not-Resuscitate issues among stroke patients. University of Illinois at Chicago, Chicago, IL.