PROSPECTIVE END-OF-LIFE DECISION-MAKING:
A STUDY OF ASIAN INDIAN HINDU YOUNGER
AND OLDER ADULTS

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ABSTRACT

This study examined the effects of age and culture on end-of-life decisions within the context of socioemotional selectivity theory. Younger (N=100) and older (N=100) Asian Indian Hindus completed a questionnaire on their preferences for life-sustaining treatments and choice of decision-maker for two end-of-life scenarios, as well as scales assessing Western and Indian acculturation and Hindu end-of-life values. Ten participants from each age group were interviewed. Sequential logistic regression showed that the majority of participants, regardless of age, indicated that they would refuse life-sustaining treatments and engage in autonomous decision-making. These results are consistent with the emphasis on positive emotional experiences predicted by socioemotional selectivity theory. Although the interviews revealed that participants based their decisions on Hindu philosophy, the acculturation and Hindu values scales did not capture that relationship. The participants drew a distinction between Hindu philosophy and Hindu end-of-life rituals, as well as between religion and health related decision-making. Supplemental data were collected from a sample of younger (N=64) and older (N=59) non-Hispanic Whites to further investigate the effects of culture. Results revealed that Asian Indians were less likely to choose life-sustaining treatments than non-Hispanic Whites. However, most non-Hispanic White participants also refused life-sustaining treatment and endorsed autonomy in decision-making. The discussion focuses on the implications of these findings for understanding the roles of socioemotional selectivity, age, and culture in end-of-life decision-making.

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CHAPTER I: INTRODUCTION

The Role and Importance of Decision-making in End-of-life Care

Decision-making is a cognitive process involving choosing one action from various alternatives (Kennerley, Walton, Behrens, Buckley & Rushworth, 2006). This definition becomes more complex when applied to decisions made at the end of life. End-of-life decision-making involves the mechanisms by which an individual, his or her family members and health care practitioners make decisions about treatment to be received at the end of life. Decision-making is often difficult because it requires understanding of technical information regarding the use of life-sustaining treatments and patients and caregivers at the end-of-life are often stressed or anxious, thus complicating research in this area (Baggs & Mick, 2000; Kyba, 2002).

The rapid increase in the aging population will result in a corresponding increase in issues related to end-of-life care (Connor, Egan, Kwilosz, Larson & Reese, 2002). End-of-life issues are unique for all individuals and their families and the nature of decisions made affect the quality of this experience significantly, especially for older adults (Schroepfer, 2006). End-of-life decisions must be made with sensitivity taking into account the context of the individual older adult's belief system (Schmidt, 2001). Egan (1998) emphasizes that death is an experience that is different for each individual and family, that there are many factors involved in the final process and this is an important last stage of life providing opportunities for growth. Decision-making about the final stages thereby becomes crucial for individuals and their families.

The process of decision-making at the end of life might take place under two different circumstances. One is at the point of actual crisis, when immediate treatment is necessary, and the other is for future treatment decisions (Faber-Langendoen & Lanken, 2000). Consequently, there might be a need for communication of preferences for treatment at different points in the life cycle for both the individual and his or her family. Decision-making for the end-of-life can involve either informal discussions with family members or medical practitioners or the use of more formal written documents. It is difficult to operationalize the construct of decision-making because it has not been specifically defined in end-of-life literature, but it is generally considered to involve issues of treatment preferences and advance directives including powers of attorney, living wills and the use of proxy respondents (Scherer, Jezewski, Graves, Wu & Bu, 2006).

Only 15 to 20% of the population have documented their end-of-life preferences by completing advance directives (Havens, 2000), either in the form of a living will or designation of a durable power of attorney for health care. This suggests that although end-of-life issues are an important concern, these decisions remain largely unplanned.

The focus in decision-making literature has been mainly on specific treatment decisions and advance directives (Hawkins, Ditto, Danks & Smucker, 2005). This has left a gap in issues like the preferred processes for planning and decision-making, which are also important. Advance care planning has been considered as the central means to understanding the decision-making process in end-of-life care with patients

discussing preferences with their medical practitioners or with surrogate decision-makers (Hines, 2001). But evaluations of the effects of advance care planning have suggested that they are often too vague to guide the decision-making process and are frequently not taken into consideration (Sulmasy et al., 1998; SUPPORT, 1995). This implies that decision-making processes in use so far need to be reconceptualised in response to the needs of the individual.

Studies have indicated that prospective decision-making processes make the transition from acute to palliative care easier and relieve much family stress and burden (Braun, Beyth, Ford & McCullough, 2008; Tilden, Tolle, Nelson & Fields, 2001; Travis, Loving, McClanahan & Bernard, 2001). Many individuals who die in hospitals are unable to make decisions at the end of life (Tilden et al., 2001). Many of these individuals often endure a long and painful dying process, often receiving unwanted medical care (SUPPORT, 1995). The value of prospective decision-making in planning for end-of-life treatments therefore cannot be denied.

Cultural Issues in Decision-making

Studies on end-of-life planning show that the non-Hispanic White population in the United States was most likely to have some form of advance care planning in comparison to any other ethnic group (Havens, 2000; Kish, Martin & Price, 2000; Waters, 2000). On the other hand, racial minorities have reduced access to palliative care as well as to pain and symptom management, leading to decreased knowledge of treatment options as a basis for decisions at the end of life (Siriwardena & Clark, 2004). The most commonly studied comparative groups in end-of-life decision-

making, and specifically with regard to advance directives are African Americans and White Americans. Factors such as how decisions are made within the family structure and how this varies among different ethnic groups become particularly important , since culture plays a fundamental role in the way people make meaning out of illness and the dying process (Haley et al., 2002 ; Kagawa- Singer & Blackhall, 2001). One of the strongest determinants of people's perceptions of end-of-life decision-making and the nature of illness and dying is their cultural background (Anderson, 2008; Helman, 2002).

Asian Indians comprise the second largest Asian ethnic group, in the United States, making up about 1% of the population. This population constitutes the fastest growing in the United States, immigrating for better educational and employment opportunities (U.S. Bureau of Census, 2002). There has also been increased family immigration in this group, leading to a growing elderly Asian Indian population (Leonard, 2000). However, most work on end-of-life decision-making that has focused on ethnic Asian groups has dealt with others subgroups, mainly Chinese, Japanese, Korean, Filipino and Vietnamese populations (Braun & Browne, 1998). About 80% of Asian Indians are Hindu (Rao, Deshpande, Jamoona & Reid, 2008) and follow Hindu principles and practices as a way of life (Pandit, 1996). With an increasing presence in the United States, Asian Indians will continue to use health care services. As this population ages, questions about end-of-life preferences in this group becomes important (Doorenbos, 2003).

This study addresses this issue by examining the views of Asian Indian emigrants regarding prospective end-of-life decision-making. It explores how those views differ for younger and older individuals, as well as how they are influenced by acculturation and Hindu values. The study adds to the literature on end-of-life decision-making in several ways. By including healthy young and older individuals, it fills a gap in the literature on prospective end-of-life preferences (Carr & Khodyakov, 2007). Most prior research has focused on individuals with certain kinds of illnesses or those hospitalized (Allen et al., 2003; Wenger et al., 2005). In addition, which aspects of culture most influence the use of life-sustaining treatments by those in different ethnic groups remains largely unexplored (Braun & Browne, 1998). The study by using methodological triangulation involving both qualitative and quantitative data provides a comprehensive perspective of end-of-life decision-making in Asian Indian Hindus. Finally, this study brings a strong theoretical focus to a consideration of end-of-life preferences, which has been absent from most prior research in this area (Cicirelli, 1997, 2001; George, 2002).

Theoretical Background

The predominant model in health decision-making in the United States is based on the bioethics of medicine, which emphasizes autonomy for the individual (Beauchamp & Childress, 1994). The main bioethical principles are: (1) autonomy or the right to decide treatment, (2) beneficence which requires the medical practitioner to consider the patient's best interests (Weisstub, Thomasma, Gauthier & Tomassy 2001), (3) non-maleficence that requires the care provider to do no harm, and (4)

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justice which points to the need for equal opportunity for all patients (Koenig, 1997). The bioethical model assumes that decision-making is a rational process and fails to consider the emotional and social components that are part of the end-of-life experience (Dutta-Bergman, 2003; Lambert et al., 2005).

Bioethical principles have been criticized for their use in a prescriptive manner in end-of-life settings rather than as frameworks for meaningful decision-making (Drought & Koenig, 2002). Bioethics is also based primarily on western and white backgrounds and values, but beliefs in other religions and cultures may vary significantly (Dupree, 2000; Hopp & Duffy, 2000; Koenig & Gates-Williams, 1995). Religion and culture especially become salient for certain ethnic groups, within the context of end-of-life decision-making, thereby making the bioethical model less relevant. The lacunae in the bioethical model point to the need for decision-making models that will accommodate the religious beliefs and cultural views of different ethnic groups.

For older adults, religion and culture help to cope with losses and limitations, find meaning and values in life and relationships, and accept and understand the reality of death and dying (Jernigan, 2001). Palliative medicine has to some extent begun to integrate the multi-dimensionality of care of the dying person, including religious elements along with the biological. The concept of "autonomy-in-relation" (Candib, 2002), which refers to the family style of decision-making preferred in many cultures needs to be recognized within any theoretical framework that explains end-of-life decision-making. Adopting the elements of the ABCDE mnemonic suggested

by Kagawa-Singer and Blackhall (2001) will help in reducing the conflicts between bioethics and culture. This involves assessing and dealing with *A*ttitudes of patients and their families, *B*eliefs about death and dying, *C*ontext of their lives and situations, *D*ecision-making style of the individual, and *E*nvironmental resources available.

Socioemotional selectivity theory (SST) combines several of these factors to fill in the gap left by bioethical models (Carstensen, 1998; Carstensen, Isaacowitz & Charles, 1999). The salience of personal experiences and emotions for older adults are well documented by studies on socioemotional selectivity theory. Socioemotional selectivity theory posits that there is a preference for emotionally meaningful as well as positively balanced experiences with increasing age (Carstensen, 1998 ; Lockenhoff & Carstensen, 2004), suggesting that this theory provides a suitable alternative to the bioethical model.

According to SST, older adults see their remaining life time as relatively scarce, elevating the importance of emotional goals in comparison to informational goals (Carstensen et al., 1999). These factors, combined with a drive to maintain positive emotional equilibrium, could affect the decision-making process at the end of life in terms of preferences for life-sustaining treatments as well as the choice of decision-maker. That is, in order to avoid possibly negatively valenced quality of life, older adults may decide to forego life-sustaining treatments when facing a terminal illness (Lockenhoff & Carstensen, 2004). In addition, older adults may also avoid painful decisions and delegate them to surrogates, although the Western medical

model presupposes autonomous decision-making (Ainslie & Beisecker, 1994;

Roberto, Weeks & Matheis-Kraft, 2001).

Research Questions

The purpose of this study is therefore to examine the role of age and culture in the process of end-of-life decision-making by Asian Indians in the United States within the framework of socioemotional selectivity theory. Specifically this study addresses two research questions:

(1) How do age, acculturation and Hindu end-of-life beliefs influence the choice of life-sustaining treatments?

(2) How do age, acculturation and Hindu end-of-life beliefs influence the choice of autonomous versus surrogate decision-making?

CHAPTER II: REVIEW OF LITERATURE

This study examined the role of age and culture in prospective end-of-life decision-making processes of Asian Indians living in the United States, using socioemotional selectivity theory as a framework. Key concepts of importance to the study are considered in this chapter, including: (1) the demographic profile of Asian Indians in the United States; (2) the role of socioemotional selectivity theory, its application to health related decision-making in general and specifically to end-of-life decisions; (3) life-sustaining treatments and the choice of using such treatments, with emphasis on age and ethnicity effects; and (4) preferred decision-maker in determining end-of-life treatments with emphasis on age and culture.

The Asian Indian Community in the United States

Asian Indians began immigrating to the United States at the beginning of the twentieth century but the number increased by 125% between 1980 and 1990 (Alagiyakrishnan & Chopra, 2001). Family reunification laws brought an increasing number of elderly Indian adults to the United States. Although there is evidence to indicate that a majority of Asian Indian elders are foreign born and do not speak English very well, only 12% are linguistically isolated (i.e., without any adult who speaks English in the household) (Desai, 1990). Many older Asian Indians who immigrated at the time of family unification are dependent on their families financially and socially and may face the challenges of a new life style and role reversal (Leonard, 2000). Religion and language are important determinants of Asian

Indian immigrants' access and utilization of health care (Weerasinghe, Maddelena & Kanth, 2008).

Hindu Indian society is driven by the notion that life has four distinct stages or *ashramas* with four goals (Van Willigen, Chadha & Kedia, 1995). Each life stage is used to prepare for the next stage with the final goal of attaining *moksha* or liberation from the cycle of births and rebirths (Pandit, 1996). The final stage of renunciation of worldly attachments or *sanyasa (*Prabhu, 1963), although not practiced in its most extreme form may still influence decisions made for and at the end of life. Therefore it is important to understand Asian Indian attitudes towards end of life and decision-making within the context of this connection to Hindu philosophy.

Health Issues and Beliefs

Studies have indicated that immigrant Asian Indian men and women have a high prevalence of coronary heart disease, coronary artery disease, non insulin-dependent diabetes and osteoporosis. They also have the second highest incidence of cancer among Asians and Pacific Islanders (Alagiyakrishnan & Chopra, 2001). In spite of the large number of Asian Indian physicians in the United States, most Asian Indians do not possess adequate health knowledge and this is carried over to inadequate knowledge of end-of-life issues as well (Doorenbos & Nies, 2003).

Certain aspects of the Hindu religion commonly affect health care decisions. Customs and practices in Hinduism are interconnected because of its social systemic nature. The concept of *Karma* is very important to Hindus, who believe that this law of action and consequences governs behavior (Prabhu, 1963). *Karma* implies that

everything that happens to an individual is a result of his or her own previous actions and therefore must be accepted with forbearance (Miltiades, 2002). This can lead to an acceptance of terminal illness as *karma*, in spite of a thorough understanding of the biological causes of the condition. This in turn might affect the individual's decision-making process regarding all or certain types of life-sustaining treatments.

Another important tenet of Hinduism is the goal of *Dharma* (Miltiades, 2002). This refers to the duties and responsibilities of a person according to his or her age and position in life. Elders are treated with respect for their age and wisdom (Bisht & Sinha, 1981). Cultural aspects of Hinduism which dictate that a person with knowledge is to be treated as superior may lead the individual to be a passive participant in medical decisions, without questioning or clarifying diagnosis or treatment (Alagiyakrishnan & Chopra, 2001). However, because of the close-knit family structure, health care decision-making may be a joint exercise with frequent consultations among family members. This indicates that family-centered decision-making as opposed to autonomous decision-making, may be preferred by Asian Indian immigrants, especially by those who are older.

Religious communities within the Hindu culture embrace certain rituals and practices for the end of life. Family members may wish to be present as the person is close to death. Washing the body after death and placing the body on the floor to be closer to Mother Earth are common Hindu practices. A Hindu priest may be present to offer prayers for the dying individual (Doorenbos, 2003). Cremation is preferred in Hindu culture over other methods of dealing with bodily remains, and an extensive

mourning period lasting between ten days to one year may exist. Adherence to these cultural practices however is dependent on the beliefs of individual families and practical issues. Integration into Western culture may also play an important role in many of these decisions.

Gupta's (1999) study of caregiving among Asian Indian immigrants indicated that this responsibility often falls on the adult children because of the lack of extended family support, mistrust of government-based social service facilities and cultural unwillingness to send the older family members to nursing homes and other assisted living facilities. This study also found that a cultural norm similar to filial piety in the Chinese culture exists among Asian Indian immigrants, but is more firmly present in the first generation of immigrants than subsequent ones. These results are consistent with the use of a family-based decision model among Asian Indians.

Socioemotional Selectivity Theory and Health-related Decision-making

According to SST, when time is seen as limited, as in end-of-life decisions, emotionally meaningful goals take precedence over information-seeking goals. Evidence for this tendency has emerged not only in studies involving older adults but also those with younger adults who faced a limited time perspective as in the case of life-threatening illnesses (Carstensen, 1993, 1995, 1998: Lockenhoff & Carstensen, 2004). A corollary is that information from personal experiences has greater emotional relevance to older persons than information from other sources such as medical professionals (Lambert et al, 2005; Lang & Carstensen, 2002). The predictions of SST regarding the role of emotion in decision-making and the effects

of age have been empirically supported (Carstensen, 2006; Carstensen & Turk-Charles, 1994; Lowenstein, Weber, Hsee & Welch, 2001). These predictions of SST have also been demonstrated to have cross-cultural validity, as shown by Fung and colleagues in research with populations in China, Hong Kong and Taiwan (Fung, Carstensen & Lutz, 1999; Fung, Lai & Ng, 2001).

Health-related decision-making has been described as a rational, time-bound and objective process (Finucane, Alkahami, Slovic & Johnson, 2000; Yates & Patalano, 1999). Rational analytic decision models like the theory of planned behavior and the health belief model assume that health-related decision-making is a step-by-step process with the individual weighing the information available and taking into consideration normative and control beliefs as well as self-efficacy (Glanz, Rimer & Lewis, 2002; Godin & Kok, 1996). However decision-making realistically includes the influences of individual goals and emotional preferences (Hsee & Kunreuther, 2000; Kunda, 1990). SST is therefore a pertinent theoretical framework to explain end-of-life decision-making since health goals are emotionally oriented.

In the health domain, older adults' preference for positive information and avoidance of negatively valenced issues can often lead to incomplete and inadequate information required for decision-making. In addition, this preference can produce an age-related positivity effect which leads older individuals to seek positive information that promotes emotional well-being. This age-related positivity effect was examined by Lockenhoff and Carstensen (2007) in the context of choosing health care plans. This computer-based study used a 2 (age: young/old) X 3 (instructional condition:

information-focused, emotion-focused or neutral) between-subjects design. The

instructional condition was emphasized in the introduction to the experiment where

the participants were asked to focus on emotional goals such as feelings, or on

information such as facts or details. In the neutral condition, neither was emphasized.

The participants evaluated different health plans and physicians. The emotional

valence of the choices was measured by the number of times the participants

reviewed the information about the plans available to them on a computer screen.

Lockenhoff and Carstensen (2007) predicted that in the control condition,

older adults would focus on and recall more positive information than younger adults.

Their second hypothesis was that reduced age differences would occur due to the

experimental manipulations, with both age groups showing positive preferences in the

emotion-focused condition and information preferences in the information-focused

condition. Results supported the first hypothesis and older adults consistently

reviewed information that had positive content. This effect was not seen in younger

adults, providing support to the positivity bias predicted in SST. The second

hypothesis was only partially supported in that there were no age differences in the

information-focused condition. Overall, the findings provide support for the

predictions of SST in health care decisions and advance understanding of age

differences in pursuing emotional goals.

Other evidence consistent with SST comes from research by Lambert and

colleagues (2005) .These investigators used interviews to examine the important

factors affecting the planning process of long term care residents as they formulated

advance directives. Qualitative results indicated that even with experiences of near death and use of minimally invasive life-sustaining treatments, these older individuals preferred to receive positive information and draw on social and spiritual considerations, rather than plan for end-of-life options. Similarly, older Asian Indians may be expected to draw from their religious and cultural backgrounds to maintain the bias towards positive experiences.

Choice of Treatment

Effects of Age on Treatment Preferences

Studies of the relationship of age to the choice of life-sustaining treatments have produced conflicting findings (Cicirelli, 1997, 2001). Some studies have shown that age is negatively correlated with the use of life-sustaining treatments and the use of advance directives (Cooper, Weber, Evans & Juozapavicius, 2001; Havens, 2000;Triplett et al., 2008), while others have shown no age differences (Cicirelli, 1997). Black, Reynolds and Osman (2008) in a more recent study found that increased age was associated with a higher likelihood of planning for the future in terms of advanced care, but the nature of the preferences for those decisions were not specified in that study. The conflicting findings in the research literature could be due to the effect of contextual factors such as religion, culture, or socioeconomic status. Other studies also found that there are definite changes in the decision-making process and attitudes towards end of life as a person grows older (Gordon & Shade, 1999; Vandecreek et al., 1995), but no explanation for the age effects have been offered.

Although there is little consistent information regarding age differences in preferences for end-of-life treatments, several studies provide insight into the factors that appear to influence older individuals' choices. Older individuals are often found to be more concerned about the effect of life-sustaining treatments on life activities, rather than the specific nature of the invasive treatment itself (Rosenfield, Wenger & Kagawa-Singer, 2000). Since most older adults tend to perceive future health states with their current state of health as a reference point, choosing treatment preferences becomes a complex emotional process (Kostopoulou, 2006). Similarly, Winter and Parker (2007) reported that in prospective end-of-life decisions, healthier older people were more likely to refuse life-sustaining treatments than were less healthy people. This indicates that older adults may be reluctant to choose prospective life-sustaining treatments that restrict their quality of life, especially if they are currently healthy.

Treatment burden, outcome, and likelihood of the outcome are three factors that older adults considered most important in decision-making at the end of life (Pearlman et al., 2000; Rosenfeld et al., 2000). For example, in a study of 23 older adults with chronic pulmonary disease, Fried and Bradley (2003) found that respondents viewed the treatment burden associated with invasive life-sustaining treatments as bearable if the outcome was desirable. The respondents in Fried and Bradley's (2003) study also indicated that treatment preferences may change with the progress of the disease. However, older adults have reported less desire for life-sustaining and invasive treatments immediately after hospital discharge, which is in contrast to their views prior to hospitalization (Ditto, Jacobson, Smucker, Danks &

Fagerlin, 2006). This indicates that negative experiences may have an influence on the type of treatment preferences.

Research on health care decisions of older adults presented with hypothetical scenarios about life-extending treatments (dialysis, tube feeding, cardiopulmonary resuscitation etc) has reported that more aggressive treatment was preferred only if it resulted in greater comfort or safety for the older adult (Cicirelli, 1997; Cohen-Mansfield, Droge & Billig, 1992; Decker & Reed, 2005; Lee & Ganzini, 1992; Roberto et al., 2001; Zweibel & Cassel, 1989).

For instance, Roberto and colleagues (2001) found that older adults based their decisions on a convergence of beliefs that included health status at the time of decision-making, prognosis and past experiences. The older adults were presented with critical health scenarios and most of the participants rejected the use of life-sustaining treatments because of the poor quality of life associated. This is in line with the predictions of SST that older adults place a greater emphasis on positive experiences (Lockenhoff & Carstensen, 2004, 2008). Other research has found that elderly patients who are in the hospital with terminal illnesses have often not discussed their end-of-life wishes during the stay and are more prone to discussing survival chances, demonstrating the need for positive information (Heyland, Tramer & Feldman-Stewart, 2000).

The current study extends this research on older adults' bias towards positive experiences and information, by testing it within the context of end-of-life decision - making. In line with the predictions of SST, this study tested the hypothesis that:

H1: Fewer Asian Indian older adults than younger adults will choose life-sustaining treatments.

Effects of Culture on Treatment Preferences

There has been scant quantitative research on groups that might have different emotional experiences as a result of varied cultural and religious values, although a few descriptive studies have been completed. Asian Americans and Mexican-Americans have perceptions on end-of-life decision-making different from the autonomous model preferred in Euro-American culture (Blackhall, Murphy, Frank, Michel & Azen, 1995). For example, a comparison of Japanese and Japanese - American focus groups indicated that fear of being a burden on the family led to the decision to withdraw or forego life-sustaining treatments (Bito et al., 2007). These results suggest that familial concerns play a significant role in the choice or refusal of life-extending treatments.

Other studies of cultural preferences for life-sustaining treatments have indicated that ethnicity is a significant predictor for the absence of do-not-resuscitate orders and preferences for hospitalization and the use of feeding tubes (Borum, Lynn & Zhong, 2000; Garrett, Harris, Nopburn, Patrick & Danis, 1993). These studies also found that minority ethnic groups have poorer knowledge and utilization of advance care planning documents. Therefore cultural effects of choice of life-sustaining treatments cannot be confirmed since minority patients may not have been aware of the exact nature of the life-extending process.

In the Asian Indian population in particular, there have been only three studies that examine end-of-life decision-making (Doorenbos, 2003; Doorenbos & Nies, 2003; Rao et al., 2008). Two of these studies focus on the tenets of the Hindu religion and suggest that patriarchal and family-based decision-making are present. The studies also focus on knowledge of and access to hospice care for Asian Indians and were exploratory with relatively small samples of 44 (Doorenbos, 2003) and 45 participants (Doorenbos & Nies, 2003) each. The participants completed an ethnic affiliation scale, a Hindu religious beliefs and rituals scale, and questions on end-of-life issues with an emphasis on advance directive completion. Results revealed that participants endorsed the importance of following Hindu rituals and of involving family members in decision-making but had minimal if any knowledge of advance directives.

Rao and colleagues (2008) conducted a study with 44 Indo-Caribbean Hindu adults aged sixty years and older to examine the use of and knowledge about advance directives as well as attitudes towards end-of-life issues. Participants felt strongly about Hindu beliefs at the time of death and wanted to include their family members in decision-making. Overall, participants felt negatively about the use of life-extending treatments but had poor knowledge of advance directives and life-sustaining technologies, which could have biased the results. The paucity of extensive research on end-of-life issues in the Asian Indian population emphasizes the importance of the current study in clarifying some of these issues.

There is evidence that religion may have an impact on end-of-life decision-making with individuals turning to spiritual concerns and religious support with the diagnosis of a terminal illness (Burdette, Hill & Moulton, 2005; Emery & Pargament, 2004; McGrath, 2003). Although Hindu scriptures do not provide specific guidelines on issues related to the end of life (Deshpande et al., 2005), the existence of a unitary life force that is eternal and that has a cycle of births and deaths is a fundamental Hindu belief (Firth, 2005; Olivell, 1996). If death is viewed as merely a stage in the cycle of births and deaths, those with Hindu values might show a preference for palliative care over life-extending treatments in order to avoid interrupting the cyclical nature of life (Pandit, 1996). Especially for older adults, life-sustaining preferences may be seen as futile because deterioration and terminal illnesses are accepted as part of the aging process (Vatuk, 1996).

A terminally ill person may also refuse medication in order to die peacefully and consider pain as penance for sin (Firth, 2005). This may create difficulties during the treatment planning process, especially if the medical practitioner is not aware of the cultural beliefs of the individual. It is therefore likely that for both younger and older Asian Indians , the effect of Hindu culture on choice of treatment preferences could be moderated by the strength of Hindu end of life values as well as integration into Western culture , making flexibility in understanding decision-making in this population very important (Gielen & Broeckaert, 2007). As a result, this study tested the hypothesis that:

H2: Regardless of age group, higher Western acculturation will be positively related to preferences for life-sustaining treatments, whereas stronger Asian Indian acculturation and Hindu end-of-life beliefs will be negatively related to preferences for life-sustaining treatments.

<div align="center">Choice of Decision-maker</div>

The choice of decision-maker is a difficult one in end-of-life situations. There are two related issues embedded in the choice of decision-maker: (1) Do individuals make decisions themselves or do they delegate them to others? And (2) If a surrogate decision-maker is chosen, which individual or individuals are preferred? The use of surrogates in end-of-life care planning may be due to three factors: (1) patients who are dying might be unable to participate in the decision-making process (George, 2002), (2) the valid notion that important end-of-life decisions cannot be made by the individual in isolation (Hopp, 2000), and (3) cultural and religious factors that determine the choice of surrogate as well inclusion of family members in decision-making.

Effects of Age on Choice of Decision-maker

Research has suggested that choosing a surrogate decision-maker, occurs in a linear fashion, and involves a number of steps (Stroud, 2002; Swigart, Lidz, Butterworth & Arnold, 1996). These include understanding the illness and prognosis, evaluating what this would mean for the patient in terms of values and life-experiences, and finally taking on the role of decision-maker or choosing a surrogate. Other studies indicate that the choice of decision-maker is a difficult process often

involving conflict as negotiations to choose the right individual are made. This process becomes more difficult with age as the social networks of the individual change over time (Kaufman, 1998; Slomka, 1992).

Individuals express a desire to discuss end-of-life issues with doctors but often fail to do so, even when decisions may be imminent (Hofmann et al., 1997; Pfieffer et al, 1994). This suggests that there might be a gap between the conceptual framework of autonomous decision-making and actual planning by older adults (Hawkins et al., 2005). This also leads to a dilemma in the choice of decision-maker. This dilemma may be compounded because individuals are torn between sparing the family from burden and delegating control of treatment preferences (Hines et al., 2001; Singer, Martin & Kelner, 1999).

SST predicts that older adults more so than younger adults will tend to delegate difficult and unpleasant decisions to others because of preference for positive information (Chen, Haley, Robinson & Schonwetter, 2002; Haley et al, 2002; Lockenhoff & Carstensen, 2004, 2007). This tendency has been confirmed in laboratory studies comparing choices of younger and older adults regarding advance directives, breast cancer options and health care plan choices (Ainslie & Beisecker, 1994; Finucane et al., 2002; Meyer, Russo & Talbot, 1995; Roberto et al., 2001).

About 86% of decisions about life-sustaining treatments are made by someone other than the patient, indicating the need to study influences on the choice of decision-maker (Swigart, et al., 1996). Older adults also tend to assume that family members would make decisions for them if needed, in accordance with their general

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views on end-of-life options (High, 1993). Puchalski et al., (2002) found that 75% of 1159 hospitalized older adults with a mean age of 73 indicated that they preferred to have their family members or physicians to make decisions regarding resuscitation.

Chen and colleagues (2002) found that married individuals wanted families to make the decisions while single, divorced, separated and widowed individuals wanted to make the decisions themselves. Cicirelli (1997) reported that about a third of 338 older adults in his study preferred to defer end-of-life decisions to a family member, friend or physician. The Asset and Health Dynamic Among the Oldest Old (AHEAD) study indicated that 95% of the 520 older adults in the sample reported that they had people they trusted to make end-of-life decisions for them. However, less than half of that group had discussed specific medical preferences with those trusted individuals (Hopp, 2000). As a result, surrogate decision-makers may make end-of-life decisions based on their own preferences rather than that of the individual. For example, in a study with 315 couples with a mean age of 69.9, Pruchno, Lemay, Field and Levinsky (2005) found that spouses preferred more aggressive methods of life-sustaining treatments (dialysis) in contrast to the terminally ill individuals' choice of palliative care. These studies point to a gap between wishes regarding end-of-life treatment and execution of those wishes, and have implications for the appropriate choice of decision-maker and communication with that decision-maker.

The hierarchical compensatory model of decision-making suggests that older adults will turn to non-family members only when a family member is not available (Cantor, 1979). Consistent with this model, Haley et al. (2002) found that older adults

usually designate a family member as their surrogate decision-maker. Similarly, Carr

and Khodyakov (2007) reported that in their study of older adults aged between 65

and 80, married people named their spouses in durable powers of attorney for health

care. Women were more likely than men to choose their children, and parents of one

or two children chose another relative. The findings of this study however, must be

interpreted with caution because the hierarchical compensatory model does not take

into account cultural as well as idiosyncratic differences in choosing a decision-maker.

Information about individuals who are the most likely to carry out the wishes of the

patient in accordance with their wishes is therefore a critical factor in choosing a

surrogate (Zettel-Watson, Ditto, Danks & Smucker, 2008).

Socioemotional selectivity theory suggests that maintaining social

relationships and emotional ties with family members (Carstensen, 1995, 1998) are

important to older adults. Research by McDonald et al. (2003) and Salmond and

Davis (2005) substantiate the view that older adults prefer to discuss end-of-life

treatment preferences with family members rather than medical professionals. Both

these studies indicated that only 5% to 20 % of individuals discuss their wishes with a

medical professional.

Effects of Culture on Choice of Decision-maker

Within North American culture, emphasis is placed on autonomous decision-

making and truth telling in order to help advanced care planning and choosing

appropriate surrogates (Candib, 2002). However, talking about advance directives, a

terminal prognosis and planning for death are not acceptable in some cultures,

especially if autonomy is not central to cultural identity (Blackhall et al., 1999; Ersek, Kagawa-Singer, Barnes, Blackhall & Koenig, 1998; Werth, Blevins, Touissant & Durham, 2002). These cultural views can create conflicts with health care professionals who operate under the principles of bioethics and can subsequently affect the choice of decision-maker (Orona, Koenig & Davis, 1994).

Although there are no specific studies that examine the choice of decision-maker in the Asian Indian population, there is some indication that older Hindus might remove themselves from decision-making processes as a means of spiritual detachment and preparation for dying (Kramer, 1988). This is consistent with the predictions of SST and studies within other populations (Chen et al, 2002; Haley et al, 2002; Lockenhoff & Carstensen, 2004, 2007).

H3: Older Asian Indian participants will be more likely to delegate end-of-life decisions to others than will younger participants.

When surrogate decision-making is selected, the choice of the surrogate is diverse even within ethnic groups (Candib, 2002).In some families, there might be only informal discussions or none at all depending on the cultural norms surrounding talk on end-of-life care (Vaughn, Kiyasu & McCormick, 2000). Such issues become further complicated when the preference of the surrogate decision-maker is not an exact replication of the patient's wishes (Allen-Burge & Haley, 1997). In an ideal situation, this problem could be resolved if there were joint decision-making (Haley et al., 2002). At this point, factors such as how decisions are made within the family

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structure and how this varies among different ethnic groups become particularly important (Haley et al., 2002).

Studies of collectivist cultural groups have indicated that respondents were more likely to adhere to a family-based model of decision-making (Blackhall et al., 1995). This may lead to the perception that certain kinds of advance directives, like the use of living wills are unnecessary (Morrison, Zayas, Mulvihill, Baskin & Meier., 1998). Asian Indian culture has been classified as collectivist with preference for strong family values and hierarchical, patriarchical systems of decision-making (Verma & Triandis, 1999). Accordingly, decision-making may not be completely autonomous as is presupposed in Western culture, even for younger individuals. Hall (1981) described non-Western cultures as low context with an emphasis on interdependence and interconnections with others which may affect the choice of decision-maker as well. Choudry (2001) indicated that elderly Asian Indian men and women prefer interdependence among family members, which may also indicate collective decision-making processes. It is therefore likely that important decisions such as end-of-like decision-making would involve not only the individual but also several family members and that family members would be the preferred surrogates for both younger and older Asian Indians. Therefore, this study tested the prediction that:

H4: Regardless of age, participants who choose surrogate decision-making will select family members as surrogates over medical professionals.

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As with preferences for life-sustaining treatment, choice of surrogate versus autonomous decision-making and the selection of a family member or medical professional surrogate may be moderated by acculturation and Hindu end-of-life values. These hypotheses were also investigated in this study:

H5: Regardless of age group, higher Western acculturation will be positively related to autonomous decision-making, whereas higher Asian Indian acculturation and strong Hindu end-of-life values will be negatively related to autonomous decision-making.

H6: Regardless of age group, higher Western acculturation will be positively related to choice of a non-family member as decision-maker, whereas stronger Asian Indian acculturation and Hindu end-of-life beliefs will be positively related to choice of a family member as decision-maker.

Summary

The review of literature on decision-making processes suggests that bioethical models do not adequately explain the complex dynamics at the end of life. Socioemotional selectivity theory, on the other hand, seems to have the most potential for integration of religious and cultural factors not encompassed in the bioethical model. SST posits that the preference for emotionally meaningful experiences with increasing age may influence decision-making more than other types of information (Lockenhoff & Carstensen, 2004). The need to obtain positive information has implications for the tendency for older adults to delegate health related issues to surrogate decision-makers (Houston, Sherrill-Mittleman & Weeks, 2001). There is a

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need for empirical validation of these assumptions, especially in the context of Asian-Indian culture and Hinduism. The key role of the perception of time in end-of-life decision-making as suggested by SST, for instance, is an interesting notion in relation to Hinduism, since death is seen as a continuum into a future life in Hindu philosophy. This study therefore examines the applicability of SST within Asian Indian culture in the context of preferences for life-sustaining treatment and autonomous versus surrogate decision-making. Specifically, it tested the predictions that older Asian Indian Hindus will refuse life-extending treatments and choose surrogate decision-makers more so than younger Asian Indian Hindus, but that those effects would be stronger in participants more strongly affiliated with Asian Indian culture and Hindu beliefs regarding death.

CHAPTER III: METHOD

The purpose of the study was to examine the effects of age, cultural identification, and cultural values on Asian Indians' choice of treatments and decision-maker/s for a terminal illness. The study employed a cross-sectional design and a questionnaire format. Older and younger Asian Indian participants residing in the United States responded to two hypothetical health scenarios depicting a terminal illness by (1) indicating their desire for a life-sustaining treatment, and (2) identifying the person or persons who should make the treatment decision. They also completed scales assessing their acculturation to the United States and their endorsement of Hindu end-of-life values, as well as several measures regarding their background and health. A subset of the participants from each age group also completed an interview regarding end-of-life decisions.

Pilot Studies

Two pilot studies were conducted to establish the validity of the health scenarios to be used in the main study, to examine the scales for cultural realism and reliability, and to test the adequacy of the interview questions. The health scenarios were evaluated on their realism and accuracy in portraying a terminal illness. The pilot studies also helped to estimate the time that would be required to administer the questionnaire and conduct the interview.

Pilot Study 1

Participants

Asian Indian younger adults (aged 24-34 years, *M* = 30.0, *SD* =4.00) and older adults (aged 64 - 71 years, *M* = 66.04, *SD*=3.05) were recruited from the local Asian Indian community. Five younger and five older adults participated in the study. Participants were not compensated for their participation in the study. All participants completed the full questionnaire for the study and two participants from each age group also completed the interview.

Materials

A structured questionnaire consisting of seven sections was developed (see Appendix A). These included a sample scenario to familiarize the participant with the format of the questionnaire, followed by (1) two end-of-life scenarios to assess treatment and decision-maker preferences, (2) an acculturation scale, (3) an end-of-life values scale, (4) a health literacy scale, (5) a health status scale, (6) questions about their knowledge of advance care planning, and (7) sociodemographic information.

End-of-life scenarios. Two end-of-life scenarios were developed for this study to measure preferences for life-sustaining treatments. These scenarios were similar in structure to those in the Life Support Preferences Questionnaire or LSPQ (Coppola et al., 1999). The LSPQ questionnaire was originally developed to measure treatment preferences across different types of life-sustaining procedures. The original questionnaire presented participants with descriptions of four kinds of life-sustaining

treatments: the use of antibiotics, cardiopulmonary resuscitation, gall bladder surgery, and artificial nutrition and hydration (ANH). It also included nine hypothetical scenarios that represent a diverse range of medical conditions varying in type of impairment, prognosis, and pain: (1) current state of health, (2) Alzheimer's disease, (3) emphysema, (4) coma with a very slight chance of recovery, (5) coma with no chance of recovery, (6) stroke with a slight chance of improvement, (7) stroke with no chance of improvement, (8) cancer with no pain, and (9) cancer with constant pain. The directions asked participants to imagine that they were in that particular health state.

For example, in the emphysema scenario, the directions read, "You have emphysema. You have constant shortness of breath. You are unable to climb stairs or walk more than a few feet. Your medical condition cannot improve. Your condition may get worse very quickly or slowly decline over several years. Your ability to think, reason and remember is unaffected." Participants were then to indicate on a 5-point scale (1 = definitely do not want treatment to 5 = definitely want treatment) if they would want to receive each of the four life-sustaining treatments for the hypothetical health condition. Because this study was focused on decision-making preferences at the end-of-life rather than how preferences differ depending upon the severity of the illness, the LSPQ was modified. Health scenarios selected for use involve (a) a patient who is cognitively intact at the time of decision-making, but (b) has a prognosis of progressive cognitive or physical decline. Two scenarios were used, one involving a severe head injury that led to a stroke and one involving advanced

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lymphoma. The two scenarios were matched for length and portrayal of terminal

illness. The scenarios are presented in Table 1.

Table 1

End-of-Life Scenarios used in Pilot Study 1

Scenario 1 (Head injury)
You are traveling in a car with a friend or family member who is driving the car. A drunken driver does not stop at a red light and hits the car on the side where you are seated. You sustain a severe head injury. One arm and leg are paralyzed. You have trouble speaking clearly but can write and understand when others speak. You rely on others for help with eating, dressing, bathing and using the toilet. In the opinion of your doctor, you have no chance of improvement.
Scenario 2 (Lymphoma)
You have lymphoma (blood cancer), which is in the final stages. You are tired and weak, requiring some help with household chores, dressing and using the toilet. Your thinking and memory are unaffected. You have chemotherapy sessions every six weeks. Chemotherapy makes you nauseous and weak and these side-effects last about one week after each treatment. In the opinion of your doctor, you have no chance of recovery.

Dependent Variables

Preference for Life-sustaining Treatment

To emphasize to participants that without the treatment the patients would die,

only two life-sustaining treatments that represent mechanical means of life support

were presented as options: artificial breathing support and artificial nutrition and

hydration. The treatments are presented in Table 2. Using a 5-point scale (1 =

definitely do not want treatment to 5 = definitely want treatment), participants were

asked to indicate if they would want to receive the life-sustaining treatment for the

hypothetical health condition. The order of the presentation of the scenarios and

treatments were counterbalanced across the participants. This resulted in four possible

scenario-treatment conditions: (a) head injury with artificial breathing support, (b) head injury with artificial nutrition and hydration, (c) lymphoma with artificial breathing support, and (d) lymphoma with artificial nutrition and hydration. After indicating their preference for life-sustaining treatment, participants noted the reasons for making the choice by responding to the question, "Why did you make the above decision? (Please explain in a few words)"

Table 2

Life-sustaining treatments

Life-sustaining treatment 1 (Artificial breathing support)
Your doctor has indicated that there is a likelihood that you will need artificial breathing support over time. Artificial breathing means the doctor puts a tube in your windpipe. Then a machine breathes for you through the tube. People on artificial breathing support cannot talk or take food or medicines by mouth. The length of time on the breathing machine varies from person to person and may range from a few hours to indefinitely. Without this intervention, one would usually die in a few hours to a day. Consider your condition as described in the preceding paragraph. If you stopped breathing, would you want to be on artificial breathing support?

Life-sustaining treatment 2 (Artificial nutrition and hydration)
Your doctor has indicated that there is a likelihood that you will lose the ability to eat and drink through the mouth over time. Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. The food goes through a feeding tube. Usually the feeding tube goes through the skin to the stomach. Without this treatment, people usually die within 7-10 days. Consider your condition as described in the preceding paragraph. If your condition becomes such that you lose the ability to take in water by food or water by mouth, would you want artificial feeding and fluids?

Choice of Decision-maker

After indicating their treatment preference for a scenario, participants were asked to choose the person or persons they would want to make the decision about their end-of-life treatment. This was assessed with a single, forced-choice question

developed for this study, which provided a choice between autonomous and surrogate decision-making: "Who do you think should make the decision about your receiving this treatment? Indicate your opinion by marking an X next to one of the options below." Response choices were "myself" and "others". Participants who chose others were asked to indicate who the other person or persons were and their relationship to the participant. Finally, the participants were asked to respond to the question, "Why did you choose yourself or another person/persons to make the decision? Please explain in a few words." The choice of decision maker was recorded as either 0 (self) or 1 (others). The person or persons chosen as decision-maker as well as the reasons for choosing a particular person as decision-maker were recorded and tabulated.

<p align="center">*Measures of Cultural Values*</p>

Degree of Acculturation

The Acculturation Rating Scale for Mexican-Americans II (ARMSA-II; Cuellar, Arnold & Maldonaldo, 1995) as adapted for use with Asian Indians by Farver, Narang, and Bhadha (2002) was used to assess degree of acculturation. The ARMSA-II has been used in one study with Asian Indian adolescents (Farver et al., 2002). ARMSA-II is a 30-item scale that has two subscales: 17 items on acculturation to Asian Indian culture and 13 items on acculturation to Western culture (see Appendix for entire scale). For example, two items on the Asian Indian subscale are: "I associate with Indians/Indian Americans" and "I enjoy Indian language movies". The comparable items on the Western subscale are: "I associate with Caucasians" and "I enjoy English language movies". The items are rated on a five-point scale (ranging

from 1 = not at all to 5 = extremely often). Higher scores represent an orientation towards Asian Indian or Western culture in each subscale. Previous research has established reliabilities as .82 for the Western subscale and .84 for the Indian subscale. In the pilot study, the reliability (computed as Cronbach's alpha) for the Western and Asian Indian subscales was .81 and .84 for younger adults and .79 and .87 for the older adults respectively.

Religious Beliefs Regarding the End of Life

Hindu end-of-life values were measured by the 14-item Hindu Religious Beliefs and Rituals Scale (Doorenbos, 2003). Examples of items on the scale include, "It is important to have the dying person on the floor at the time of death" and "It is important to have 10 to 14 days of mourning". Participants rate their endorsement of the rituals and beliefs on a 1 (strongly disagree) to 5 (strongly agree) scale. Higher scores indicate that Hindu religious beliefs and rituals are extremely important to the individual at the end of life. In prior studies, scale reliabilities have ranged from .83 to .89 (Doorenbos, 2003; Doorenbos & Nies, 2003).The reliability was established at .79 and .83 for the younger and older adults in the pilot study.

Validity of the Scenarios and the Hindu Religious Beliefs and Rituals Scale

Two scales were developed to test the quality of each scenario. Realism was assessed using a four-item semantic differential measure on which participants indicated on a scale of 1 to 5 the extent to which each scenario was: Realistic – Unrealistic, Believable – Unbelievable, Plausible – Implausible, and True to life – False. The realism scale had reliabilities of .35 and .42 for the younger and older

adults respectively for the head injury scenario and .33 and .40 for the lymphoma scenario. Even when the most problematic item (plausible-implausible) was removed, the reliabilities remained low: .47 and .48 for the head injury scenario for younger and older adults and .51 and .49 for the lymphoma scenario. The low reliabilities of the items did not allow for the treatment of these items as a single scale.

To establish that the scenarios portrayed terminal conditions, a three-item semantic differential measure was constructed. That scale asked participants to indicate on a 1 to 5 scale the extent to which the condition would result in: Recovery– Death, Positive health outcome – Negative health outcome, and Gradual health decline – Rapid health decline. The terminal decline scale had reliability coefficients of .86 and .87 for the younger and older adults respectively for the head injury scenario and .81 and .83 for the lymphoma scenario. The mean of these three items was computed for analysis.

Finally, one semantic differential item examined participants' perceptions of the realism of the Hindu end-of-life values scale. Participants were asked to respond on a 1 (realistic) to 5 (unrealistic) to the question, "Were the questions on culture realistic or unrealistic?"

Sociodemographic and Background Characteristics

Sociodemographic Information

Participants were asked to provide information on the following sociodemographic characteristics (See Appendix A): Gender (Male = 0, Female = 1), education in years, occupation, marital status (0 = Never married, 1= Married, 2 =

Widowed, 3 = Separated, 4 = Divorced, 5 = Other), number of children, and number

of years in the United States.

Health Literacy

The short form of the Test for Functional Health Literacy in Adults (S-

TOFHLA) was used to assess functional literacy in the sample (Baker, Parker,

Williams & Clark, 1998). This instrument measures functional literacy assuming that

negotiating the health care system requires more than formal education. The S-

TOFHLA takes about seven minutes to administer and consists of 36 items using a

modified Cloze procedure. These items are in two passages that use materials from

real health care settings. A score of 23-36 is considered as adequate, 17-22 marginal

and 0-16 inadequate health literacy. Prior research has established the internal

consistency of the S-TOFHLA at .97 with correlation to the full TOFHLA at .91

(Baker et al., 1998). Reliability was established at .90 and .92 for the younger and

older adults in this study.

Health Status

General health was assessed with a twenty item General Health Survey

(Stewart, Hays & Ware, 1988). This measure evaluates six health concepts that

include physical, role and social functioning as well a mental health, health

perceptions and pain. The survey takes about 5 minutes to complete. Poor health is

defined as having more than one limitation on the physical, role and social

functioning scales; moderate, severe or very severe pain; and a total score of less than

67. The items are reverse coded and transformed linearly to scores ranging from 0 to

100 for each health concept and then averaged to get the general health score.

Reliabilities have been established between .81 and .96 for the General Health Survey

(Stewart et al., 1988). The internal consistency in the present study was established at

.85 and .83 respectively for younger and older adults.

Advance care planning

Knowledge of advance care planning was assessed with six questions

developed for this study: (1) Do you know what an advance directive or living will

is? (2) Have you completed and advance directive or living will? (3) Do you know

what a Durable Power of Attorney for Health Care is? (4) Have you completed a

Durable Power of Attorney for Health Care? (5) Have you discussed your wishes

regarding end-of-life decisions with anyone? And (6) Do you know about the

different legal end-of-life options available in your state? Possible responses were yes

(0), no (1), and not sure (2).

Procedure

After signing the informed consent, participants completed the questionnaire.

Participants took between 15 and 25 minutes to complete the study. Two older and

two younger individuals were interviewed. The interviews were tape recorded and

transcribed verbatim.

Results

Scenario validity and realism of end-of-life values scale. The means and

standard deviations of the items on the semantic differential items of the realism and

terminal illness scales are reported in Table 3. Independent samples t-tests were

conducted to compare younger and older adults' evaluations of the scenarios based on the four realism items. Results indicated no differences due to participant age for all items : (a) Head injury scenario, Realistic-Unrealistic, $t(8) = -1.41$, $p > .05$, Believable-Unbelievable, $t(8) = 1.41$, $p > .05$, Plausible-Implausible, $t(8) = -1.00$, $p > .05$, and True to life- False, $t(8) = 1.00$, $p > .05$; and (b) Lymphoma scenario, Realistic-Unrealistic, $t(8) = 1.45$, $p > .05$, Believable-Unbelievable, $t(8) = -1.00$, $p > .05$, Plausible-Implausible, $t(8) = -1.21$, $p > .05$, and True to life- False, $t(8) = 0.00$, $p > .05$. Since there were no significant differences in the means for younger and older adults, Table 3 reports the combined means for the entire sample for each scenario. The means for the items on the realism scale ranged from 2.50 to 3.30 suggesting that respondents did not perceive the scenarios as being real and accurate in portraying the health condition.

Independent samples t-tests were conducted to compare younger and older adults' evaluations of the scenarios based on the combined terminal illness items. Results indicated no differences due to participant age, for the head injury scenario, $t(8) = -1.00$, $p > .05$, and the lymphoma scenario, $t(8) = -1.12$, $p > .05$. The combined means for each scenario are reported below in Table 3. The means of 4.75 for the head injury scenario and 4.60 for the lymphoma scenario on the terminal illness item indicated that the participants perceived the scenarios as portraying a terminal illness.

Table 3

Means and Standard Deviations of the Realism items and Terminal Illness Scale by

Scenario

Item	Head injury Scenario		Lymphoma Scenario	
Realism	*M*	*SD*	*M*	*SD*
Realistic-Unrealistic	3.00	.41	3.30	.38
Believable-Unbelievable	3.00	.46	3.10	.37
Plausible-Implausible	3.22	.42	3.20	.32
True to life-False	2.50	.43	3.00	.44
Terminal Illness	4.75	.44	4.60	.43

An independent sample t-test was conducted to compare younger and older

adults' evaluations of the realism of the Hindu Religious Beliefs and Rituals scale

(Doorenbos, 2003). Results indicated no differences due to participant age, $t(8) = -$

1.00, $p > .05$. The realism item, combined for both age groups, had a mean of 4.2 and

a standard deviation of .45, indicating that the participants found the items on Hindu

end-of-life rituals and beliefs to be realistic.

As described in the methods section, all cultural value and background

variable scales indicated satisfactory reliability for use in the study.

Semi-structured interview. Another aim of the pilot study was to determine the

adequacy of the interview questions and to ascertain if the questions elicited detailed

responses about choices of treatment preference and decision-maker, which would aid

in a more comprehensive interpretation of the quantitative data. Each interview lasted

between 25 to 35 minutes. Each interview was transcribed verbatim. The transcripts

were read and reread to look at the emergence of themes that would increase understanding of the decision-making process. The participants were able to respond to all the interview questions and several important categories emerged from the transcribed data. Some sample themes that emerged were (a) need to be an independent decision-maker, (b) intergenerational differences in end-of-life caregiving, and (c) differentiation between religious beliefs in life and in health situations. It was determined that the interview questions were comprehensive enough to be included in the main study without any revisions. Debriefing the participants about the questionnaire also revealed that the treatments were perceived as more real than the health scenarios themselves. One participant indicated that the portrayal of the scenario may not be comprehensive enough and that it was the treatment that made the scenario seem terminal more than the actual scenario itself.

Length of study session. Participants took between 15 to 25 minutes to complete the questionnaire alone. Sessions with interviews lasted between 45 minutes to one hour.

Pilot Study 2

The results of the first pilot study indicated that the scenarios were considered to be portraying a terminal illness and the Hindu Religious Beliefs and Rituals scale was perceived as realistic by the participants. However, the scenarios were not perceived as realistic. Therefore the scenarios were revised and a second pilot study conducted. To make the head injury scenario more realistic as a precursor to the two life sustaining treatments, a moderately severe stroke was included as a result of the

head injury. In addition, the risk of a second fatal stroke was emphasized. To improve

the realism of the lymphoma scenario in the context of choosing one of the life

sustaining treatments, the presence of constant pain controlled by medication was

added to the description along with a prognosis of having less than a year to live. The

revised scenarios are presented in Table 4 with the additional sentences highlighted in

bold.

Table 4

End-of-Life Scenarios used in Pilot Study 2

Scenario 1 (Head injury)
You are traveling in a car with a friend or family member who is driving the car. A drunken driver does not stop at a red light and hits the car on the side where you are seated. You sustain a severe head injury **which leads to a moderately severe stroke**. One arm and leg are paralyzed. You have trouble speaking clearly but can write and understand when others speak. You rely on others for help with eating, dressing, bathing and using the toilet. In the opinion of your doctor, you have no chance of improvement and **are at high risk for another fatal stroke at any time**.

Scenario 2 (Lymphoma)
You have lymphoma (blood cancer), which is in the final stages. You are tired and weak, requiring some help with household chores, dressing and using the toilet. Your thinking and memory are unaffected. You have chemotherapy sessions every six weeks. **You are in constant pain which is controlled by medication.** Chemotherapy makes you nauseous and weak and these side-effects last about one week after each treatment. In the opinion of your doctor, you have no chance of recovery and **may have less than a year to live.**

Two steps were taken to improve the reliabilities of the items on the realism

scale. First, the Plausible-Implausible item was removed because results from the first

pilot indicated that removing the item increased reliability. Second, the rating scale

was revised so that lower numbers indicated less realism, whereas in the first pilot

lower numbers indicated more realism. This change served to make the anchors on

the scale conform to participant expectations about normal relationships between numerals and judgments of the presence versus absence of a quality.

Participants

Five younger Asian Indian Hindus and five older Asian Indian Hindus were recruited for the second pilot study by convenience sampling.

Measures

The dependent measures, cultural scales, and background information items used in the first pilot study were used with the revised scenarios and revised validity of scenario measures (see Appendices B and C).

Procedure

The participants completed the informed consent forms and proceeded to complete the questionnaire. Participants were not interviewed since the adequacy of the interview questions was established in the previous pilot study.

Results

Scenario validity and realism of end-of-life values scale. The realism scale items had reliability coefficients of .85 and .90 for the head injury and lymphoma scenarios respectively for the younger adults and .84 and .88 for the older adults. Accordingly, means of the combined items was used for the analysis. Independent samples t-tests were conducted to evaluate the older and younger adults' evaluations of each scenario on the realism scale. Results indicated that there was no difference between the two groups for the head injury, $t(8) = .00, p > .05$, and lymphoma, $t(8) = .00, p > .05$, scenarios. The combined sample means for the head injury ($M = 4.24$,

SD = .54) and lymphoma (*M* = 4.35, *SD* = .41) scenarios indicate that the revised scenarios were perceived as realistic by the participants.

The terminal illness scale had reliability coefficients of .87 and .84 for the head injury and lymphoma scenarios respectively for the younger adults and .87 and .80 for the older adults. The means of the combined items were computed for analysis. Independent samples t-tests were conducted to compare younger and older adults' evaluations of the scenarios terminal illness scale. Results indicated no differences due to participant age, for the head injury scenario, *t* (8) = 1.27, *p* > .05, and the lymphoma scenario, *t* (8) = 1.14, *p* > .05. The combined sample means for the head injury (*M* = 4.16, *SD* = .44) and lymphoma (*M* = 4.10, *SD* = .52) scenarios indicate that participants perceived the revised scenarios as portraying a terminal illness.

An independent samples t-test was conducted to compare younger and older adults' evaluations of the realism of the Hindu Religious Beliefs and Rituals scale. Results indicated no differences due to participant age, *t* (8) = .45, *p* > .05, and the means were combined for both age groups. The realism of scale item had a mean of 4.30 and a standard deviation of .59 indicating that the participants found the rituals and beliefs items to be realistic. The acculturation scale, Hindu Religious Beliefs and Rituals scale and background variables scales continued to have satisfactory reliabilities to be included in the study. Those reliabilities were .83 for the acculturation scale, .84 for the Hindu Religious Beliefs and Rituals scale, .81 for the health status scale and .89 for the health literacy scale.

The results from the pilot study indicated that the scenarios were perceived as realistic and as portraying a terminal illness. The Hindu Religious Beliefs and Rituals scale was also perceived to be realistic and the entire questionnaire was determined to be satisfactory for use in the main study.

Main Study

Participants

The sample for the main study consisted of 100 younger and 100 older Asian Indian Hindu adults living in the Midwest. The younger adults were 18 to 35 years old and the older adults were aged 60 years and older. A non-probability method of convenience sampling was used to recruit participants for the study. An advertisement was placed in the monthly magazine of a local Hindu temple, and flyers were placed at Indian grocery stores and restaurants (see Appendix D). In addition, those who completed the study were asked to provide names and contact information for other potential participants. Participants were required to identify themselves as Hindu, have lived in the United States for at least two years and be able to speak, read and write English. Only one participant per family was recruited in order to avoid inter-participant bias and diffusion effects that could affect internal validity. In addition, participants who were in the medical profession including doctors, nurses and pharmacy graduates were not included to prevent their professional knowledge from biasing the hypothetical decisions made in the study.

All interested individuals who met the inclusion criteria were contacted by the researcher and told about the purpose of the study. Those consenting to participate

were then scheduled to meet with the researcher at a convenient time and place to complete the questionnaire. The researcher met with all participants at a place of their convenience and administered the questionnaire. The researcher met most participants individually ($n = 107$), but also administered some of the questionnaires ($n = 56$) in groups of three to eight participants in a community hall.

Some participants were also recruited from a different city in the Midwest. Participants contacted the researcher through information on flyers placed in several Indian businesses and through an advertisement on a temple website in that city. The informed consent forms and questionnaires were then mailed to the participants with postage paid envelopes to return the questionnaires. A total of fifty-five questionnaires were mailed and thirty seven were returned.

While these methods may limit generalizability, they were necessary given the relatively small size of the Asian Indian Hindu population in the Midwest. The personal contact and individual data collection method were also necessary to achieve an adequate response rate, especially when dealing with a sensitive topic such as end-of-life treatment preferences (Rubin & Babbie, 2008).

Characteristics of the sample. A total of 100 younger and 100 older Asian Indian Hindu adults completed the study with ten participants in each group also completing the semi-structured interview. All participants were volunteers and were not compensated for completing the study. Demographic information about the sample is presented in Table 5.

The sample was 57% female overall. There was a higher number of females in both age groups, younger adults ($N =55$) and older adults ($N = 59$), but there was no significant difference between the number of males and females in the sample: $\chi^2 (1) = .57, p > .05$. The older and younger adult participants differed significantly on education, number of years in the United States, marital status and knowledge of advance care planning. Older adults were significantly more educated, $t (198) = -2.81, p < .01$, had more children, $t (198) = -7.72, p < .01$ and were more likely to be married, $\chi^2 (2) = 21.45, p < .05$. The older adult group had lived in the United States for a greater number of years than the younger adults with a statistically significant difference between the groups, $t (198) = -24.83, p < .01$.

Older adults were also significantly more aware than younger adults, of end-of-life planning documents like advance directives, $\chi^2 (2) = 42.38, p < .05$ and durable powers of attorney for health care, $\chi^2 (2) = 67.536, p < .05$. Older adults were also more likely than younger adults to have completed advance directives, $\chi^2 (2) = 81.53, p < .05$ and durable powers of attorney, $\chi^2 (2) = 84.48, p < .05$, as well as to have discussed their wishes with others, $\chi^2 (2) = 90.82, p < .05$. Only 7% of younger adults compared to 77 % of younger adults were aware of state options. This difference was statistically different, $\chi^2 (2) = 86.67, p < .05$.

The entire sample had acceptable health literacy and health status. The health literacy scale had reliability coefficients of .89 and .90 for the younger and older adults. The health status scale had reliabilities of .82 and .83 for younger and older adults respectively. A score greater than 23 indicates adequate health literacy. All

participants scored above that minimum, with a range of 34 to 36 for younger adults and range of 33 to 36 for older adults. Means for the two groups are given in Table 5. Younger and older adult participants also reported that they were in good health, as demonstrated by scores on the health status scale of 67 or greater. Younger adults' reported health status ranged from 88.31 to 100 and older adults' from 83.31 to 100. Means by age group are listed in Table 5.

Table 5

Description of the Sample

Variables	Younger adults (N=100)		Older adults (N=100)	
	M	SD	M	SD
Age	30.60	4.05	67.81	5.32
Education	16.97	1.65	17.85**	2.67
Number of children	.79	.69	1.54**	.69
Years in the U.S	6.62	.44	32.62*	.59
Health literacy	35.84*	3.22	35.69	4.65
Health Scale	99.66*	4.57	98.31	9.42
	N	*%*	*N*	*%*
Gender				
Male	45	45	41	41
Female	55	55	59	59
Marital Status				
Single/Never Married	15*	15	0	0
Married	85	85	94*	94
Widowed	0	0	6	6
Advance care planning				
Knowledge of Advance Directives (yes)	46	46	89*	89
Completion of Advance Directives (yes)	5	5	66*	66
Knowledge of DPAHC (yes)	31	31	88*	88
Completion of DPAHC (yes)	4	4	66*	66
Discussion of end-of-life wishes	12	12	79*	79
Awareness of state options	7	7	77*	77

Note: Age groups differ significantly at * $p < .05$; Age groups differ significantly at ** $p < .01$. Health literacy: 23-36 is considered adequate. Health status: A score greater than 67 indicates good health.

Materials

The questionnaire for the main study used the same format as that for the second pilot study, with scenario validity scales and the realism evaluation of the Hindu Religious Beliefs and Rituals scale deleted (see Appendix A). The order of presentation of the two scenarios and two treatments was counterbalanced for participants within age groups to create four orders of presentation. Twenty-five participants in each age group were randomly assigned to each order of presentation.

Procedure

The participants were informed that they were participating in a study to look at how decisions are made for certain end-of-life situations. They were also told that they would be completing measures on religion and culture. After reading and signing the informed consent forms, the participants completed the questionnaires. Participants took between fifteen to thirty minutes to complete the questionnaires. The semi-structured interviews lasted between twenty to forty minutes. Each questionnaire had a unique identifying number assigned and no personal information was recorded to ensure confidentiality. The interviews were tape-recorded. The interviews were transcribed verbatim and the transcripts were read for clarity and themes. The recordings were used to clarify ambiguities in the transcripts and the tapes were erased after final transcription.

Reliabilities and Descriptive Data on the Cultural Variables

For the acculturation scale, the reliabilities (all computed as Cronbach's alpha) for the Hispanic and Western subscales were .83 and .86 on the original subscales and

have been established at .82 and .84 for the modified Indian version. In the main study, the reliability for the Western and Asian Indian subscales was .83 and .81 for younger adults and .77 and .84 for the older adults respectively.

Overall, the sample was moderately high on Western acculturation ($M = 47.53$). Results of the independent samples t- test indicated that there was a significant difference in the age groups on Western acculturation, $t(198) = -8.86$, $p < .05$. The older adults ($M = 51.28$, $SD = 4.96$) were higher in Western acculturation than the younger adults ($M = 43.77$, $SD = 7.11$). The sample was moderate on Indian acculturation ($M = 68.26$) with a range from 41 to 85. There was no significant difference between the younger ($M = 69.51$, $SD = 8.89$) and older adults ($M = 67.04$, $SD = 9.06$) on the level of Indian acculturation, $t(198) = -1.12$, $p > .05$

The Hindu Religious Beliefs and Rituals scale had a reliability of .79 for the younger adults and .81 for the older adults. Internal reliability has been previously established as 0.89 for this scale. The average of the strength of Hindu end-of-life beliefs for the sample was 30.40 with a range from 12 to 65. There was a significant difference between the age groups on the strength of end-of-life beliefs, $t(198) = 5.34$, $p < .05$. Younger adults had higher strength of end-of-life beliefs ($M = 34.35$, $SD = 10.94$) than older adults ($M = 26.55$, $SD = 9.38$). These age group differences in acculturation and Hindu end-of-life values were taken into account in interpreting the results of the logistic regression tests of the hypotheses.

Dependent Variables

Choice of Life-sustaining Treatment

Examination of the distribution of the treatment preference variable revealed that its distribution was bimodal in both age groups and for both scenarios. The interval variable for the choice of life-sustaining treatment was converted into a dichotomous variable indicating "want treatment" and "do not want treatment". This is the practice in prior studies using the LSPQ and other medical scenario based studies (e.g., Coppola, Ditto, Danks & Smucker, 2001; Emanuel, Barry, Emanuel & Stoeckle, 1994; Houts, Smucker, Jacobson, Ditto & Danks, 2002), which have found that combining the "probably want" treatment item with "definitely want" and "probably do not want" item with "definitely do not want" on the scale do not provide statistically different findings and are clinically more relevant than treating the four items as separate. Scores of 1 and 2 (definitely and probably do not want treatment) were combined into "do not want treatment" and 3, 4 and 5 (not sure, probably and definitely want treatment) into "want treatment". A score of 3 indicates that the respondent is not sure if they want treatment or not. Since the default in medical situations when the patient is unclear is to provide treatment, this was combined into the "want treatment" category (Emanuel et al., 1994).

Frequencies were computed for preference for each treatment condition (artificial breathing support and artificial nutrition and hydration) within scenarios. Separate chi square analyses were conducted within age groups to examine whether

preferences for the two treatments varied for each scenario. Results revealed that young participants' preferences for each treatment did not differ significantly for either the head injury scenario, χ^2 (1) = 4.56, $p >.05$, or the lymphoma scenario, χ^2 (1) = 7.61, $p > .05$. Likewise older participants' preferences for each treatment did not differ significantly for either scenario: head injury, χ^2 (1) = 3.55, $p > .05$; lymphoma, χ^2 (1) = 4.17, $p > .05$. As a result, the within-scenario effects of type of life-sustaining treatment were not computed in the preliminary analysis examining the equivalence of the preference for a life-sustaining treatment across the two scenarios (described next) or the binary logistic regression analyses used to examine the hypotheses.

Separate chi square analyses were conducted within age groups to examine whether preference for a life-sustaining treatment varied by scenario. Results indicated a significant difference in treatment preferences by scenario for the younger adults, χ^2 (1) = 23.59, $p < .05$, and older adults, χ^2 (1) = 65.28, $p < .05$. Therefore binary logistic regression was conducted separately for each scenario in testing the hypotheses.

Choice of Decision-maker

Frequencies were computed for decision-maker preference for each treatment condition (artificial breathing support and artificial nutrition and hydration) within scenarios. Separate chi square analyses were conducted within age groups to examine whether preferences for decision-maker varied across the two scenarios. Results revealed that young participants' preferences for decision-makers did not vary significantly for either the head injury scenario, χ^2 (1) = 6.38, $p > .05$ or the

lymphoma scenario, χ^2 (1) = 4.00, $p > .05$. Likewise, older participants' preferences

for decision-maker did not vary significantly for either scenario: head injury, χ^2 (1) =

4.27, $p > .05$ and lymphoma, χ^2 (1) = 4.27, $p > .05$. As a result, the within scenario

effects were not computed in the binary logistic regression analyses used to examine

the hypotheses or in the preliminary analysis examining the equivalence of the choice

of decision-maker across the two scenarios.

Separate chi square analyses were conducted within age groups to examine

whether preferences for decision-maker varied by scenario. Results indicated a

significant difference in decision-maker preference by scenario in younger adults, χ^2

(1) = 51.10, $p < .05$ and older adults, χ^2 (1) = 80.02, $p < .05$. Therefore binary logistic

regression was conducted separately for each scenario in testing the hypotheses.

Statistical Analyses

Quantitative Analyses

Logistic regression was used to examine the effects of age on choice of (a)

life-sustaining treatments, and (b) autonomous versus surrogate decision-makers. The

statistical analysis program SPSS (version 16) was used for all analyses in the study.

Sample size. A sample size of around 200 participants is considered as

adequate with a moderate effect size to detect a significant model (Cohen, 1988)

(power = .08 and alpha = .05) with binary or continuous independent variables (Hsieh,

Block & Larsen, 1998). The size of the smallest of the classes of the dependent

variable must be at least 10, although most statistical literature has not specified

sample size rules for logistic regression (Peng, Lee & Ingersoll, 2002). Another

recommendation for sample size is a minimum of 100 with a 10 to 1 observation to predictor ratio (Peng et al., 2002; Tabachnick & Fidell, 2001).The sample in the study meets all these assumptions and hence is considered adequate to conduct logistic regression.

Rationale for the use of logistic regression. Logistic regression was the statistical technique of choice because it does not require that assumptions of normality be met in the dependent variables and also allows predictors to be continuous, dichotomous or ordinal (Tabachnick & Fidell, 2001) with a binary dependent variable. The initial plan of analysis for the first dependent variable (choice of life-sustaining treatment) was to use multiple regression analysis. However with the dichotomization of the dependent variable as well as its non-normal distribution, binary logistic regression was a more appropriate method of analysis, in contrast to ordinary least squares regression or linear discriminant function analysis both of which have strict statistical assumptions about normality, linearity and continuity (Peng et al., 2002).

Logistic regression models. In logistic regression, the dependent variable is a dichotomous variable coded 0 and 1. For the dependent variable of choice of life-sustaining treatment, the dichotomous coded variable is 0 (do not want treatment) and 1 (want treatment). For the dependent variable for the choice of decision-maker, the dichotomous variable is 0 (myself as decision-maker) and 1 (others as decision-maker). Dummy codings of 0 and 1 are used for categorical predictors (age group: 0 = younger and 1 = older) and scale means for the continuous predictors Western

acculturation, Indian acculturation and Hindu end-of-life values. The error term is not normally distributed because Y takes one of two values.

In the present study, Model 1 is the intercept only model. Model 2 includes age group as a predictor. Western acculturation, Indian acculturation and Hindu end-of-life values were added in step 3 (Model 3). The final model (Model 4) added the interactions of age with Western and Indian acculturation and Hindu end-of-life values. Centered means were used for the Acculturation and Hindu Religious Beliefs and Rituals scales to prevent the effects of multicollinearity from affecting the results (Tabachnick & Fiddell, 2001).

In a logistic regression equation, Logit (Y) = natural log (odds) = $In[p/(1-p)]$ = $A + B X + e$, where p is the probability that Y occurs, $p/1-p$ is the odds ratio and $In[p/(1-p)]$ is the logit or log odds ratio. There is a constraint for the probabilities to stay between 0 and 1 in the logistic distribution (Estrella, 1998). The slope coefficient is the rate of change in the log odds as X increases but is usually not interpreted in logistic regression. Since $[p/(1-p)] = exp\ (A + BX),$ exp(B) is the effect of the independent variable on the odds ratio. Exp (B) is the logit or the natural logarithm of the odds ratio (Peng et al., 2002).

The relationship between X and the logit of Y is determined by the value of the coefficient B. This implies that when B is greater than zero, larger X values lead to larger logits of Y and vice versa (Tabachnick & Fiddell, 2001). On the other hand, when B is smaller than zero, larger X values lead to smaller logits of Y and vice versa. The null hypothesis therefore is that B is equal to zero and there is no linear

relationship in the population. Maximum likelihood estimation is applied to the

dependent variable after transforming it into a logit variable, which is the natural log

of the odds of wanting treatment or not. Therefore, logistic regression estimates the

odds that a certain event will occur (Allison, 2006).

Evaluation of the logistic regression model. Evaluating the logistic regression

model consists of several steps: (a) evaluation of the model overall, (b) testing the

individual predictors, (c) examining goodness of fit statistics, and (d) validating

predicted probabilities (Peng et al., 2002). The likelihood ratio tests and Wald statistic

provide an evaluation of overall model fit. A logistic model is considered a good fit if

it shows an improvement over the null model or intercept only model with the tests

mentioned above (Tabachnick & Fiddell, 2001). The individual predictors are then

tested by using the Wald chi-square statistic. The fit of the logistic model against

outcomes is tested by the goodness-of-fit statistics. Of this, the Hosmer-Lemeshow

statistic yields a chi-square and must not be statistically significant in order to

conclude that the model was a good fit with the data (Peng et al., 2002).

Other descriptive goodness-of-fit statistics like the Cox R square and

Nagelkerke R square can be considered similar to the R square in ordinary linear

regression. But in logistic regression, they cannot be considered to exactly determine

the proportion of variance in the dependent variable accounted for by the predictors

(Menard, 2000). They must therefore be used in conjunction with other, more reliable

evaluators of the logistic regression model such as the likelihood ratio and Wald

statistics tests. Finally, predicted probabilities are assessed by a classification table

that shows the validity of those probabilities. This test needs to be used as supplementary to other model fit statistics and not be considered the sole indicator of model evaluation (Hosmer & Lemeshow, 2000). In addition to model fit characteristics, odds ratios for predicting one outcome over another are also reported in logistic regression results.

Qualitative Analyses

 Themes for choice of treatment preferences and decision-maker. Participants were asked to write the reasons for their choice of treatment preference and decision-maker for each scenario. Each of the reasons for the choice of treatment was recorded and categorized by common themes.

 Qualitative interviews. Each of the twenty interviews (ten in each age group) was read several times to elicit the main themes. This was done by using Glasser and Strauss' constant comparative method (Lincoln & Guba, 1985), based on grounded theory (Strauss & Corbin, 1990). Grounded theory refers to theory that has been developed inductively from data (Bruner, Goodnow & Austin, 1972). In the constant comparative method, the transcript is read and similar themes belonging to a category are identified. This is done until several categories are identified throughout the data (Bruner et al., 1972). Each event (or unit of measurement) for the interviews in this study were identified as a word, sentence or paragraph containing a theme. As each event was identified, it was compared to previously identified themes and included as an instance of one of those or classified as a new theme. As this process continued,

themes were combined in some instances and subthemes created. The most relevant

themes for younger and older adults are reported in the qualitative results.

CHAPTER IV: RESULTS

Results from the quantitative and qualitative analyses of the Asian Indian sample data are presented in this chapter. The results pertaining to the hypotheses regarding the effects of age and culture are presented in the first section, followed by the results from the open-ended questions and interviews.

Choices of Treatment Preferences and Decision-Makers: Test of Hypotheses

The hypotheses regarding the effects of age and culture on participants' choice of life-sustaining treatment and decision-maker were examined using sequential logistic regression. In the first step, each dependent variable was regressed on age group alone. Western acculturation, Indian acculturation and strength of Hindu end-of-life values were entered as additional predictors in the second step. The interactions of the covariates with age were entered in the third step. Results for each analysis report model fit statistics and individual predictor contributions, including odds ratios. The correlations between the cultural predictors for the older and younger adults are presented in Table 6. There was a significant negative correlation between Western and Indian acculturation for both older and younger Asian Indians.

Table 6

Intercorrelations between Cultural Predictors for Older (N=100) and Younger (N=100) Asian Indian adults

Predictor	1	2	3
Younger adults			
1. Western acculturation	-	-.51**	-.01
2. Indian acculturation	-	-	.11
3. Hindu end-of-life values	-	-	-
Older adults			
1. Western acculturation	-	-.27**	-.16
2. Indian acculturation	-	-	.10
3. Hindu end-of-life values	-	-	-

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

Choice of Life-sustaining Treatment

The first hypothesis predicted that fewer Asian Indian older adults than younger adults would choose life-sustaining treatments. The second hypothesis predicted that regardless of age group, higher Western acculturation would be positively related to preferences for life-sustaining treatments, while higher Indian acculturation and Hindu end-of-life values would be negatively related to preferences for life-sustaining treatments. Sequential logistic regression tested these hypotheses separately for each scenario. In both, the analysis assessed prediction of membership in one of two categories of outcome (do not want life-sustaining treatment, coded 0, or want life-sustaining treatment, coded 1), first on the basis of group membership to test Hypothesis 1, and then to test Hypothesis 2, after addition of the three cultural predictors, followed by the interactions of the cultural predictors with age. The group membership predictor was age (younger, coded 0, or older, coded 1) and the cultural

predictors were Western acculturation, Indian acculturation and Hindu end-of-life values.

Head Injury Scenario

Model fit statistics are presented in Table 7. These statistics assess whether the inclusion of the predictors significantly improves the ability to account for choice of life sustaining treatment over the constant model. In addition, the Nagelkerke R^2 provides an estimate of the variability in treatment choice attributable to each model. As Table 7 reveals, none of the models was significant, although the final model which included the interactions of age with the cultural variables approached significance. The comparison of log-likelihood ratios across the three models reveals that although model fit was not impressive on the basis of age group membership alone, it improved with the addition of the cultural predictors in Model 2 and their interactions with age group in Model 3. In addition, the Nagelkerke R^2 increased from .02 in Model 1 to .14 in Model 3.

Table 7

Model summary for Choice of Life-sustaining Treatment Preference: Head Injury Scenario

Model	Chi-square	df	*p*	-2 log likelihood
Model 1	1.63	1	.20	114.70
Model 2	7.98	4	.09	108.34
Model 3	12.96	7	.07	103.36

Note: Model 1 includes age group. Model 2 adds the cultural predictors (Western acculturation, Indian acculturation and Hindu end-of-life values). Model 3 adds the interactions of cultural predictors with age.

Table 8 shows the relationship between treatment preference and the categorical predictor, age.

Table 8

Frequency (Percentage) of Treatment Choice by Age Group: Head Injury Scenario

Age group	Treatment preference		
	Do not want treatment	Want treatment	Total
	N (%)	*N (%)*	
Younger (0)	89 (89%)	11 (11%)	100
Older (1)	94 (94%)	6 (6%)	100
Total	183 (91.5%)	17 (8.5%)	200

Note: Younger adults $N = 100$ and Older adults $N = 100$

Overall classification was adequate for all three models, but in all models the cases were overclassified into the largest group: do not want treatment. On the basis of age group alone, correct classification rates were 100% for refusing treatment and

0% for wanting treatment. The overall classification rate was 91.5%. The rates remained the same with the addition of the cultural predictors in Model 2. With the addition of the interactions, there was improvement in the classification rate for wanting treatment to 5.9% and the overall classification rate increased to 92%.

The regression coefficients, odds ratios and 95% confidence intervals for odds ratios for each of the predictors in the final model are presented in Table 9. The statistics for the age group effect indicate a trend consistent with the prediction in Hypothesis 1 that younger adults would be more likely to select life-sustaining treatments than older adults, but this effect only approached significance. Only one predictor in the final model, Hindu end-of-life values, reliably enhanced prediction. A model run with Hindu end-of-life values omitted was not reliably different from the constant only model indicating that Hindu end-of-life values is the only reliable predictor of treatment preference. As Hindu end-of-life values increased, the odds that an individual would choose the life-sustaining treatment increased by over 5, contrary to the prediction in Hypothesis 2 that higher endorsement of Hindu values would be associated with refusal of life-sustaining treatment.

Table 9 also reveals that the interaction of age with Hindu end-of-life values, approached significance as a predictor of treatment choice. To explore the nature of this interaction, separate logistic regression models were analyzed for younger and older adults. Results indicated that Hindu end-of-life values is a significant predictor of treatment preference for younger adults only, Wald's χ^2 (1) = 5.57, p = .02; B =

1.01, S.E = .43, Odds ratio = 2.75 with 95% confidence intervals of 1.18-6.36. Again, however, the direction of this effect contradicted Hypothesis 2.

Table 9

Summary of Logistic Regression Analysis for variables predicting Life-sustaining Treatment Preferences: Head Injury Scenario

Predictor	B	SE B	OR	CI	p
Age group	-2.45	1.48	.09	.01-1.58	.09
Western acculturation(W)	.84	1.55	2.31	.11-48.51	.59
Indian acculturation (I)	2.19	1.74	8.93	.30-268.19	.21
Hindu EOL values (H)	1.74*	.75	5.72	1.33-24.70	.02
AGExW	-.02	.04	.98	.92-1.05	.57
AGExI	-.02	.03	.97	.91-1.04	.48
AGExH	-.03	.02	.97	.94-1.00	.07
Constant	1.84				

Note: Older adults are the reference category. OR indicates Odds Ratios. CI indicates 95% confidence interval for the odds ratios. * indicates $p < .05$ as tested by the Wald's chi-square statistic.

Lymphoma Scenario

Model fit statistics are presented in Table 10. None of the models was significantly different from the constant only model. The comparison of log-likelihood ratios across the three models reveals that model fit improved over the age only model with the addition of the cultural predictors in Model 2 and their interactions with age group in Model 3. In addition the Nagelkerke R^2 increased from .02 in Model 1 to .09 in Model 3.

Table 10

Model Summary for Life-sustaining Treatment Preferences: Lymphoma Scenario

Model	Chi-square	df	*p*	-2 log likelihood
Model 1	1.44	1	.23	89.34
Model 2	2.72	4	.61	88.07
Model 3	6.86	7	.44	83.93

Note: Model 1 includes age group. Model 2 adds the cultural predictors (Western acculturation, Indian acculturation and Hindu end-of-life values). Model 3 adds the interactions of cultural predictors with age.

Table 11 shows the relationship between treatment preference and the categorical predictor, age.

Table 11

Frequency (Percentage) of Treatment Choice by Age Group: Lymphoma scenario

Age group	Treatment preference		
	Do not want treatment	Want treatment	Total
	N (%)	*N (%)*	
Younger (0)	92 (92%)	8 (8%)	100
Older (1)	96 (96%)	4 (4%)	100
Total	188 (94%)	12 (6%)	200

Note: Younger adults *N* = 100 and Older adults *N* = 100

Overall classification was adequate, but the cases were overclassified into the largest group: do not want treatment. On the basis of age group alone, correct classification rates were 100% for refusing treatment and 0% for wanting treatment.

The overall classification rate was 94 %. The rates remained the same with the addition of the cultural predictors in Model 2 and the interactions in Model 3.

The regression coefficients, odds ratios and 95% confidence intervals for odds ratios for each of the predictors in the final model are presented in Table 12. Contrary to Hypothesis 1, age group was not a significant predictor of treatment choice for this scenario. Two predictors in the final model reliably enhanced prediction, Western acculturation and the interaction of age with Western acculturation.

A model run with Western acculturation omitted was not reliably different from the constant only model indicating that this is the only reliable predictor of treatment preference. As Western acculturation increased, the odds of an individual choosing life-sustaining treatment increased by over 57. This is consistent with the predicted hypothesis 3. However, the large odds ratio, as well as the wide confidence interval indicate that there is zero variance in one of the classes of outcome for the predictor (Davies, Crombie & Tavakoli, 1998). A larger sample size is required before the results of this odds ratio can be interpreted.

The odds ratio for the Western acculturation and age group interaction does not exhibit this problem, and therefore was explored further. Separate logistic regression models for younger and older adults were analyzed. Results revealed that Western acculturation did not approach significance as a predictor for the younger or older Asian Indian adults. The interaction effect may partly have been due to the higher Western acculturation scores of the older adults, in comparison with the younger Asian adults.

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Table 12

Summary of Logistic Regression Analysis for variables predicting Life-sustaining Treatment Preferences: Lymphoma Scenario

Predictor	B	SE B	OR	CI	*p*
Age group	1.26	1.64	3.52	.14-87.89	.44
Western acculturation(W)	4.05*	1.99	57.19	1.17-2799.94	.04
Indian acculturation (I)	2.29	1.71	9.85	.34-282.68	.18
Hindu EOL values (H)	-.45	.94	.64	.10-4.04	.63
AGExW	-.08*	.04	.93	.86-.99	.05
AGExI	-.03	.04	.97	.90-1.04	.36
AGExH	.01	.01	1.01	.97-1.04	.71
Constant	-3.98				

Note: Older adults are the reference category. OR indicates Odds Ratios. CI indicates 95% confidence interval for odds ratios. * indicates *p* < .05 as tested by the Wald's chi-square statistic.

Summary: Choice of Life-sustaining Treatment

Logistic regression analyses provided little support for the hypotheses that participant age and cultural values would affect choice of life-sustaining treatments. Although regression coefficients for some of the individual predictors were significant or approached significance, these effects must be interpreted with caution because none of the logistic regression models were significantly different from the constant only model. This is particularly the case for the results of the lymphoma scenario.

Results of the analysis of treatment choices for the head injury scenario indicated a trend consistent with the prediction in Hypothesis 1 that younger adults would be more likely to select life-sustaining treatments than older adults. This effect

did not emerge for the lymphoma scenario, although the pattern of treatment choice by age was in the predicted direction.

The cultural variables improved model fit in the analyses for both scenarios. However, no consistent pattern emerged. For the head injury scenario, endorsement of Hindu end-of-life values significantly predicted treatment choice, but contrary to the prediction in Hypothesis 2, increases in Hindu values were associated with selection rather than refusal of life-sustaining treatments. Subsequent analysis revealed that this effect held only for the younger participants. For the lymphoma scenario, Western acculturation and the interaction of age with Western acculturation emerged as a significant predictor of treatment choice. Separate logistic regression analyses by age group did not indicate that Western acculturation was a significant predictor, indicating that the higher Western acculturation scores of the Asian Indian older adults might have led to the significant interaction effect.

Choice of Decision-Maker (Self or Other)

Hypothesis 3 predicted that more Asian Indian older adults than younger adults would delegate decisions to others. Hypothesis 5 predicted that regardless of age group, higher Western acculturation would be positively related to autonomous decision-making whereas higher Asian Indian acculturation and stronger Hindu end-of-life values would be negatively related to autonomous decision-making.

Sequential logistic regression tested these hypotheses separately for each scenario. In both, the analysis assessed prediction of membership in one of two categories of outcome (self as decision-maker, coded 0, or others as decision-maker,

coded 1), first on the basis of group membership to test Hypothesis 3, and then, to test

Hypothesis 5, after addition of the three cultural predictors, followed by the

interactions of the cultural predictors with age. The group membership predictor was

age (younger, coded 0, or older, coded 1) and the cultural predictors were Western

acculturation, Indian acculturation and Hindu end-of-life values.

Head Injury Scenario

Model fit statistics are presented in Table 13. None of the models was

significantly different from the constant only model. The comparison of log-

likelihood ratios across the three models reveals that model fit improved over the age

only model with the addition of the cultural predictors in Model 2 and their

interactions with age group in Model 3. In addition, the Nagelkerke R^2 increased

from .02 in Model 1 to .09 in Model 3.

Table 13

Model Summary for Choice of Decision-Maker: Head Injury Scenario

Model	Chi-square	df	*p*	-2 log likelihood
Model 1	1.63	1	.20	114.70
Model 2	2.93	4	.57	113.40
Model 3	7.77	7	.35	108.56

Note: Model 1 includes age group. Model 2 adds the cultural predictors (Western acculturation, Indian acculturation and Hindu end-of-life values). Model 3 adds the interactions of cultural predictors with age.

Table 14 shows the relationship between decision-maker choice and the categorical predictor, age.

Table 14

Frequency (Percentage) of Choice of Decision-Maker by Age Group: Head Injury Scenario

Age group	Decision-maker		
	Self (0)	Others (1)	Total
Younger (0)	94 (94%)	6 (6%)	100
Older (1)	89 (89%)	11(11%)	100
Total	183 (91.5%)	17 (8.5%)	200

Note: Younger adults *N* = 100 and Older adults *N* = 100

Overall classification was adequate for all three models, but in all models the cases were overclassified into the largest group: self as decision-maker. On the basis of age group alone, correct classification rates were 100% for self as decision-maker

and 0% for surrogate decision-makers. The overall classification rate was 91.5%. The rates remained the same with the addition of the cultural predictors, as well as with the addition of the interactions.

The regression coefficients, odds ratios and 95% confidence intervals for odds ratios for each of the predictors in the final model are presented in Table 15. Contrary to Hypothesis 3, age group was not a significant predictor of choice of decision-maker for this scenario. Likewise, none of the cultural variables in the final model reliably enhanced prediction, although Indian acculturation and the interaction of Indian acculturation with age approached significance.

Indian acculturation was positively related to the selection of others as decision-maker as predicted in Hypothesis 5. However, the odds ratio was higher than 92 and the wide confidence intervals signify that this variable must be interpreted with caution and a larger sample size may be required to interpret this result adequately (Davies et al., 1998). The odds ratio for the Indian acculturation and age group interaction does not exhibit this problem, and therefore was explored further. Separate logistic regression models for younger and older adults were analyzed. Results revealed that Indian acculturation approached significance as a predictor only for the younger adults, Wald's χ^2 (1) = 3.16, p = .08, B = 2.43, S.E = 1.37, Odds ratio = 11.33 with 95% confidence intervals of .78 -164.85. These results indicate a trend consistent with Hypothesis 5. As Indian acculturation increased, the probability that younger adults would choose others as decision makers increased.

Table 15

Summary of Logistic Regression Analysis for variables predicting Choice of Decision-Maker: Head Injury Scenario

Predictor	B	SE B	OR	CI	p
Age group	.04	1.48	1.04	.05-21.32	.98
Western acculturation(W)	.35	1.55	1.42	.04-48.62	.85
Indian acculturation (I)	4.52	1.74	92.03	.81-10514.12	.06
Hindu EOL values (H)	-1.16	.75	.32	.04-2.33	.28
AGExW	-.01	.04	.99	.93-1.05	.70
AGExI	-.07	.03	.93	.86-1.00	.06
AGExH	.02	.02	1.02	.99-1.05	.32
Constant	-4.40				

Note: Older adults are the reference category. OR indicates Odds Ratios. CI indicates 95% confidence interval for odds ratios. The significance of the regression coefficients were tested by the Wald's chi-square statistic.

Lymphoma Scenario

Model fit statistics are presented in table 16. None of the models was significantly different from the constant only model. The comparison of log-likelihood ratios across the three models reveals that model fit improved over the age only model with the addition of the cultural predictors in Model 2 and their interactions with age group in Model 3. In addition, the Nagelkerke R^2 increased from .02 in Model 1 to .10 in Model 3.

Table 16

Model Summary for Choice of Decision-Maker: Lymphoma Scenario

Model	Chi-square	df	*p*	-2 log likelihood
Model 1	1.25	1	.27	100.21
Model 2	4.39	4	.36	97.07
Model 3	8.11	7	.32	93.35

Note: Model 1 includes age group. Model 2 adds the cultural predictors (Western acculturation, Indian acculturation and Hindu end-of-life values). Model 3 adds the interactions of cultural predictors with age.

Table 17 shows the relationship between decision-maker choice and the categorical predictor, age.

Table 17

Frequency (Percentage) of Choice of Decision-Maker by Age Group: Lymphoma Scenario

Age group	Decision-maker		
	Self	Others	Total
	N (%)	N (%)	
Younger (0)	95 (95%)	5 (5%)	100
Older (1)	91 (91%)	9 (9%)	100
Total	186 (93%)	14 (7%)	200

Note: Younger adults *N* = 100 and Older adults *N* = 100

Overall classification was adequate, with overclassification into the largest

group: self as decision-maker. On the basis of age group alone, correct classification rates were 100% for self as decision-maker and 0% for surrogate decision-makers. The overall classification rate was 93%. The rates remained the same with the addition of the cultural predictors, as well as with the addition of the interactions.

The regression coefficients, odds ratios and 95% confidence intervals for odds ratios for each of the predictors in the final model are presented in Table 18. Contrary to Hypothesis 3, age group was not a significant predictor of choice of decision-maker for this scenario. Likewise, Hypothesis 5 received no support: None of the cultural variables significantly predicted choice of decision-maker.

Table 18

Summary of Logistic Regression Analysis for variables predicting Choice of Decision-Maker: Lymphoma Scenario

Predictor	B	SE B	OR	CI	p
Age group	.76	1.67	2.15	.06-56.30	.65
Western acculturation(W)	-1.27	1.97	.28	.01-13.35	.52
Indian acculturation (I)	1.97	2.44	7.18	.06-863.47	.42
Hindu EOL values (H)	-1.69	1.17	.18	.02-1.81	.15
AGExW	.01	.04	1.01	.94-1.08	.85
AGExI	-.04	.04	.96	.89-1.04	.30
AGExH	.03	.02	1.03	.99-1.06	.16
Constant	-5.95				

Note: Older adults are the reference category. OR indicates Odds Ratios. CI indicates 95% confidence interval for the odds ratios. The significance of the regression coefficients were tested by the Wald's chi-square statistic.

Summary: Choice of Decision-Maker (Self or Other)

Logistic regression analyses provided little support for the hypotheses that participant age and cultural values would affect choice of autonomous versus surrogate decision-making. Although as predicted in Hypothesis 3, more older than younger participants opted for a surrogate decision-maker in response to both scenarios, these differences were not significant. The cultural variables improved model fit in the analyses for both scenarios. However no consistent pattern emerged and none of the logistic regression models were significantly different from the constant only model.

For the head injury scenario, Indian acculturation and its interaction with age group approached significance as predictors of choice of decision-maker. As predicted in Hypothesis 5, higher Indian acculturation was associated with an increased probability of choosing a surrogate decision-maker. Exploratory analysis showed that this effect was particularly true for younger participants. This effect was not replicated in the decision-maker choices for the lymphoma scenario. Further, the absence of significant effects for the overall logistic regression models emphasizes the need to treat this result as tentative.

Preferred Surrogate Decision-Maker

Hypothesis 4 predicted that regardless of age group, an available family member would be chosen as surrogate decision-maker over a medical professional. Hypothesis 6 predicted that cultural values would play a role in the selection as well,

with higher Western acculturation positively related to selection of medical professional, but higher Asian Indian acculturation and stronger Hindu end-of-life values positively related to choice of a family member.

Of the 11 older adults who chose surrogate decision-makers in the head injury scenario, 7 indicated that spouses should make the decision and 4 indicated that children should make the decisions. Similarly, in the lymphoma scenario 9 older adults chose surrogate decision-makers with 7 choosing spouses and 2 choosing children. In the younger adult group, 6 in the head injury scenario and 5 in the lymphoma scenario chose surrogate decision-makers. All the younger adults chose spouses as surrogates. None of the older or younger participants selected a medical professional or other non-family member as a surrogate. These results confirm the prediction in Hypothesis 5. Given the small number of participants who chose surrogate decision-makers, Hypothesis 6 regarding the effects of the cultural variables on the choice of the surrogate could not be examined.

Additional Analyses

To look at the effects of multicollinearity on the results of logistic regression, collinearity diagnostics were conducted. Variables with significant correlations of .6 and above were considered (Hosmer & Lemeshow, 2000). Two pairs of variables met these criteria: (1) Western acculturation and the interaction of age with western acculturation = .68 and, (2) Indian acculturation and interaction of age with Indian acculturation = .72. Western and Indian acculturation were also significantly correlated for both younger (-.51) and older adults (-.27). Although multicollinearity

must be taken into consideration before interpretation of the results of logistic regression, it does not bias the coefficients, but inflates the standard errors of the coefficients (Tabachnick & Fidell, 2001). Therefore VIF is a more accurate indicator of multicollinearity.

A VIF of 10 and above is considered high and the variables may need to be removed for accurate statistical interpretation of results. However, VIFs of 2 and above must be taken into account in logistic regression (Allison, 2006). Several covariates had a VIF above 2 in the model: Age group, Western acculturation, Indian acculturation, interaction of age with Indian acculturation and interaction of age with Western acculturation. Logistic regression was repeated for both dependent variables after removing the interactions of age with western and Indian acculturation. This did not provide statistically significant changes in the prediction of both dependent variables and did not improve model fit.

Finally, the relationship between end-of-life decision-making and sociodemographic factors like gender, marital status, education and children has been discussed in previous research (Hopp & Duffy, 2000). Logistic regression was conducted controlling for these variables and results indicated that there were no statistically significant relationships between these variables and either life-sustaining treatment or decision-maker choices for the Asian Indian sample in this study.

Reasons for Decisions: Analysis of Open-Ended Responses and Interviews

The purpose of the open-ended questions and interviews was to gain insights into the reasons behind the choices of life-sustaining treatment and decision-maker, as

well as to provide support to the results of the hypotheses from the quantitative analyses. The reasons for life-sustaining treatment preferences and choice of decision-maker offered in response to the open-ended questions on the questionnaire were recorded for all participants and tabulated. A total of 98 younger participants and 99 older participants provided reasons for at least one scenario with 96 younger adults and 97 older participants providing responses for both the head injury and lymphoma scenario.

Ten younger and ten older adults participated in the interview. Questions in the semi-structured interview elicited responses from the participants that addressed issues of culture in the decision-making process, the role of religion, intergenerational experiences, and the role of family in decision-making. The interviews also clarified the reasons for the specific preference for life-sustaining treatment and the choice of autonomous versus surrogate decision-maker. As indicated in Chapter III, each of the open-ended responses and interview transcripts was read several times for themes. Each word, sentence or paragraph containing a theme was considered the unit of analysis. When repeated reading of the responses and interview transcripts did not provide additional themes, the categories were combined. The results of these analyses, for the open-ended responses and interviews are presented together as they relate to the reasons behind the choice of treatment or decline of treatment, selection of oneself or a surrogate decision-maker, by age group. In addition, similarities and differences between older and younger adult participants are also presented.

Older Adults' Themes

Sense of having lived a long life

Several older adults indicated in their open-ended responses that they refused treatment because of the sense of being "old". This theme was also elicited in the interview responses. Older adults who did not want to use life-sustaining treatments often indicated that they had already lived long lives and did not want to extend it by using artificial means. This theme had two subcategories. The first centered on the futility of adding a few more days. For example, a 67 year old male interviewee said, "I have done everything that a person needs to do. What am I going to do by living another month or two?" Similarly, a 71 year old man stated, "I have lived long and experienced happiness and sorrow. This would only seem like extending the pain."

The second sub-theme described feelings of being '*old*' or '*elderly*'. A 62 year old woman said, "I am already old." Another female participant asked rhetorically, "Who wants an old person like me hanging around?" This sub-theme was also reflected in the choice of decision-maker. A 69 year old male indicated that his age entitled him to make his own decisions: "I am at a point in my life where I don't have to ask others before making a decision and I think this is the same thing. I am old and I can do what I want." This was substantiated in some of the open-ended responses as well, with one female participant, for example, mentioning that being old was a "license to do what one wanted. End-of-life decision-making is not that very different in that respect."

Quality of Life

The quality of life while on life-sustaining treatments was a second major theme for older adults choosing to decline treatment. More than half the participants, who responded to the open-ended questions, mentioned that quality of life was very important in choosing to use life-sustaining treatments. Seven of the older adults interviewed in this study were worried about poor quality of life associated with the treatments. As a 76 year old man indicated, "I don't think the treatment is going to improve my quality of life." Other responses reflecting this theme included, "I prefer not to live in such a state" and "When I am in a helpless state, I want to be released from my body" (61 year old woman). A 68 year old male interviewee expanded on this perspective, saying:

> I think with both of the conditions, there are advantages and disadvantages. In both though, you are not going to have that great of a life in whatever time is left. And even if your thinking and memory is not affected, physically you are and you will feel the pain and discomfort. I don't want to have that. That is the reason for my refusing to have treatment.

Burden

Others were concerned about the financial, emotional and physical burden the treatment might place on their families in light of the prognosis. This concern was similar for both the choice of treatment preference as well as for the choice of decision-maker and was another common theme expressed in the open-ended

responses as well as interviews. For instance a 68 year old man stated that, "It will be too expensive to prolong my life…I am a practical person. I don't want to be ruled by emotions. " Similarly, a 61 year old woman asserted, "It is a waste of time and money for certain death." The poor quality of life for spouses having to look after an ill person was another issue. A 71 year old man expressed concern for this wife stating "My wife will have to bathe and dress me. I don't want her to do that. It is not necessary."

A sub-theme for the older participants' refusal of life-sustaining treatment and choice of self as decision-maker were intergenerational concerns. Older participants' experiences with their parents or grandparents, made them determined to spare their children the burden of caregiving. Differences with family members of different generations were two-fold for older adults. The first was with parents and parents-in-law, and the second was the differences with children. Older adults also indicated that they did not have the same expectations from their children as their parents had of them.

For instance, a 61 year old woman stated, "My parents expected me to take care of them and I did. But I don't expect that from my children. If I wanted all that, I should have gone back to India when they were younger. But to be frank, I don't think even in India, parents are looked after as they were in the olden days." A 65 year old man acknowledged the difficulties associated with caregiving, "My wife looked after my parents for a few years before we moved here and they expected that from her. Now I see that it was difficult for her." Similarly, a 61 year old woman said

"I was the only daughter. My parents wanted me to take care of them. But I couldn't leave my job and family here to go to them. I am sure they were upset but we were all helpless."

The intergenerational difference with their children was also an important issue that affected decision-making. A 73 year old man stated that he did not want to burden his child, "It is more of a friendly relationship between us, not like a father and son which used to be with my own father. I don't think a friend will want to stay with me 24/7." This was echoed by several other participants. For instance, a 65 year old woman indicated, "Even if I expect something, I don't think they can do it. It is the way of life now. It may not be because it is the USA. It is the same in India too." Another 61 year old female respondent said, "I don't expect my child to take care of me. She has her own life."

Religion/culture and Health are Separate

Eight of the older adults interviewed indicated that their choice of decisions and decision-maker was not affected by their religious or cultural backgrounds. They also indicated that they saw a separation between religious beliefs and medical decisions. Expressing this view, a 73 year old man said, "I am religious but I am a realist too." A few older adults indicated that it was necessary to interpret Hinduism in a different way, as a result not only of living in the United States, but also one's general life experience. As a 61 year old woman said, "Those are all old beliefs. I do believe in them but their strength is not as much as it was before." Similarly, a 63

year old man said, "We can talk about the purpose of life and all that in Hinduism. Maybe my purpose is not to trouble anyone further and end my life peacefully."

According to a 65 year old female, "Holding on to Hindu beliefs and saying my soul will be unhappy if I use life-sustaining treatments because I am holding on to it is not the right thing." These interviewees draw a distinction between acting in accordance with Hinduism and ritual behaviors of traditional Hinduism. This distinction is clearly articulated in the following comments of a 65 year old male interviewee:

> It all used to be in the olden days and maybe still works in India. But we cannot mix religion and health here. Religion is about your beliefs but saying that you want holy water won't work out…..We need to look at Hinduism in a way that is helpful to ourselves and others and not interpret it literally. Hinduism says that our actions lead to certain consequences. We must try to see that our action of extending life will prolong misery for everyone and therefore not do it.

On the other hand, a more traditional religion was clearly important to the choices of a 71 year old woman who wanted to use life-sustaining treatment and wanted family members to make the decisions. She stated that, "I trust that the doctor will tell me and my children what is right. I believe in God but that cannot help me with my decisions, although He plays a role in other parts of my life. My religion will help me find the peace that is necessary to take the final step." This theme was mainly elicited in the interview responses and was not seen in the open-ended responses. This

theme also reflected the choice of life-sustaining treatment preference and did not seem to influence the choice of decision-maker. Most participants indicated that religion did not play any role in choosing a decision-maker, saying that although religion and culture were guidelines to behavior, they did not determine the actions one must take. As a 68 year old man stated, "I don't think my religion can tell me who to choose as decision-maker. It tells me that I must respect elders and knowledgeable people, but they are not the ultimate authority when it comes to my life. That is me."

Need for Independent Decision-making

Control of one's own decisions was an important issue for eight interviewees, as illustrated by these statements: "I want to be in charge of my fate" (71 year old male) and "I will talk to my wife and children of course, but the end decision is mine" (73 year old male). A 65 year old woman said, "Who else should decide my destiny but me? I think that this is the right thing to do." A sub-theme to the need for control over one's decisions was revealed in the open-ended responses, which indicated that participants were afraid that the right decisions would not be made by surrogate decision-makers. A 67 year-old woman's response illustrates this clearly: "I don't want treatment and if someone else in my family wants it, there will be a clash. So, I should decide."

At the same time, some respondents indicated that they wanted to make decisions for themselves in order to avoid burdening their family members. A 71 year old male interviewee articulated this perspective, saying:

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I don't want others to feel guilty. So I will make the final decision. If my wife

or children do something and then it is worse than expected, they will keep

thinking about it for the rest of their lives. It will be a huge burden for them.

This way, they know that it was my wish and they will feel more happy about

that even if I am here or not.

End -of -life Planning

 A majority of older adults had discussed end-of-life preferences with family

members, especially spouses. Three older adult interviewees had also completed

advance care planning documents and were aware of options available to them. A 71

year old male stated that "I think planning for the end of your life is very important. I

have talked with my wife about it and we decided to get our documents done. You

never know what is going to happen at this age." Others indicated in spite of

awareness, they had not completed any documents. According to a 61 year old female,

"we know about all this but putting it down in writing is very scary. Even at this age,

it is difficult to think about death. My husband says we should do it soon but I keep

putting it off."

Table 19 presents a summary of the major themes of the open-ended

responses and interviews for older adults.

Table 19

Summary of Open-ended Responses and Interview Themes for Older Adults

Theme	Example	Theme elicited in interview or open-ended response
1. Sense of having lived a long life	I am old. What is the point in living any longer?	Both
2. Quality of life	I do not want to live with such misery.	Both
3. Burden	Avoiding pain to others is important above all.	Both
4. Separate religion/culture and health	I trust that God will give me the strength, but I have to make my own decisions.	Only interviews
5. Independent decision-making	I don't trust others to do what is right for me.	Both
6. End-of-life planning	It is important to have a plan for the unknown.	Only interviews

Younger Adults' Themes

Quality of Life

Most younger adults were concerned about the quality of life due to the use of life-sustaining treatments. This was evident in the responses to the open-ended questions as well as the interview responses. As a 34 year old woman stated, "Well, if I am not going to be like I am now, what is the point in living?" A 25 year old man had the same views, saying, "It is sad because I am not old enough, but if this is the way it is going to be I am not so sure." The quality of life for spouses and children was also another issue of focus as indicated by the response of a 34 year old male interviewee:

I want to see my wife and child but not at the cost of their future. What if we cannot afford the life-sustaining treatment and what quality of life will I have? They are going to find it very difficult to take care of me since I make most of the money. No, so I don't think it is a good idea for me and family that I choose life-sustaining treatments of any kind.

A 29 year old female interviewee did not want to choose treatment for the head injury scenario but was not sure about the lymphoma scenario, reiterating the importance accorded to quality of life: "I hear that there are cures for cancer nowadays and there may be something at that point that may cure me. Maybe, I will even be able to have some sort of a normal life. I definitely would not want to extend my life for the head injury but maybe with the cancer, I will think about it."

Dependence on Self

Younger adults also indicated that the decisions about treatment had to be made by themselves because they did not have a support system in the United States. Responses to the open-ended questions elicited this theme as well. This theme had two aspects. The first focused on the need for independent decision-making because of the unavailability of other sources of emotional support. A 27 year old man talked about the difficulties of decision-making without the support of family members, "I am by myself, all alone and away from my family. Who else will make the decision?"

The second sub-theme, on the other hand, dealt with the need to control the decision-making process. A 29 year old man indicated "I am not going to put anyone else in the position of deciding for me. It is my life and my body and relationships are

secondary to how I want to live, especially when it is such an important decision." A 34 year old female interviewee talked about her discussions with her spouse, with the stipulation that she would make the final decision:

> I told him that I want to make the decision and I am telling him only because he should not take whatever decision he wants. I know he will want me to live under any circumstance, but I don't think that s a good choice. That is why I want to be the decision-maker.

Role of Religion

Younger adults indicated that although religion was a part of their lives, they did not take this into consideration when thinking about decision-making at the end of life. Although religion was an important part of younger adults' experiences, decision-making was not affected by Hindu philosophy. As a 25 year old man said, "I believe in all those things but not blindly." A 31 year old man talked about religion being a part of older adults' lives, " I do pray and everything but really those end-of-life belief questions are more for the older generation, I think. I don't know anyone in my age group, at least among my friends who believe deeply in such things. However, I have not discussed such things with them." Some indicated that even if rituals were important it was not possible to follow them accurately. As a 34 year old woman opined, "it may be essential to do all that but not in these kinds of situations where health especially is a consideration." A 33 year old woman illustrated this distinction between beliefs in Hinduism and blind adherence to rituals clearly:

I think I remember that my father had some water from the Ganges at home for my grandmother or something like that, but I don't know if it ever was used. But for one thing, I don't believe in such things and the other thing is that it is not very practical to hold on those beliefs here if you were a real follower. I mean you cannot keep the body for long or do any of those things. I respect people who want to do all that but ritualism is not my way of respecting my culture or religion.

Influence of Western Culture

Younger adults indicated that it was not possible to hold on to entirely Indian beliefs when living in another culture. A 26 year old woman was of the opinion that one needed into integrate with Western culture, "I cannot hold on to my Indian beliefs when I am here….I must mix into the culture here and have a blend of both Western and Indian values." A 34 year old man had similar thoughts:

We have to live according to our circumstances. Trying to recreate the life that we had growing up in India is not practical in any sense. We are not doing ourselves or our children any good because of that. They will only be confused. Instead we should tell them that we have a different origin but we are here now and we should combine both cultures. I think the same thing is applicable for this kind of decisions. We need to think of what is important for us and then combine it with the realities of the situation.

The blending of cultures was a significant theme elicited in the interviews. Many younger adults stated that Western culture allowed an individual to make one's own

decisions and this was one of the reasons for their choice of themselves as decision-maker.

Changes in Expectations

Intergenerational differences and expectational shifts were discussed by younger participants. These changes allowed them to think and act independently, which led to their treatment and decision-maker choices. A 25 year old man said, "I left my family and came here. I have my own life here and therefore no expectations. I don't think my parents should too although I will help in any way I can. But I don't think physical presence is going to be possible anymore." A second 32 year old male interviewee concluded, "I have talked to my wife. I don't think I need to discuss with my children. What can they do for me and they are too young now." Talking about intergenerational differences, the same interviewee further said,

My parents don't want me to worry about them. I do but what can I do for them from here. I can discuss options but they have to take the decision themselves. Maybe when one of them is not here, it will be a different story. But I am not thinking about all that right now.

Participants also suggested that moving to the United States had changed the expectations of their parents but also that traditional families were getting less prevalent in India as well. As a 34 year old woman said, "Caregiving of older people has been outsourced in India. There are maids and nurses to help parents now."

Hypothetical Nature of Scenarios

A few participants suggested that their choice of treatment and decision-maker may not be the same if faced with the decision in real life. This theme was prevalent in both the open-ended responses as well as the interviews. A 33 year old female speculated on the strength of her decision, "I don't think I want treatment now but don't know what I will think in the future." A 34 year old male interviewee had the same concerns, "Maybe I will change my mind, who knows? But this is what I think I will do if I am in that circumstance." They also indicated that this made planning difficult. A 25 year old male said, "say I plan all this in great detail and talk to a lawyer and write it down somewhere. What will happen if I want to change my mind? I think that is why I have a problem with all these types of things. I don't want to plan in advance and want to see how things go and how the future turns out to be."

Table 20 presents a summary of the responses to the open-ended questions and interviews for the younger adults.

Table 20

Summary of Open-ended Responses and Interview Themes for Younger Adults

Theme	Example	Theme elicited in interview or open-ended response
1. Quality of life	I do not want to suffer.	Both
2. Dependence on self	There is no one else to rely on.	Both
3. Role of religion	I pray but I don't think it will cure me.	Only interviews
4. Influence of Western culture	When I live in the U.S. I need to do things this way.	Only interviews
5. Changes in expectations	Don't depend on others and they won't too.	Both
6. Hypothetical nature of scenarios	It is difficult to say what I would really do.	Both

Summary of Reasons for Decisions

Several common themes for younger and older adult participants emerged from the analyses of the open-ended responses and interviews. The most important of these common themes were quality of life and burden. The fear of a poor quality of life combined with the fear of being a physical and emotional burden to family members and caregivers prompted interviewees to decline life-sustaining treatment and/or choose autonomous decision-making.

Another major theme that emerged irrespective of age group was the need to control decision-making as well as depend on oneself. While this originated in life experiences and age for older adults, younger adults' sense of independence was derived from their leaving their country and facing challenges of living in a new culture. Therefore, integration into Western culture was a theme that was more

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important to younger than older adult participants. On the other hand, older participants' relied on their age and sense of having lived long to decide on life-sustaining preferences.

The role of religion was also a relevant theme from the analyses. The interviews indicated that the participants in the sample made distinctions between the Hindu way of life, as evidenced in values and thinking and Hindu rituals and practices. These were mutually exclusive and being a Hindu did not mean that an individual followed Hindu traditions for all decision-making processes. Finally, the older and younger participants differed on two themes. Older participants emphasized the importance of planning for the end of life, which may be indicative of their position in the developmental life-span, while younger adults stressed the hypothetical nature of the scenarios. This could indicate that the perception of time differs with age, leading to a different process in decision-making, although the decision may be the same.

Summary of Results

Results of the statistical analyses provided little support for the hypotheses regarding age differences in preferences for life-sustaining treatments and the choice of autonomous versus surrogate decision-making. Overwhelmingly, the participants from both age groups indicated that they did not want life-sustaining treatments and that they preferred to make those decisions themselves. Likewise, the analyses did not support the hypotheses that participants' choices would reflect the strength of their Western and Indian acculturation or their endorsement of Hindu end-of-life values.

Only the hypothesis that those who preferred surrogate decision-making would select family members over medical professionals received unequivocal support.

At the same time, some results were suggestive of age group and cultural effects consistent with the hypotheses. This was further supported by the interview results, which suggest that religion though important may be subsumed by other factors like their experience in adapting to Western culture. Given these findings as well as the exploratory nature of this research, a supplemental sample of non-Hispanic Whites was recruited to further explore these issues and to provide a comparison group for the findings for the Asian Indian Hindu sample.

CHAPTER V: SUPPLEMENTAL DATA COLLECTION AND ANALYSIS

Research on socioemotional selectivity theory has indicated that there are age effects in health-related decision-making (Lockenhoff & Carstensen, 2004). These studies have primarily been conducted with non-Hispanic White populations. The analyses with the Asian Indian population, described in the previous chapter indicated that the hypotheses on age effects were not supported. Likewise the hypotheses regarding the effects of cultural affiliation and Hindu end-of-life values were not supported. However, there was evidence suggestive of underlying age and cultural influences on these judgments from both the questionnaire and interview data.

Interpreting these results is complicated by the scarcity of prior studies that deal specifically with the process of decision-making in the Asian Indian population, and by the fact that no studies have compared the decisions of Asian Indians to those of the non-Hispanic white population which has been the target of most prior research. As a result, a supplemental sample of younger and older non-Hispanic white participants was recruited to provide a point of comparison for the Asian Indian sample, and to aid in providing insights into the roles of culture and age in end-of-life decision-making by Asian Indians. Comparing the responses of the non-Hispanic white sample to those of the Asian Indian sample was also aimed at helping to place the results reported in Chapter IV within the context of prior research on end-of-life decision-making.

Culture is operationalized in this supplemental study as membership in one of two ethnic groups: Asian Indian or non-Hispanic White. The additional data in this

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study answers the following research questions within the theoretical framework of SST: How do age and culture influence the choice of (1) life-sustaining treatments, and (2) autonomous versus surrogate decision-makers?

In line with the predictions of socioemotional selectivity theory on age and cultural effects, from previous research (Carstensen, 1995, 1998) and from the knowledge of Asian Indian Hindu practices (Alagiyakrishnan & Chopra, 2001; Doorenbos, 2003), the following hypotheses were tested regarding end-of-life treatment preferences:

H1: Fewer older adult participants than younger adult participants will choose life-sustaining treatments.

H2: Asian Indian participants will be less likely to choose life-sustaining treatments than non-Hispanic White participants.

H3: Ethnicity and age will interact to affect the likelihood that participants will select life-sustaining treatments. Specifically, in comparison to non-Hispanic White young participants, Asian Indian young participants will be less likely to select life-sustaining treatments.

In addition, the following hypotheses were tested regarding choice of decision-maker:

H4: Fewer younger adult participants than older adult participants will delegate decisions to others.

H5: Asian Indian participants will be more likely to delegate decisions to others than non-Hispanic White participants.

H6: Age and ethnicity will interact to affect the likelihood of delegating decisions to others. Specifically, in comparison to non-Hispanic White young participants, Asian Indian young participants will be more likely to delegate decisions to others.

H7: Regardless of age group and ethnicity, participants who choose surrogate decision-making will select family members as surrogates over medical professionals.

Method

Pilot Testing

Pilot testing was conducted with five younger adult participants (aged 19-23 years, $M = 21.3$, $SD = 2.1$) recruited from a university Communication Studies program to see if the non-Hispanic White sample had any issues with the questionnaire and also to assess the time taken for completion of the study. Participants were given course credit for completing the study. The structured questionnaire used in the Asian Indian sample was used with the ARMSA-II and Hindu Religious Beliefs and Rituals Scale removed. Changes were also made to the demographic information items. Items on ethnicity and affiliation (described in the main study section) were included. The health literacy scale had a reliability coefficient of .87 and the health status scale had an internal consistency of .82 for these participants. Participants completed the questionnaire in ten to twenty minutes, and indicated no problems in interpreting the scenarios or dependent measures during debriefing. The questionnaire was determined to be satisfactory for use in the main study without changes.

Participants

The sample consisted of younger and older non-Hispanic White adults living in the Midwest. The younger adults were 18 to 35 years old and the older adults were aged 60 to 82 years. A non-probability method of convenience sampling was used to recruit participants for the study. All participants were volunteers and were not paid to complete the study. Participants who were in the medical profession including doctors, nurses and pharmacy graduates were not included to prevent their professional knowledge from biasing the hypothetical decisions made in the study. As with the Asian Indian sample, only one participant per family was recruited in order to avoid interparticipant bias and diffusion effects that could affect internal validity.

Some of the younger participants (*n* = 15) were recruited from undergraduate communication studies courses and were given course credit for participation in the study. The remainder of the younger participants (*n* =49) were recruited by word of mouth and snowballing procedures. Older non-Hispanic White participants were recruited by word of mouth through a local church and other groups. Those consenting to participate were scheduled to meet with the researcher at a convenient place and time to complete the questionnaire and the interviews. Questionnaires were mailed out to two participants. The final sample totaled 123 non-Hispanic White younger (*n* = 64) and older (*n* = 59) adults. Seven of those participants also completed the interview used in the main study.

After reading and signing the informed consent forms, the participants completed the questionnaires. Participants took between fifteen to thirty minutes to complete the questionnaires. The semi-structured interviews lasted between twenty to forty minutes. The entire session length was between 40 minutes to an hour for participants completing both quantitative and qualitative portions of the study. Each questionnaire had a unique identifying number assigned and no personal information was recorded to ensure confidentiality. The interviews were tape-recorded. The interviews were transcribed verbatim and the tapes were deleted after transcription.

Measures

The questionnaire used for the Asian Indian sample was modified for the non-Hispanic White sample. The acculturation scale and end-of-life values scale were removed. An item on the sociodemographic questionnaire on the number of years in the United States was eliminated. Two additional items on religion and ethnicity were added. Participants were asked to report their religious affiliation (Christian = 0, Jewish =1, Muslim =2, Hindu = 3, Buddhist =4, Other = 5) and ethnicity (non-Hispanic White = 0, non-Hispanic Black =1, Hispanic = 2, Asian/Pacific Islander = 3, Native American = 4, Multi-ethnic = 5, Other = 6). All the other variables remained the same.

Health Literacy

Reliability was established at .92 and .89 for the older and younger adults in this sample. Previous research has indicated that the reliability of the S-TOFHLA is .91 (Baker et al., 1998)

Health Status

The internal consistency in the present study was established at .81 and .83 for the younger and older adults respectively. Previous research has indicated that reliabilities for the general health survey range from .81 to .96 (Stewart et al., 1988).

Characteristics of the Non-Hispanic White Sample

A total of 64 younger (52 %) and 59 older adults (48 %) completed the study with four younger and three older adults completing the interview. Demographic information for the sample is presented in Table 21. The sample was 55.3 % female overall, but there was no significant difference in the number of males and females in the two age groups, $\chi^2 (1) = .39$, $p > .05$.

The sample was highly educated with an average of 15.76 years of education. There was no statistically significant difference in the years of education by age group, $t (121) = 1.942$, $p > .05$. Differences in marital status between the age groups were significant, Pearson's $\chi^2 (2) = 48.32$, $p < .05$, with the percentage of those married higher among older adults. Older participants also had significantly more children than did younger participants, $t (121) = -12.29$, $p < .01$.

The entire sample identified themselves as non-Hispanic White, and the majority ($N = 122$) identified themselves as Christian. There was no significant difference between the age groups on religious affiliation. The entire sample had acceptable health literacy and health status. A score greater than 23 indicates adequate health literacy and all participants scores above that minimum, with a range of 33-36 for younger adults and 31-36 for older adults. Means for the two groups are

given in Table 21. Younger adults' reported health status ranged from 88-100 and older adults' from 79-100. Means by age group are listed in Table 21.

Older adults were also significantly more aware than younger adults, of end-of-life planning documents like advance directives, χ^2 (2) = 39.23, $p < .05$ and durable powers of attorney for health care, χ^2 (2) = 47.70, $p < .05$. Older adults were also more likely than younger adults to have completed advance directives, χ^2 (2) = 45.37, $p < .05$ and durable powers of attorney, χ^2 (2) = 50.35, $p < .05$, as well as to have discussed their wishes with others, χ^2 (2) = 64.91, $p < .05$. Fewer younger adults compared to older adults were aware of state options. This difference was statistically significant, χ^2 (2) = 71.12, $p < .05$.

Table 21

Description of the non-Hispanic White Sample

Variables	Younger adults (N=64)		Older adults (N=59)	
	M	*SD*	*M*	*SD*
Age	26.45	5.18	68.92**	5.42
Education	16.00	1.49	15.49	1.40
Number of children	.20	.48	2.00**	1.07
Health literacy	35.76*	.78	34.71	1.23
Health Scale	98.97*	2.82	93.86	6.63
	N	*%*	*N*	*%*
Gender				
Male	31	49.40	24	30.60
Female	33	51.60	35	69.40
Marital Status				
Single/Never Married	38**	59.30	0	0
Married	26	41.62	49**	83.10
Widowed	0	0	10**	16.90
Ethnicity- Non Hispanic White	64	100	59	100
Religious affiliation	63	99.2	59	100
Christian	1	.80	0	0
Other				
Advance care planning				
Knowledge of Advance Directives (yes)	28	42.98	55*	93.22
Completion of Advance Directives (yes)	9	1.56	33*	56
Knowledge of DPAHC (yes)	30	46.80	57*	96.60
Completion of DPAHC (yes)	2	3.12	38*	63.72
Discussion of end-of-life wishes	11	17.18	53*	89.83
Awareness of state options	4	6.25	42*	71.18

Note: Age groups differ significantly at * *p* <.05; Age groups differ significantly at ** *p* <.01. Health literacy: 23-36 is considered adequate. Health status: A score greater than 67 indicates good health.

Comparability of the Non-Hispanic White sample to the Asian Indian Hindu sample

There was a significant difference in age between the younger adults of the Asian Indian ($M = 30.60$) and non-Hispanic White ($M = 26.45$) samples, t (162) = 5.73, $p < .01$. However the mean ages of the older adults in the Asian Indian sample ($M = 67.81$) and non-Hispanic White ($M = 68.91$) sample did not differ significantly, t (157) = -1.26, $p > .05$. The Asian Indian sample ($M = 17.41$) reported a statistically significant higher number of years of education than the non-Hispanic White sample ($M = 15.76$), t (321) = 7.24, $p < .01$. There was no significant difference between the groups on marital status, χ^2 (2) = 40.92, $p > .05$; knowledge, χ^2 (2) = 3.88, $p > .05$, and use of advance directives, χ^2 (2) = 2.85, $p > .05$; use of durable powers of attorney for health care, χ^2 (2) = 2.14, $p > .05$; discussion of end-of-life wishes, χ^2 (2) = 2.36, $p > .05$ and awareness of state options, χ^2 (2) = .05, $p > .05$. The ethnic groups differed significantly on the knowledge of durable powers of attorney for health care, χ^2 (2) = 6.69, $p < .05$ with more non-Hispanic Whites indicating such knowledge than Asian Indian Hindus.

The Asian Indian sample had higher health literacy scores, t (321) = 9.13, $p < .01$ and reported better health status, t (321) = 4.48, $p < .01$ than the non-Hispanic White sample, although both groups fell into the acceptable range for both health literacy and health status scores, as reported earlier.

Non-Hispanic White sample

A dichotomous variable was created with all scores of 1 and 2 assigned a value of 0 (definitely do not want treatment) and 3, 4 and 5 assigned a value of 1(definitely want treatment), similar to the analyses of the Asian Indian sample.

Frequencies were computed for preference for each treatment condition (artificial breathing support and artificial nutrition and hydration) within scenarios. Separate chi square analyses were conducted within age groups to examine whether preferences for the two treatments varied for each scenario. Results revealed that young participants' preferences for each treatment did not differ significantly for either the head injury, χ^2 (1) = 2.61, p >.05 or lymphoma scenarios, χ^2 (1) = 7.33, p > .05. Likewise, older adults' preferences for each treatment did not differ significantly for either scenario: head injury, χ^2 (1) = .30, p > .05 or lymphoma, χ^2 (1) = .73, p > .05. Separate chi square analyses were conducted within age groups to examine whether preference for a life-sustaining treatment varied by scenario. Results indicated a significant difference in treatment preferences by scenario for the younger adults: χ^2 (1) = 30.92, p < .05 and older adults: χ^2 (1) = 46.58, p < .05.

Combined Sample of non-Hispanic Whites and Asian Indian Hindus

Frequencies were computed for preference for each treatment condition (artificial breathing support and artificial nutrition and hydration) within scenarios. Separate chi square analyses were conducted within the ethnic groups to examine whether preferences for the two treatments varied for each scenario. Results revealed

that Asian Indians' preferences for each treatment did not differ significantly for either the head injury, χ^2 (1) = 6.54, p >.05 or lymphoma scenarios, χ^2 (1) = 7.82, p > .05. Likewise, the non-Hispanic Whites' preferences for each treatment did not differ significantly for either scenario: head injury, χ^2 (1) = 1.59, p > .05 or lymphoma, χ^2 (1) = 2.07, p > .05. As a result, the within scenario effects of type of life-sustaining treatment were not computed in the preliminary analysis examining the equivalence of preference for a life-sustaining treatment across the two scenarios (described next) or the binary logistic regression analyses were used to examine the hypotheses.

Separate chi square analyses were conducted within ethnic groups to examine whether preference for a life-sustaining treatment varied by scenario. Results indicated a significant difference in treatment preferences by scenario for the Asian Indians: χ^2 (1) = 72.59, p < .05 and non-Hispanic Whites: χ^2 (1) = 78.92, p < .05. Therefore binary logistic regression was conducted separately for each scenario in testing the hypotheses.

<div align="center">Choice of Decision-maker</div>

Non-Hispanic White Sample

A majority of the sample (81.3%) wanted to make end-of-life decisions themselves. 23 participants wanted others to make the decision for them in the head injury. Of this, 12 participants wanted a spouse to make a decision for them, 7 wanted parents, 2 wanted children and 2 respondents wanted a medical practitioner to make the end-of-life decisions. In the lymphoma scenario, 22 participants wanted others to make the decision for them. 13 participants wanted a spouse to make the decision for

them, 7 wanted parents, 1 wanted a child and 1 respondent wanted a medical

practitioner to make end-of-life decisions.

Frequencies were computed for decision-maker preference for each treatment

condition (artificial breathing support and artificial nutrition and hydration) within

scenarios. Separate chi square analyses were conducted within age groups to examine

whether preferences for decision-maker varied across the two scenarios. Results

revealed that young participants' preferences for decision-makers did not vary

significantly for either the head injury, χ^2 (1) = 1.42, $p > .05$ or lymphoma scenario, χ^2

(1) = 0.00, $p > .05$. Likewise, older participants' preferences for decision-maker did

not vary significantly for either scenario: head injury, χ^2 (1) = .73, $p > .05$ or

lymphoma, χ^2 (1) = .74, $p < .05$. Separate chi square analyses were conducted within

age groups to examine whether preferences for decision-maker varied by scenario.

Results indicated a significant difference in decision-maker preference by scenario in

younger adults, χ^2 (1) = 49.37, $p < .05$ and older adults, χ^2 (1) = 53.60, $p < .05$.

Combined Sample of non-Hispanic Whites and Asian Indian Hindus

Frequencies were computed for decision-maker preference for each treatment

condition (artificial breathing support and artificial nutrition and hydration) within

scenarios. Separate chi square analyses were conducted within ethnic groups to

examine whether preferences for decision-maker varied across the two scenarios.

Results revealed that Asian Indians' preferences for decision-makers did not vary

significantly for either the head injury, χ^2 (1) = 6.68, $p > .05$ or lymphoma scenario, χ^2

(1) = 3.38, $p > .05$. Likewise, non-Hispanic Whites' preferences for decision-maker

did not vary significantly for either scenario: head injury, χ^2 (1) = .89, p > .05 or

lymphoma, χ^2 (1) = .56, p > .05. As a result, the within scenario effects were not

computed in the binary logistic regression analyses used to examine the hypotheses or

in the preliminary analysis examining the equivalence of the choice of decision-

maker across the two scenarios.

Separate chi square analyses were conducted within ethnic groups to examine

whether preferences for decision-maker varied by scenario. Results indicated a

significant difference in decision-maker preference by scenario in Asian Indians, χ^2 (1)

= 137.74, p < .05 and non-Hispanic Whites, χ^2 (1) = 103.83, p < .05. Therefore binary

logistic regression was conducted separately for each scenario in testing the

hypotheses.

<center>Results</center>

Results from the quantitative and qualitative analyses of the supplemental data

are presented in this section. The results pertaining to the hypotheses regarding the

effects of age and culture are presented first, followed by the results from the open-

ended questions and interviews.

Choices of Treatment Preferences and Decision-Makers: Test of Hypotheses

The hypotheses regarding the effects of age and ethnicity on participants'

choice of life-sustaining treatment and decision-maker were examined using

sequential logistic regression. In the first step, each dependent variable was regressed

on age group alone. Ethnicity was entered as an additional predictor in the second

step. The interaction of age and ethnicity was entered in the third step. Results for

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each analysis report model fit statistics and individual predictor contributions, including odds ratios.

Choice of Life-Sustaining Treatment

The first hypothesis predicted that fewer older adults than younger adults would choose life-extending treatments, regardless of ethnicity. The second hypothesis predicted that fewer Asian Indians would choose life-sustaining treatments than non-Hispanic Whites, while the third hypothesis predicted that ethnicity and age will interact to affect the likelihood that participants will select life-sustaining treatments. Specifically, in comparison to non-Hispanic White young participants, Asian Indian young participants will be less likely to select life-extending treatments. Sequential logistic regression tested these hypotheses separately for each scenario. In both, the analysis assessed prediction of membership in one of two categories of outcome (do not want life-sustaining treatment, coded 0, or want life-sustaining treatment, coded 1) first on the basis of age group membership to test Hypothesis 1, second on the basis of ethnicity to test Hypothesis 2, followed by the interaction of age with ethnicity to test Hypothesis 3. The group membership predictors were age (younger, coded 0, and older, coded 1) and ethnicity (Asian Indian Hindus, coded 0 and non-Hispanic Whites, coded 1).

Head injury scenario. Model fit statistics are presented in Table 22. These statistics assess whether the inclusion of the predictors significantly improves the ability to account for choice of life-sustaining treatment over the constant model. In addition, the Nagelkerke R^2 provides an estimate of the variability in treatment choice

attributable to each model. As Table 22 reveals, although model fit was not

impressive with the addition of age group membership alone, the addition of ethnicity

and the interaction improved model fit. Model 2 and the final model 3 were

significant and indicate an improvement over the constant only model. The

comparison of log-likelihood ratios also reveals the same trend. In addition, the

Nagelkerke R^2 increased from .00 in Model 1 to .13 in the final model. The Hosmer-

Lemeshow test also indicated that the final model was a better fit than the constant

only model, χ^2 (2) = 0.00, $p > .05$.

Table 22

Model summary for life-sustaining treatment preferences: Head injury scenario

Model	Chi-square	df	p	-2 log likelihood
Model 1	.33	1	.56	281.43
Model 2	20.89	2	.00	260.88
Model 3	25.64	3	.00	256.12

Note: Model 1 includes age group. Model 2 adds ethnicity. Model 3 adds the
interaction of age with ethnicity.

Table 23 shows the relationship between treatment preference and the

categorical predictors, age and ethnicity.

Table 23

Frequency (percentage) of treatment choice by ethnicity and age group: Head injury scenario

Predictors		Treatment Choice				
Ethnicity	Age Group	Do not want treatment		Want treatment		Total
		N	(%)	N	(%)	N
Asian Indian	Younger	89	(89%)	11	(11%)	100
	Older	94	(89%)	6	(6%)	100
Total		183	(91.5%)	17	(8.5%)	200
Non-Hispanic White	Younger	51	(79%)	13	(11%)	64
	Older	38	(64%)	21	(36%)	59
Total		89	(72%)	34	(28%)	123
	Total Younger	140	(85%)	24	(15%)	164
	Total Older	132	(83%)	27	(17%)	159
	Total N	272	(84%)	51	(16%)	323

Note: Rows total to 100%; Asian Indian $N = 200$; Non-Hispanic White $N = 123$.

Overall classification was adequate for all three models, but in all models the cases were overclassified into the largest group: do not want treatment. On the basis of age group alone, correct classification rates were 100% for refusing treatment and 0% for wanting treatment. The overall classification rate was 84.2%. The rates remained the same with the addition of ethnicity in Model 2 and the interaction in Model 3. With the addition of the interaction, there was no change in the classification rate.

The regression coefficients, odds ratios and 95% confidence intervals for odds ratios for each of the predictors in the final model are presented in Table 24. The statistics for the age group effect do not indicate support for Hypothesis 1 regarding

age differences in the choice of life-sustaining treatments. The contribution of ethnicity to the second model indicated that it is significant, Wald's χ^2 (1) = -1.42, p = .00, B = -1.42, S.E = .32, Odds ratio = .24 with a 95% confidence interval of .13-.45. The direction of prediction was consistent with Hypothesis 2, indicating that the Asian Indian Hindus were less likely to choose life-sustaining treatment in comparison to non-Hispanic Whites.

Only one predictor in the final model reliably enhanced prediction. The interaction of age with ethnicity was significant as a predictor of treatment choice, as predicted by Hypothesis 3. Logistic regression analyses were conducted to test the effects of ethnicity separately for each age group. Results indicate that ethnicity predicted the preferences for life-sustaining treatments only for older adults, B = -21.6, S.E = .50, p = .00, Odds ratio = .12 with 95% confidence intervals between .04 and .31. The odds ratio for this effect suggests that Asian Indian older adults would be less likely to choose life-sustaining treatments than their age group peers. This is consistent with the interaction effect predicted in Hypothesis 3, but not with the direction that younger Asian adults would be less likely to choose life-sustaining treatments than younger non-Hispanic Whites.

Table 24

Summary of logistic regression analysis for variables predicting life-sustaining treatment preferences: Head injury scenario

Predictor	B	SE B	OR	CI	p
Age group	.66	.53	1.94	.68-5.46	.21
Ethnic group	-.72	.45	.49	.20-1.16	.10
Age X Ethnicity	1.44*	.67	4.20	1.13-15.63	.03
Constant	-2.03				

Note: Older adults and non-Hispanic Whites are the reference categories. OR indicates Odds Ratios. CI indicates 95% confidence interval for the odds ratios. * indicates $p < .05$ as tested by the Wald's chi-square statistic.

Lymphoma scenario. Model fit statistics are presented in Table 25. As Table 25 reveals, model fit was not impressive on the addition of group membership alone. After addition of ethnicity, in Model 2, model fit significantly improved as did the addition of the interaction in Model 3. The comparison of log-likelihood ratios across the three models reveals that although model fit was not impressive on the basis of age group membership alone, the addition of ethnicity in Model 2 and the interaction of age and ethnicity in Model 3 improved model fit. In addition, the Nagelkerke R^2 increased from .00 in Model 1 to .18 in Model 3. The Hosmer-Lemeshow test also indicated that the final model was a better fit than the constant only model, χ^2 (2) = 0.00, $p > .05$.

Table 25

Model summary for life-sustaining treatment preferences: Lymphoma scenario

Model	Chi-square	df	*p*	-2 log likelihood
Model 1	.01	1	.91	271.49
Model 2	32.06	2	.00	239.46
Model 3	34.62	3	.00	236.88

Note: Model 1 includes age group. Model 2 adds ethnicity. Model 3 adds the interaction of age with ethnicity.

Table 26 shows the relationship between treatment preference and the categorical predictors, age and ethnicity.

Table 26

Frequency (percentage) of treatment choice by ethnicity and age group: Lymphoma scenario

Predictors		Treatment Choice				
Ethnicity	Age Group	Do not want treatment		Want treatment		Total
		N	(%)	N	(%)	N
Asian Indian						
	Younger	92	(92%)	8	(8%)	100
	Older	96	(96%)	4	(11%)	100
Total		188	(94%)	12	(6%)	200
Non-Hispanic White	Younger	48	(75%)	16	(25%)	64
	Older	41	(70%)	18	(30%)	59
Total		89	(72%)	34	(28%)	123
	Total Younger	140	(85%)	24	(15%)	164
	Total Older	135	(84%)	24	(16%)	159
	Total N	275	(85%)	58	(15%)	323

Note: Rows total to 100%; Asian Indian $N = 200$; Non-Hispanic White $N = 123$.

Overall classification was adequate for all three models, but in all models the cases were overclassified into the largest group: do not want treatment. On the basis of age group alone in Model 1, correct classification rates were 100% for refusing treatment and 0% for wanting treatment. The overall classification rate was 85.1 %. The rates remained the same with the addition of ethnicity in Model 2 and the interaction of age and ethnicity in Model 3.

The regression coefficients, odds ratios, and 95% confidence intervals for odds ratios for each of the predictors in the final model, are presented in Table 27. The statistics for the age group effect indicate that the prediction in Hypothesis 1, that younger adults would be more likely to choose life-sustaining treatments than older

adults was not supported. Ethnicity reliably enhanced prediction in the final model. A

model run with ethnicity omitted was not reliably different from the constant only

model, indicating that ethnicity is the only reliable predictor of treatment preferences.

The direction of prediction was consistent with Hypothesis 2, indicating that Asian

Indian Hindus were less likely to choose life-sustaining treatments in comparison to

non-Hispanic Whites.

Table 27

Summary of logistic regression analysis for variables predicting life-sustaining treatment preferences: Lymphoma scenario

Predictor	B	SE B	OR	CI	p
Age group	.74	.63	2.09	.61-7.17	.24
Ethnicity	-1.34*	.49	.26	.10-.65	.00
Age X Ethnicity	1.17	.75	3.21	.75-13.83	.12
Constant	-1.83				

Note: Older adults and non-Hispanic Whites are the reference categories. OR indicates Odds Ratios. CI indicates 95% confidence interval for odds ratios. * indicates $p < .05$ as tested by the Wald's chi-square statistic.

Summary – Choice of Life-Sustaining Treatment

Logistic regression analyses provided little support for Hypothesis 1 that

participant age would affect choice of life-sustaining treatments. However, there was

support for Hypothesis 2 that ethnicity would affect choice of life-sustaining

treatments in the lymphoma scenario, as well as the hypothesis that age and ethnicity

would predict the choice of life-sustaining treatment in the head injury scenario. For

both scenarios, Asian Indian participants were less likely to choose life-sustaining

treatments than were non-Hispanic White participants. Results for the analysis of

treatment choices for the head injury scenario were consistent with the prediction in Hypothesis 3 that age and ethnicity would interact to affect treatment choices. However, the prediction that younger Asian Indians would differ more from non-Hispanic White age peers than would older Asian Indian participants was not supported. Instead, older Asian participants differed more in their treatment preferences from their non-Hispanic White age peers than did younger Asian Indians. This effect did not emerge in the lymphoma scenario.

Choice of Decision-maker

Hypothesis 4 predicted that more older adults than younger adults would delegate decisions to others. Hypothesis 5 predicted that fewer non-Hispanic Whites would delegate decisions to others than Asian Indians, regardless of age group. Hypothesis 6 predicted that age and ethnicity will interact to affect the likelihood of delegating decisions to others. Specifically, in comparison to non-Hispanic White young participants, Asian Indian young participants would be more likely to delegate decisions to others.

Sequential logistic regression tested these hypotheses separately for each scenario. In both, the analysis assessed prediction of membership in one of two categories of outcome (self as decision-maker, coded 0, or others as decision-maker, coded 1), first on the basis of group membership to test Hypothesis 4, second on the basis of ethnicity to test Hypothesis 5 and finally, on the basis of the interaction of age and ethnicity to test Hypothesis 6. The group membership predictors were age

(younger, coded 0, or older, coded 1) and ethnicity (Asian Indian Hindu, coded 0, or Non-Hispanic White, coded 1).

Head injury scenario. Model fit statistics are presented in Table 28. As revealed in Table 28, model fit was not impressive on the basis of age group membership alone. The addition of ethnicity in Model 2 improved model fit, as did the addition of the interaction of age and ethnicity in Model 3. The comparison of log-likelihood ratios across the three models revealed that model fit improved over the age only model with the addition of ethnicity in Model 2 and the interaction of age and ethnicity in Model 3. In addition, the Nagelkerke R^2 increased from .00 in Model 1 to .18 in Model 3. The Hosmer-Lemeshow test also indicated that the final model was a better fit than the constant only model, χ^2 (2) = 0.00, $p > .05$

Table 28

Model summary for choice of decision-maker: Head injury scenario

Model	Chi-square	df	p	-2 log likelihood
Model 1	2.13	1	.14	239.80
Model 2	9.42	2	.01	232.51
Model 3	9.53	3	.02	232.40

Note: Model 1 includes age group. Model 2 adds ethnicity. Model 3 adds the interaction of age with ethnicity.

Table 29 shows the relationship between decision-maker choice and the categorical predictors, age and ethnicity.

Table 29

Frequency (percentage) of decision-maker choice by ethnicity and age group: Head Injury scenario

Predictors		Decision-maker				
Ethnicity	Age	Self		Others		Total
	Group	*N*	*(%)*	*N*	*(%)*	*N*
Asian Indian						
	Younger	94	(94%)	6	(6%)	100
	Older	89	(89%)	11	(11%)	100
Total		183	(91.5%)	17	(8.5%)	200
Non-Hispanic White	Younger	54	(84%)	10	(16%)	64
	Older	46	(78%)	13	(22%)	59
Total		100	(72%)	23	(28%)	123
	Total Younger	148	(90%)	16	(10%)	164
	Total Older	135	(85%)	24	(15%)	159
	Total *N*	283	(87.6%)	40	(12.4%)	323

Note: Rows total to 100%; Asian Indian $N = 200$; Non-Hispanic White $N = 123$

Overall classification was adequate for all three models, but in all models the cases were overclassified into the largest group: self as decision-maker. On the basis of age group alone, correct classification rates were 100% for self as decision-maker and 0% for surrogate decision-makers. The overall classification rate was 87.6%. The rates remained the same with the addition of ethnicity in Model 2, as well as with the addition of the interaction of age and ethnicity in Model 3.

The regression coefficients, odds ratios and 95% confidence intervals for odds ratios for each of the predictors in the final model are presented in Table 30. Contrary to Hypothesis 4, age group was not a significant predictor of choice of decision-

maker for this scenario. Only ethnicity reliably enhanced prediction in model 2. Since

the interaction does not give additional information, the main effect of ethnicity is

interpreted. The odds ratio for this effect indicated that Asian Indian Hindus were

less likely than non-Hispanic Whites to choose others as decision-makers. Although

ethnicity effects were predicted in Hypothesis 5, the direction of the significant

effects was not consistent with the predictions of the hypothesis that Asian Indians

would be more likely to delegate decisions to others than non-Hispanic Whites.

Table 30

Summary of logistic regression analysis for variables predicting choice of decision-maker: Head injury scenario

Predictor	B	SE B	OR	CI	p
Age group	-.66	.53	.52	.18-1.46	.21
Ethnicity	-1.07*	.54	.35	.12-1.00	.05
Age X Ethnicity	-.24	.71	.79	.20-3.14	.74
Constant	-1.03				

Note: Older adults and non-Hispanic Whites are the reference categories. OR indicates Odds Ratios. CI indicates 95% confidence interval for odds ratios. * indicates $p < = .05$ as tested by the Wald's chi-square statistic.

Lymphoma scenario. Model fit statistics are presented in Table 31. As Table

31 reveals, the inclusion of age group membership did not improve fit over the

constant only model. The addition of ethnicity in Model 2 improved model fit, as did

the addition of the interaction of age and ethnicity in Model 3. The comparison of

log-likelihood ratios across the three models revealed that model fit improved over

the age only model with the addition of ethnicity in Model 2 and the interaction of

age and ethnicity in Model 3. In addition, the Nagelkerke R^2 increased from .02 in

Model 1 to .08 in Model 3. The Hosmer-Lemeshow test also indicated that the final

model was a better fit than the constant only model, χ^2 (2) = 0.00, $p > .05$

Table 31

Model summary for choice of decision-maker: Lymphoma scenario

Model	Chi-square	df	p	-2 log likelihood
Model 1	3.52	1	.06	222.29
Model 2	12.68	2	.00	213.13
Model 3	12.71	3	.01	213.09

Note: Model 1 includes age group. Model 2 adds ethnicity. Model 3 adds the interaction of age with ethnicity.

Table 32 shows the relationship between decision-maker choice and the

categorical predictors, age and ethnicity.

Table 32

Frequency (percentage) of decision-maker choice by ethnicity and age group:
Lymphoma scenario

Predictors		Decision-maker				
Ethnicity	Age	Self		Others		Total
	Group	*N*	*(%)*	*N*	*(%)*	*N*
Asian Indian						
	Younger	95	(95%)	5	(5%)	100
	Older	91	(89%)	9	(11%)	100
Total		186	(93%)	14	(7 %)	200
Non-Hispanic White	Younger	56	(88%)	8	(12%)	64
	Older	45	(75%)	14	(15%)	59
Total		101	(81%)	22	(19%)	123
	Total Younger	151	(92%)	13	(8%)	164
	Total Older	136	(86%)	23	(14%)	159
	Total *N*	287	(89%)	36	(11%)	323

Note: Rows total to 100%; Asian Indian *N* = 200; Non-Hispanic White *N* = 123.

Overall classification was adequate. On the basis of age group alone,

correction classification rates were 100% for self as decision-maker and 0% for

surrogate decision-makers. The overall classification rate was 88.9%. The rates

remained the same with the addition of ethnicity, as well as with the addition of the

interaction. The cases were overclassified into the largest group: self-as decision-

maker.

No predictors in the final model reliably enhanced prediction, and that model

was not significantly different from the constant only model. As a result, the

regression coefficients, odds ratios and 95% confidence intervals for odds ratios for

each of the predictors in Model 2 are presented in Table 33. Age was a significant

predictor of decision-maker outcome, with the odds ratio indicating that younger

adults were less likely than older adults to select others as decision-makers, which is

consistent with Hypothesis 4. Ethnicity was also a significant predictor of the

outcome, with the odds ratio indicating that Asian Indians were less likely than non-

Hispanic Whites to choose others as decision-maker. Although ethnicity effects are

present, the results are not in the direction of Hypothesis 5. Hypothesis 6 regarding

the interaction of age and ethnicity was not supported.

Table 33

Summary of logistic regression analysis for variables predicting choice of decision-maker: Lymphoma scenario

Predictor	B	SE B	OR	CI	p
Age group	-.71*	.37	.48	.24-1.01	.05
Ethnicity	-1.09*	.37	.34	.16-.69	.00
Constant	-1.19				

Note: Older adults and non-Hispanic Whites are the reference categories. OR indicates Odds Ratios. CI indicates 95% confidence interval for the odds ratios. * indicates $p <= .05$ as tested by the Wald's chi-square statistic.

Summary: Choice of Decision-Maker

Logistic regression analyses provided support for the hypothesis that

participant ethnicity would affect the choice of autonomous versus surrogate

decision-making. Age effects were seen only in the lymphoma scenario. Although as

predicted in Hypotheses 4, more older than younger participants opted for a surrogate

decision-maker in response to both scenarios, these differences were not significant

for the head injury scenario. Ethnicity improved model fit in the analyses for both

scenarios. However, although ethnicity effects were present in both scenarios, those

effects were not in the direction predicted in Hypothesis 5. In contrast to that hypothesis, non-Hispanic Whites were more likely to choose surrogate decision-makers than were Asian Indians. Hypothesis 6 predicting the interaction of age with ethnicity in the choice of decision-maker was not supported.

Preferred Surrogate Decision-Maker

Hypothesis 7 predicted that regardless of age group and ethnicity, an available family member would be chosen as surrogate decision-maker over a medical professional. In the head injury scenario, for both the Asian Indian and non-Hispanic White samples, older adults who chose surrogate decision-makers most often chose spouses or children, which is consistent with the hypothesis. Only two older participants chose medical professionals as surrogate decision-makers. Similarly, younger adults also chose spouses or parents, which is also as predicted, indicating that the final hypothesis about choice of a family member as surrogate was supported. Given the small number of participants who chose surrogate decision-makers, Hypothesis 7 could not be examined.

Reasons for Decisions: Analysis of Open-Ended Responses and Interviews

The purpose of the open-ended questions and interviews was to gain insights into the reasons behind the choices of life-sustaining treatment and decision-maker, as well as to provide support to the results of the hypotheses from the quantitative analyses. These results also helped to make specific distinctions between the views of non-Hispanic White and Asian Indian adults on end-of-life decision-making, as well as to elicit themes that were similar as well as different in the two cultures and age

groups. The reasons for life-sustaining treatment preferences and choice of decision-maker offered in response to the open-ended questions on the questionnaire were recorded for all participants and tabulated. A total of 61 younger participants and 57 older participants provided reasons for at least one scenario with 60 younger adults and 55 older participants providing responses for both the head injury and lymphoma scenarios.

Four younger and three older adults participated in the interview. The semi-structured interview schedule used with the Asian sample was used as a guide to the interviews with the non-Hispanic White participants. The interviews and the open-ended responses clarified the reasons for the specific preference for life-sustaining treatment and the choice of autonomous versus surrogate decision-maker. The results of these analyses for the open-ended responses and interviews are presented together as they relate to the reasons behind the choice of treatment or decline of treatment, selection of oneself or a surrogate decision-maker, by age group. In addition, similarities and differences between older and younger adult participants are also presented. Finally, the views of the non-Hispanic White interviewees are compared with those of the Asian Indian interviewees that were reported in Chapter IV.

Older Adults' Themes

Quality of life. The need to maintain a good quality of life was a major theme in the open-ended responses and interviews. Interviewees maintained that if the quality of life was very poor as suggested by the scenarios as well as the treatment conditions, they did not want to consider the use of life-extending treatments. This

was emphasized by a 63 year old man, "If I am going to be lying on the bed in the hospital room with my children and wife visiting only once a day, I don't want any procedure that would force me to be in that state." A 74 year old woman interviewee had the same concern, asking, "people at our age and especially with that kind of a condition, shouldn't even think twice about making these decisions. What is there to live for when you cannot do anything by yourself?" These views were also endorsed by a 77 year old male, "You know all the importance we give to quality of life. It is true. There is nothing like it." The loss of quality of life and consequently independence was an important concern to this 74 year old woman who said:

Driving is very very important to me. I go everywhere myself. I love to go grocery shopping and I have a friend that I visit almost three or four times a week. We discuss recipes and the shows on television, but if I was in a situation where I was not able to do these things, life would almost be unbearable for me. I think it would be so much better to have a peaceful death and not continue to hang around with the hope that I will be able to do those things again when it is obvious that I won't, when the doctor has already told you.

Burden. Older adults who refused life-sustaining treatments as well as the only interviewee who wanted to use treatment to extend life were concerned about being a burden to others. This theme was elicited in both open-ended questions as well as the interviews. Older participants declined life-sustaining treatments and chose autonomous decision-making in order spare family members from the multiple

stresses of caregiving and decision-making. A 74 year old woman interviewee said, "Like I said, I enjoy going out and meeting my friends. So I am independent and my daughter just checks in on me over the phone. Not any more, if I was bedridden...... She has her own life. She loves me of course, but think of how much burdened she would be. A mother cannot do that to her child." Concern for a spouse, specifically, was an important sub-theme. Many older participants opined that their spouses would be in a constant state of stress if life-extending treatments were used or if they had to make decisions about withdrawing life-support. As a 77 year old male said, "My wife depends on me for a lot of things. If I was unable, my son would jump in. But I don't think she would be able to handle the daily stress of seeing me in the hospital."

Other respondents indicated that the desire to live outweighed their concerns about causing stress to others. This is illustrated in the responses of a 63 year old woman who chose to extend life:

> I would want to live for some time longer, of course. But I also think of what it would do to my husband. It will be too much for him to handle by himself. I hope we will get the strength to make the right decision when it is necessary. We have discussed this before and have everything planned, but I know it is not going to be easy for him.

Need for control. Making the decision by themselves gave participants a sense of control over a situation that they could not solve. As a 77 year old male said, "I have to go with what the doctors say about my diagnosis. But at least the decision to use these kinds of treatments will be mine." This was corroborated by both the female

interviewees: "I don't want anyone else to decide what has to be done for me. I am a control freak and want to make decisions for myself" (63 year old woman) and "My strength is in being independent even at this age. My daughter respects that and she knows I want to be that way. I think she would agree that it is my decision and I need to make this myself." (74 year old woman).

Collective decision-making. Older participants often advocated a collaborative approach to decision-making. Some responses to the open-ended interviews suggested that even if the ultimate decision was made by the individual themselves, options would be discussed with family members. Two interviewees suggested that decision-making needed to be done in consultation with family members and sometimes medical professionals. As a 63 year old woman stated, "We did sit down together when we were writing the power of attorney document. I didn't want anything to be a surprise for the kids and I wanted to hear their opinions too. I didn't want it to be a decision that mom made without even telling us…..we are a family and I think it is important we make the decision together as a family." This theme of family involvement was further described by a 77 year old man, "Though we have everything documented, I know that if such a point comes, we will discuss this to death and we will also have to listen to what our doctor says."

Strength from religion. Religion was an important theme elicited only in the interviews. The role of faith was an important factor in decision-making for two of the participants. A 63 year old woman interviewee talked about deriving emotional strength from religion "I think I would derive comfort from my faith, if I were to hear

that I was suffering from a cancer or something like that. That is what my father did and we believe in faith and the strength of prayer as a family." Similarly, a 77 year old man said, "Yes, I believe in God's powers and I will derive strength and grace to deal with my situation from that." This theme was also emphasized by the 74 year old woman interviewee:

I am involved in a lot of church activities. I think of my age sometimes and at home when I look at R's pictures and our lives together and think of all the fun times we had. But then I realize it is all up to Him and He will give me the courage. Prayer helps a lot you know.

Science versus religion. The conflict between religion and science was another major theme alluded to by the interviewees. However, there were diverse points of view within the same theme. A 63 year old woman said, "I am not sure what religion or my faith says in particular about making these decisions. I know that life is precious and a gift. So, maybe if I am urged to make a decision, it is a conflict. I don't know," while a 77 year old man stated, "The media covers these issues so much that you can't help thinking about it. What would your religion say about stem cell research etc etc. I think it is not wise to get invested in the whole science versus religion issue. Better to think about what is good for you."

Table 34 presents a summary of the major themes of the open-ended responses and interviews for older adults.

Table 34

Summary of Open-ended Responses and Interview Themes for Older Adults

Theme	Example	Theme elicited in interview or open-ended response
1. Quality of life	I cannot bear not to do the things I do.	Both
2. Burden	My spouse cannot handle the stress.	Both
3. Need for control	I am in charge of my own body.	Both
4. Collective decision-making	We will talk about what is right for us.	Both
5. Strength from religion	It is a comfort during times like these.	Only interviews
6. Science versus religion	They don't always advocate the same thing.	Only interviews

Younger Adults' Themes

Autonomous decision-making. Younger adults indicated that it was very important to make the decision about life-sustaining preferences by themselves. This theme was echoed in the reasons for declining life-sustaining preferences as well, where participants indicated that declining treatment provided a sense of control. A 35 year old man elaborated on this theme saying, "I think that there is nothing to even think about this. My wife would make the decision for herself and I would for me." A 20 year old woman on the other hand, talked about the difficulties associated with these decisions, "I don't know. It is very difficult to think about these things. I would ask my parents and my sister, but the final decision would have to be mine." This was reiterated by other participants including a 32 year old woman, "of course, I am the decision-maker, if you want to call it that" and a 19 year old man, "No way, someone

else is telling me to keep my body going. I don't want it to and I want to make that decision."

Quality of life. The loss of quality of life with the use of life-sustaining treatments was a recurrent theme with the younger adult participants. A 19 year old man pointed out that the thought of being inactive propelled his declining life-sustaining treatments, "Lying on a bed in a hospital all day. I think that is the main reason for not choosing to extend life." A 20 year old woman had similar views, "If I knew that everything was going to work and get back to my life, I would attempt to do something. But not when I am going to be in this stage". The stress on the family because of poor quality of life was noted by a 35 year old male:

> I have two young kids and my wife will have to take care of the three of us if I am in such a state. I mean not literally take care, since I will be in a hospital. With little or no hope for survival, and two toddlers, it is just not doable.

Advances in research. Interviewees' choices of life-sustaining treatment were affected by the knowledge that in the future, technological advancements and research might help in making these decisions. A 19 year old man thought about these issues, "You know what, I have a great life ahead and I am not going to worry too much about all these things. For all you know biotech research is going to be really advanced when I am in a position to need it." A 32 year old woman had similar perspectives, "Isn't there tons of research in this area now? With cancer treatment and everything. They should find a cure soon. But in the mean time, I guess we have to live with these kinds of decision-making and worrying about it."

Lack of experience. The younger adults indicated that not having faced these situations before affected their perceptions of decision-making. Responses to the open-ended questions revealed this theme in that younger adults indicated that they were not sure how to make these decisions. As a 20 year old woman said, "I have not had a situation like this before. So, I don't know what others have done. My grandparents are healthy and I have not paid much attention when my mother discusses with my aunt. Maybe now I will." A 32 year old woman said, "My parents do not have terrible physical problems now. I ask them about their health and everything, but that is about it. I wouldn't say I have any experience with making or hearing about these kinds of decisions."

Other recurrent themes that were seen in the open-ended responses and not in the interviews included: (1) not willing to die, as reported by older and younger participants as a reason for accepting life-extending treatments, (2) the reasoning that those who bear the burden of caregiving have the right to decide appropriate end-of-life decisions and (3) younger adults' views that parents should have decision-making capabilities.

Table 35 presents a summary of the major themes of the open-ended responses and interviews for younger adults.

Table 35

Summary of Open-ended Responses and Interview Themes for Younger Adults

Theme	Example	Theme elicited in interview or open-ended response
1. Autonomy	I should have the right to decide about my life.	Both
2. Quality of life	I do not want to live in such a sorry state.	Both
3. Lack of experiences	I have never thought about this before.	Both
4. Advances in research	Cancer will be cured someday.	Only interviews
5. Not willing to die	I don't think I have lived enough.	Only open-ended responses
6. Caregivers and parents should make decisions	If my parents are going to be doing all the work, then they get to decide.	Only open-ended responses

Comparison of non-Hispanic White younger and older adults' themes

Younger and older adult non-Hispanic White interviewees endorsed quality of life and burden as significant factors affecting end-of-life decision-making. The need to control decisions and autonomy was also reported by both age groups. While younger adult participants talked about advances in research and lack of experience with such decisions, older adults raised the themes of collective decision-making and the gaps between science and religion. Older adults' derived strength from their faith which was unique to this age group.

Comparability with the Asian Indian sample

Older adults in both the non-Hispanic White and Asian Indian samples indicated that quality of life and fear of being a burden to family members were

important considerations in the choice of treatment preferences. Likewise, younger adults in both samples were similar in their endorsement of sparing family members from stress and refusal to live in a dependent state. Older adults in both samples did not want to lose control over decision-making. Older adults also indicated a fear that surrogates would not make the right decision as a reason for choosing autonomous decision-making. An important distinction emerged in the concept of control for the younger adults in both ethnic groups. Asian Indian younger adults' indicated a need for control in the decision-making process, whereas non-Hispanic White younger adults were concerned about ownership of the body. Both groups of younger adults wanted to spare family members from burden.

Quality of life and burden to others were significant themes for older adults, irrespective of ethnicity. Older adults in the non-Hispanic White sample indicated that decision-making in consultation with family members was important. Asian Indian older adults agreed with the concept of joint decision-making, but placed emphasis on autonomy. Both groups talked about deriving strength from religion. While the non-Hispanic White older adults talked about the separation between science and religion, Asian Indian adults wanted to keep religion different from end-of-life decisions. The most significant difference in the themes of the two ethnic groups, especially for the older adult participants was the theme of culture and religion. For Asian Indian interviewees, Hindu philosophy was integral to their experience of understanding end-of-life decision-making, but was very distinct when it related to specific rituals and decisions. Older non-Hispanic Whites did not draw these distinctions between the

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practice and beliefs of religion, but derived emotional strength from it. It was also evident in the interviews, that the Asian Indian sample had a conscious approach to religion and culture and awareness of the role of Hinduism in their lives that was unique to this ethnic group. Contrasting religious beliefs emerged in the interviews as the beliefs relate to the decision to accept or refuse treatment. For the Asian Indian interviewees, declining treatment fit with Hindu philosophy but for at least one non-Hispanic White interviewee not accepting treatment conflicted with the Christian belief in the value of life.

Autonomy in decision-making and the futility of treatment were recurring themes for younger adults in both samples. Younger adults in the Asian Indian sample also cited the importance of religion in their lives, but talked about the need to differentiate blind beliefs from practical health-related decision-making. Asian Indians also discussed their integration within Western culture and about intergenerational differences from their parents, suggesting that their cultural values were evolving to be more similar to that of non-Hispanic Whites depending on circumstances. Younger non-Hispanic White adults on the other hand, professed hope in science and advancement in treating terminal illnesses as a reason to accept treatment or avoid making such decision. They also openly acknowledged their lack of knowledge and experience with end-of-life decision-making, which Asian Indian younger participants did not.

Summary of Supplemental Analyses

Results of the statistical analyses provided little support for the hypotheses regarding age differences in preferences for life-sustaining treatments and the choice of autonomous versus surrogate decision-making. The hypothesis regarding age differences in choice of treatment preferences were not supported in either the head injury or the lymphoma scenario. Age effects for the choice of decision-maker were seen only in the lymphoma scenario. Participants from both age groups indicated that they did not want life-sustaining treatments and that they preferred to make those decisions themselves.

At the same time, results were suggestive of cultural effects consistent with the hypotheses, although not always in the direction predicted. Non-Hispanic Whites were more likely to choose surrogate decision-makers which was contrary to the hypothesis on ethnic differences. Only the hypothesis that those who preferred surrogate decision-making would select family members over medical professionals received unequivocal support.

Ethnicity effects were supported by the results of the open-ended responses and interviews, which suggest that religion and culture were interpreted differently by the non-Hispanic White and Asian Indian Hindu participants. The findings of the supplementary analyses along with the qualitative results indicate that although there are similarities in both ethnic groups in choice of treatment preferences and decision-makers, individual cultures do play a role in decision-making. The degree of significance accorded to cultural and religious background differentiated the two

groups of participants, with Asian Indians' themes signifying their awareness of these issues more so than their age group peers. The ethnic groups were similar in their perception of the importance of quality of life and burden to family members as determinants for their acceptance or refusal of life-sustaining treatment and selection of decision-maker.

CHAPTER VI: DISCUSSION

End-of-life decision-making is a complex process because of its fluid and developmental nature. This study looked at the effects of age and culture on decision-making choices in a sample of 100 younger and 100 older Asian Indian Hindus in the Midwest, within the framework of socioemotional selectivity theory. A binary sequential logistic regression model was applied to study age differences, effects of Western and Indian acculturation and Hindu end-of-life values on the choices of life-sustaining treatment and choice of decision-maker. Interviews were used to supplement the results from the quantitative analyses.

The findings for the hypotheses predicting age effects for life-sustaining treatment preferences and decision-maker choices based on the tenets of socioemotional selectivity theory showed an interesting trend in the refusal to prolong life with a terminal illness and in the choice of decision-maker. For the Asian Indian sample, older adults' refusal of life-extending treatments was consistent with SST, as was younger participants' preference for autonomous decision-making. However, contrary to expectations, older and younger participants did not differ in their choice of treatments or decision-maker. The cultural variables accounted for more variance in these choices than did participant age, but the pattern of results did not always conform to the predictions about the role of Asian Indian culture in decision-making. Qualitative analyses provided insight into the cultural differences in decision-making.

To explore further the lack of age differences and the role of ethnicity, supplemental data was collected from a sample of 64 younger and 59 older non-

Hispanic Whites. Again, age effects did not emerge, but ethnicity had a significant influence on the preferences for life-sustaining treatment as well as choice of decision-maker in both scenarios.

This chapter reflects on these results (1) as they relate to the predictions of socioemotional selectivity theory and its implications for similarities and differences in the Asian Indian and non-Hispanic White samples, (2) the role of culture, and (3) other factors such as education and health status contributing to end-of-life decisions. In addition, the chapter addresses strengths and limitations of this study and outlines directions for future research.

Socioemotional Selectivity Theory: The Framework and its Implications

The findings of this study are examined within the context of socioemotional selectivity theory, first to discuss the preferences for life-sustaining treatments and subsequently, the choice of decision-maker.

Age and Preferences for Life-sustaining Treatments

Most previous research has indicated that older adults are less likely to choose life-sustaining treatments than are younger adults (Cooper et al., 2001; Triplett et al., 2008). A similar pattern was predicted for this study, but results did not fully support that prediction. Instead, there were no significant differences between the age groups in choosing life-sustaining treatments, both in the Asian Indian Hindu and non-Hispanic White sample. The overwhelming majority of both older and younger participants in the two ethnic groups did not want to use artificial means to extend life when faced with a prospective terminal illness. This indicates that there is

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considerable agreement between cultures on the refusal to use life-sustaining treatment.

Despite the lack of support for age differences, a key postulate of socioemotional selectivity theory (Carstensen, 1998) was supported. Specifically, the results showing the importance placed on quality of life in selecting treatments are consistent with the bias towards positive emotional experiences on the part of older individuals at the heart of SST (Lockenhoff & Carstensen, 2004, 2007). Older participants tended to refuse life-sustaining treatments that would have an impact on quality of life, as has been documented in previous research (Coppola et al., 1999; Decker & Reed, 2005; Heyland et al, 2000).

One of the major themes elicited from the interviews revealed the importance placed on quality of life issues by older participants. They emphasized that choosing life-sustaining treatments did not mean being able to lead a normal life and this had an impact on the decision to refuse treatment. Another reason offered by older participants for refusing treatment supports the prediction in SST that older individuals' awareness of their position in the lifespan underlies their preference for positive emotional experiences (Carstensen, 1998). They mentioned "a sense of having lived a long life" as one of the reasons for refusing life-sustaining treatments. Such comments indicate that they were cognizant of the relationship between their age and proximity to death, and saw that as a basis for refusing treatment when facing terminal illness.

On the other hand, the corollary from SST is that younger adults should choose life-sustaining treatments given their age and the expectation of a long life. This was not supported by the results of this study: younger and older participants were equally likely to refuse treatment. The shortened time perspective used in the health scenarios to emphasize the terminal nature of the illness may have influenced the younger participants in this study in their treatment decisions. This is corroborated by socioemotional selectivity research findings that younger adults when faced with terminal illness and therefore a shorter lifespan respond like older adults (Frederickson & Carstensen, 1990). This may lead to the decision to forego life-sustaining treatments. This implies that terminal illness situations may reduce age group differences. Carstensen and colleagues (1999) also suggest that when time is seen as limited, individuals try to maximize the quality of time left, which may have led the participants in this study to refuse potentially distressing life-sustaining treatments.

The operationalization of terminal illness in this study versus other studies assessing end-of-life decision-making must be acknowledged as a possible explanation for the lack of age differences. Malloy, Wigton, Meeske and Tape (1992) have suggested that the language used in presenting terminal illness conditions may affect the choice of life-support, with positive descriptions leading to increased acceptance of life-sustaining treatments. The current study emphasized the short time left for the individual, by indicating that the person had only a specific time period left, as well as the seriousness of the terminal illness. Similarly, Cicirelli's (1997)

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study utilized scenarios that placed a high emphasis on the fatal nature of the illness (for example, "a person with a large incurable brain tumor with 6 months to a year to live") and did not find any support for age differences.

On the other hand, Cooper and colleagues (2001) presented their sample of 151 participants aged 18 years and older with seven vignettes, indicating that the prognosis was poor for a parent, child, relative or acquaintance. The vignettes did not offer detailed explanations of the illness. The older the hypothetical person was, the less likely was the decision to extend life. The age of the respondent also was positively correlated with the decision to refuse treatment. Triplett and colleagues (2008) also found that older adults were less likely to indicate preferences for life-sustaining treatments in their advance directives. This study too did not provide enough information to the participants about the symptoms and course of the illness, and only stated that the prognosis was poor. The nature of the operationalization of the terminal condition in these studies, may have elicited the age differences, in contrast to the current study.

Finally, the qualitative differences in the head injury and lymphoma scenarios may have affected the treatment decisions. The lymphoma scenario may have been considered as more terminal since a time frame of six months to a year was specified, in contrast to the more ambiguous time perspective for the head injury scenario. This difference was noted for the younger age group in both cultures, who more often refused treatment in the lymphoma scenario than the head injury scenario. This is consistent with the predictions of socioemotional selectivity theory that younger

people will behave like older people when faced with a shortened time perspective associated with terminal illness (Carstensen, 1993; Frederickson & Carstensen, 1990).

Age and Choice of Decision-maker

Although older Asian Indian participants were expected to choose surrogates more often than younger adults in the Asian Indian sample, results did not support this hypothesis. There were no age differences in the choice of decision-maker for either the head injury or lymphoma scenarios, with a majority of participants across both age groups choosing themselves as the decision-maker. Since making decisions about terminal illness is seen as creating negative emotional experiences, it was predicted that older adults would be more likely to delegate these decisions to others, based on the positivity effect in SST (Carstensen, 1995). This prediction was not supported. This was only true however for the Asian Indian sample and when the sample size was increased by adding the non-Hispanic White sample, age differences emerged, in the lymphoma scenario.

Research shows that as people move closer towards the end of life, either by age or through the process of a terminal illness, conflicting preferences arise between the desire to transfer decision-making power to their family and with the desire to spare the family from burden (Hines et al., 2001; Singer et al., 1999). This may have influenced the responses of older participants in this study as well. It is well documented that family members find withholding or removing life-sustaining treatments a very traumatic and painful experience (Hansen, Archbold & Stewart, 2004; Tilden, Tolle, Nelson, Thompson & Eggman, 1999). The struggle between

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delegating decision-making, and as a result burden to family members, may have motivated the participants to choose autonomous decision-making in the face of the terminal health scenarios presented in this study. This is corroborated by responses from the interviews as well as the reasons for choice of decision-maker mentioned by the participants. For instance a 71 year old woman stated, "I think it would be very difficult for anyone else to make this kind of a decision. I would not want them to go through that."

Considered from this perspective, the selection of autonomous decision-making by older participants is consistent with the tenets of socioemotional selectivity theory that older individuals wish to avoid negative emotions and maximize positive interactions with intimate others (Carstensen, 1998), albeit not in the way originally anticipated. That is, reducing the burden to family by making one's own decisions can serve as a means to avoid negative emotions and optimize social experiences at the end of life. The fear of unwanted medical help may be another factor that motivated individuals to make their own decisions especially since it has been documented that when unsure, receiving medical treatment is the default clinical option (Emanuel et al., 1994). This may be of concern especially to older adults who want to avoid negative emotional experiences as suggested by socioemotional selectivity theory. However, it would also be intuitive for older adults to allow others to make difficult decisions to avoid the process of decision-making. The findings of this study therefore provide an interesting juxtaposition of the older adults' avoidance of personal stress in decision-making versus protection of others from the stress of

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making decisions for them. The lack of age differences may indicate that burden to surrogates is a significant concern across all age groups, which is also corroborated by the qualitative results.

Most couples designate spouses as surrogates if they choose others as decision-makers (Carr & Khodyalov, 2007). This was replicated in the results of the Asian Indian sample in the study although very few people wanted others to make the decisions for them. Spouses may also be the first choice of decision-maker, since caregiving requires proximity to the older person and spouses most often are the only sources of support for the elderly individual. At the same time, children may not be chosen as surrogate decision-makers since discussions about end-of-life decision-making most often occur between spouses (Hopp, 2000). Consequently, the spouse is the individual who most often knows the wishes of the elderly person, either through informal discussion or the use of advance care planning. These findings were also corroborated by the results of the combined sample with both ethnic groups choosing family members, over medical professionals as surrogate decision-makers, suggesting that family influences in the process of decision-making are strong, and are consistent with previous research in this area.

Summary and Implications

The study examined the application and replicability of socioemotional selectivity theory in the Asian Indian Hindu population. Results of analyses from the Asian Indian and non-Hispanic White samples did not support the age differences predicted by socioemotional selectivity theory. However, this may be indicative of

the nature of the study, focusing on end-of-life decisions, which have been shown to elicit similar responses from older individuals and terminally ill younger adults (Carstensen, 1998). The findings in this study emphasize the need to further examine the decision-making process within socioemotional selectivity theory, primarily because the findings do confirm the bias towards positive experiences in terms of refusal of treatment and sparing burden to decision-makers.

Although the results were not fully consistent with hypotheses regarding age differences, the basic premise of socioemotional selectivity theory that allows for the inclusion of multiple individual, familial and cultural variables was upheld. Most studies on socioemotional selectivity (Carstensen, 1994; Lockenhoff & Carstensen, 2004) and life-sustaining treatment preferences have less specific operationalizations of the terminal illness condition than was used in this study. A final factor to consider in interpreting the lack of age differences is that younger adults in the SST studies (Carstensen, 1998; Lockenhoff & Carstensen, 2004) were primarily college-age students, whereas the younger adults in both the Asian Indian and non-Hispanic samples were older.

Role of Culture

The majority of the Asian Indian sample decided against the use of life-sustaining treatments, which supported the hypotheses on cultural effects for this group. This supports the findings of Rao and colleagues (2008) who found that Asian Indian older adults often refuse life-sustaining treatments. However, the cultural predictors of Western acculturation, Indian acculturation and Hindu end-of-life values

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did not explain the choices of treatment preferences made by the participants. This was contrary to earlier research findings that Hindu beliefs were important at the time of death (Doorenbos, 2003; Rao et al., 2008). This may be indicative of methodological limitations of these predictors in assessing cultural values. The distinction between the value systems of Hinduism as applied to everyday life and rituals and practices, as portrayed in the interviews may be another significant factor.

On the other hand, the findings in this study are in line with the basic tenets of Hinduism which suggests acceptance of a terminal illness as part of life (Miltiades, 2002). But the failure of the participants in the study to endorse Hindu end-of-life values suggests that this may not be an adequate explanation. It is not clear how Hindu adults differentiate between religion and culture, since Hindu religion is in itself considered a part of Indian culture (Alagiyakrishnan & Chopra, 2001), and certain aspects of religion pertaining to acceptance of hardships may take precedence over other aspects like endorsement of Hindu end-of-life values. The non-significant findings for acculturation and Hindu end-of-life values suggest that there may be other cultural indicators that drive the ethnic differences in the choice of treatment preferences.

Analyses of the supplemental data provided additional information on cultural effects and confirmed the hypothesis that the choice to accept or decline life-sustaining treatment was determined to a certain extent by ethnic background. The differences between Asian Indian and non-Hispanic White groups on choice of treatment preference was in the direction of the predicted hypothesis. Non-Hispanic

Whites were found to be more likely to choose life-sustaining treatments, in comparison to Asian Indians, irrespective of the effects of age. It implies that there are cultural differences leading to the choice of treatment preferences. This is line with previous research findings that indicate that ethnicity is a significant predictor of treatment preferences (Borum et al., 2000; Garrett et al., 1993). Both ethnic groups emphasized that religion helped to relieve the stress of decision-making, which is consistent with previous research (Burdette et al., 2003; McGrath, 2003). However, Asian Indian Hindus believed that religious factors must not intervene with choice of treatment preference. The lack of specific guidelines about the end-of-life in Hinduism, (Deshpande et al., 2005) may have influenced these beliefs.

The Asian Indian participants endorsed the autonomous model of decision-making as opposed to more collective methods that were presupposed due to their cultural backgrounds. The Asian Indian participants were relatively high on scores of Western acculturation, especially the older adults who had lived longer in the United States than the younger adults.

Although acculturation may account for Asian Indian participants' choice to make end-of-life decisions themselves, a practical explanation may also apply. Previous research shows that one of the most significant barriers to designating surrogate decision-makers is the lack of availability of such a surrogate (Morrison et al., 2001). For Asian Indians, who are considered to be part of a collective society, autonomous decision-making could be considered a default option in the absence of extended families. It has been suggested that members of certain ethnic groups which

value group decision-making may not designate family members as surrogates (Morrison et al, 2001). This is due to the concern that other important individuals may not be allowed to participate in decision-making if a single person is designated a surrogate. Though the study by Morrison and colleagues (2001) was based on a Hispanic population, social and community values are similar in the Asian Indian community and may have an effect on their choice of decision-maker.

Autonomous decision-making and disclosure of diagnosis is often discouraged in family-oriented societies (Koenig & Gates-Williams, 1995). However the findings of this study indicate that autonomous decision-making is highly valued by the Asian Indian participants. Use of surrogates in decision-making and delegating of critical decisions may be seen as impossible in Western settings by Asian Indian individuals. This may also have driven the nature of the results in the supplemental analyses, which indicate that more Asian Indian adults prefer autonomous decision-making than non-Hispanic Whites. This is contrary to the hypotheses that collective cultures prefer delegation of decisions to significant family members. However this may also indicate that there are no such family members available to serve as surrogates, as has been discussed.

Another factor to consider is the nature of the Asian Indian sample in this study, whose move to the United States away from extended families and cultural backgrounds in itself signifies autonomous decision-making processes. The Western model of ethics in medicine considers the principle of autonomy as integral to the decision-making process (Ersek et al., 1998). Since the participants in the Indian

sample were moderately high on Western acculturation, they might have considered autonomy as important in end-of-life decision-making as well. The comparison of the Asian Indian and non-Hispanic White groups indicate that there are mostly no age differences in both ethnic groups on choice of decision-makers, with younger and older adults preferring to make their own decisions. This is consistent with the autonomous decision-making associated with North American culture (Candib, 2002).

Summary and Implications

Asian Indians were less likely to choose life-sustaining treatments than Non-Hispanic Whites, as predicted in the hypotheses. This effect was more pronounced for the older adult participants. Autonomy in decision-making and quality of life was important to both cultures. However, it is also important to note that important cultural differences in terms of the choice of surrogates with non-Hispanic Whites being more likely to delegate decision-making. Differences also emerged in the qualitative analyses on the role of religion in health related decisions, especially with the Asian Indian sample drawing a distinction between the values and rituals in Hindu culture. Overall, the results supported the hypotheses regarding the role of culture in the choice of life-sustaining treatment and decision-maker, though not always in the direction predicted.

Other Factors Influencing Treatment Preferences and Decision-maker Choices

Other possible explanations for the tendency of participants to refuse life-sustaining treatment can be found in research on the effects of health status and education on treatment choices. The respondents in this sample were all in good

health, and there is evidence that healthy people may be more likely to refuse life-sustaining treatments than those with poorer health (Winter & Parker, 2007). As suggested by Kostopoulou (2006), individuals use their current health status as a reference point for future decision-making, which might have affected their decision to refuse life-sustaining treatment. The terminal nature of the scenarios in the study is in contrast to the current health status of the participants influencing their decision to refuse life-sustaining treatments.

Education has been associated with choice of life-sustaining treatment in that those with higher years of education are less likely to choose aggressive types of treatment (Cicirelli, 1997; Mutran, Danis, Bratton, Sudha & Hanson, 1997). Participants in the study were all well-educated and healthy and may not be typical of all Asian Indian Hindus. However the overall knowledge of advance directives is low in the Asian Indian population (Doorenbos, 2003) and the effect of this lack of knowledge may have played a role in the refusal of treatment. Similarly, non-Hispanic Whites in the sample were also healthy and well-educated, and were more likely to refuse than to choose life-sustaining treatments. Education has also been associated with control in decision-making processes and highly educated individuals often prefer to make decisions about their own health care (Mirowsky & Ross, 1998). Although participants in the study did not have professional medical training, most of them were highly educated and this could have an impact on choosing self as decision-maker.

Another important factor to consider is the change in decisions about the end-of-life over time (Danis, Garrett, Harris & Patrick, 1994). Younger Asian Indian adult participants in this study, especially those who have not lived in the United States for a long time as well as those who do not have knowledge of the uses and purposes of advance care planning, may take a different approach to decision-making over time. This may also be true for the non-Hispanic White younger adults, who were less knowledgeable on advance care procedures, in comparison to their older adult counterparts. As noted in the qualitative analyses, younger adults may have found it difficult to relate to hypothetical scenarios and used their current health status as a point of reference for future decision-making. Likewise, younger adults expressed a hope for the future and the emergence of research that would deal with terminal disease conditions suggesting that they may have a long time-perspective.

Strengths of the Study and Implications

The present study adds to the scant literature on end-of-life decision-making of Asian Indian Hindus. The findings suggest that previous studies on this population have not captured the complexity of the Hindu value system in explaining decision-making processes. The emergence of the clear distinction between the practice and philosophy of Hinduism is one of the salient findings of this study, along with the need for very precise operationalizations of culture.

Only three previous studies have specifically addressed end-of-life decision-making in Asian Indians (Doorenbos, 2003; Doorenbos & Nies, 2003; Rao et al., 2008). This study advances knowledge of earlier research by suggesting that Asian

Indians are more aware of advance care planning than indicated in that research. Many of the older adults in this sample had discussed their end-of-life wishes with their spouses and were aware of the use of advance directives and durable powers of attorney for health care. This knowledge may have affected their choice of treatment and decision-maker. The previous studies also used a more simplistic conceptualization of Hinduism than demonstrated by the results of this study. For example, Doorenbos (2003) and Doorenbos and Nies (2003) suggest that Hindu end-of-life practices are important to individuals with terminal illness. This study, on the contrary suggests that the Hindu values are a part of the decision-making process without emphasis on rituals and religious beliefs. The interview data further shows that although religion offers emotional support to the individual, it does not always lead to a specific type of decision.

The ecological validity of previous research on end-of-life decision-making are challenged by the results of this study. Studies that used health scenarios (for example, Coppola et al., 1999; Emanuel et al., 1994) did not emphasize the shortened life expectancy and terminal nature of the illness as clearly as the scenarios in this study. This becomes particularly important in light of the differences in preferences for life-sustaining treatments as the end of life grows nearer (Danis et al., 1994).

Using a mixed methods design helped clarify aspects of the decision-making process that might not have been possible with an approach that used a single methodology. The importance of positive emotional experiences as postulated by socioemotional selectivity theory was supported to a certain extent. The predictions

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regarding age differences were not supported, but indicate that there is similarity across cultures in the perception of time with terminal illness. This implies that SST is an adequate framework to explain end-of-life decision-making in terms of the emotional impact, but it may not explain cultural nuances. This points to a need for reconceptualizing the definitions of culture in examining end-of-life decision-making, since such decisions involve more than following prescribed behavioral or affective norms.

The study also demonstrated the need for medical practitioners and other professionals to be aware of the diverse needs of ethnic groups, while at the same time indicating that these needs may not often be in directions expected. Although the findings of the study show that there are similarities in life-sustaining treatment preferences with studies conducted with non-Hispanic Whites, the qualitative data suggests that other aspects of the cultural background may come into play during the actual decision-making process.

The study displays a need for understanding decision-making at the end-of-life within a lifespan perspective, and a need for determining the point at which decision-making needs to occur. Individuals have shown preference to make end-of-life decisions in an optimal state of health due to the fear that the presence of terminal illness may affect their preferences and decision-making capacities (Ditto, Hawkins & Pizarro, 2005). The study underscores the importance of educating different ethnic groups regarding advance care planning. Advance directives may not always enhance patient-physician communication or influence the type of care received (Tilden et al,

1999) but thinking and discussing about end-of-life preferences allows for less stress during the process of decision-making. It is also helpful for surrogates to be aware of and prepare for eventual decision-making experiences.

Limitations

The homogeneity of the Indian sample is a limitation of the study. Highly educated Asian Indian Hindus may not reflect the views of all Asian Indians in the United States. The older participants had lived in the United States far longer than had the younger participants, which may have affected the endorsement of Hindu values as well as Indian and Western acculturation.

The qualitative interviews raised the issue of the hypothetical nature of the terminal illness conditions. Although attempts were made to make the scenarios seem realistic and accurate in portraying terminal illnesses, some younger adults mentioned that hypothetical scenarios may not indicate decisions made in real situations. This may have biased decisions made by the participants and needs to be considered in making conclusions about decision-making preferences. This is similar to views expressed in previous research where individuals' prospective decisions changed from refusing treatment to desiring treatment as the illness progressed (Fried & Bradley, 2003). However it is important to keep in mind that there are ethical issues in conducting research with people at the end-of-life and therefore prospective studies with hypothetical scenarios can provide a framework to understanding process issues in decision-making.

It is necessary to acknowledge the methodological limitations of the measures used in the study. The Hindu Religious Beliefs and Rituals scale may not reflect the actual cultural values of the Asian Indian sample. Culture and religion have been used fairly interchangeably in this study since it has been indicated that Hinduism is a way of life to most Asian Indian Hindus and Hindu practices are integrated into daily life (Alagiyakrishnan & Chopra, 2001). Making this distinction clearer may have elicited a more nuanced view of the cultural effects of decision-making and future studies need to pay attention to this aspect. Although acculturation and Hindu end-of-life values were used as specific indicators of culture, conceptual distinctions between values and attitudes towards decision-making within the context of Hinduism may have made the discussion more relevant.

Suggestions for Future Research

There are several studies that indicate that about 30% of life-sustaining treatment preferences change over time (Carmel & Mutran, 1999; Danis et al., 1994). This indicates a need for longitudinal approach to understanding the process of decision-making. Life circumstances and experiences play an important role in making these decisions along with sociocultural variables. Following a cohort of individuals over a period of time may be one of the best methods of studying treatment preferences. Pairing this with a life-span developmental perspective and including a middle-aged adult group would make the approach more comprehensive. This is especially important in the case of specific ethnic groups, like the Asian Indian sample studied here, which do not have extensive research literature available.

Since it may be difficult to retain a sample for longitudinal studies, presenting scenarios that asks the individual to consider themselves at different developmental periods in life may help to clarify the extent to which preferences for life-sustaining treatments change over time.

This study used a Hindu Religious Beliefs and Rituals scale to assess the strength of end-of-life values in the participants. A more general assessment of adherence to Hinduism in general, without restricting it to end-of-life in particular might have helped to clarify some of these issues. The qualitative interviews threw some light on the effects of the participants' religious background, but were not supported by the qualitative acculturation and end-of-life values, signaling the need for culturally appropriate and methodologically sound assessments. Extending the research to include individuals with more heterogeneity such as Asian Indians from different socioeconomic backgrounds, educational backgrounds and family compositions would throw light on specific cultural contexts as well as within group differences. Extending this research to include Asian Indians of two different religious backgrounds may be more effective in eliciting the specific aspects of Indian culture that affect end-of-life decision-making. For example, end-of-life values that are generalizable to Asian Indian culture and not specific to only Hinduism may elicit a more cohesive view of culture. It would be valuable for researchers to conduct cross-national studies to compare Asian Indians in the United States with Asian Indians living on the Indian subcontinent. This would clarify differences in acculturation and prevalence of Hindu end-of-life values.

Finally cross-cultural studies need to be conducted in order to fully establish differences in culture in end-of-life decision-making. Comparable techniques must be used by matching participants using semantic and metric equivalence (Liang & Jay, 1990). The development of scales that measure the nuances of cultural differences is therefore very important. The participants must be matched across some cultural and demographic characteristics (Van de Vijver & Leung, 1997). Using diverse scenarios over a wide range of severity of illnesses and disease conditions may also clarify whether there are differences in treatment preferences and decision-maker choices and if cultural differences prevail.

Conclusions

The study contributes to the literature on end-of-life decision-making by emphasizing the importance of understanding contextual factors in explaining the effects of culture during terminal illness. It indicates that cultural values may take precedence in certain situations over others and that certain aspects of decision-making are similar across all cultures. For instance, the study finds that autonomy in decision-making is valued highly and that quality of life may be an important indicator of the choice of life-sustaining treatment for Asian Indian Hindus, similar to previous studies in non-Hispanic white populations. The study also emphasizes the need to utilize theoretical frameworks to understand the process of decision-making from a developmental perspective and acknowledges the role of socioemotional selectivity theory in making these decisions. Finally this research demonstrates the varied and complex nature of end-of-life decision-making and shows that a single

model, even one as strong as socioemotional selectivity theory, is unlikely to be

sufficient to account fully for those complexities within cultural contexts.

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APPENDIX A: Questionnaire

End-of-life decision-making

This questionnaire concerns decisions that people are often asked to make at the end of life. It asks you to consider two different aspects of decision-making: (1) choice of treatment under certain health conditions and (2) choice of individuals to make those decisions.

There is no right or wrong answer to any of the questions. We are simply interested in the types of decisions and choices of decision-makers at the end of life.

Part 1: You will read two scenarios and treatment options in the next section. Imagine yourself having the illness and conditions described in each. When you have read the scenario, consider the medical situation, which requires a decision about a treatment option. For each situation you will be asked to indicate whether you would wish to use a treatment option. You will indicate your intention to use the treatment by circling one of the numbers on a 1-5 scale.

Sample Scenario: You have emphysema. You have constant shortness of breath. You are unable to climb stairs or walk more than a few feet. Your medical condition cannot improve. Your condition may get worse very quickly or slowly decline over several years. Your ability to think, reason and remember is unaffected.

Your doctor has indicated that there is a possibility of your developing infections as your illness progresses. Consider your condition as described in the preceding paragraph. If you developed a serious infection like pneumonia, would you want an antibiotic to treat this condition? Circle the number below that indicates your wishes.

Definitely would not want this treatment	Definitely would want this treatment
1………………2……………...3…………………4………………..5	

If you are unsure about your response, please choose one of the numbers between 2 and 4 that most closely reflects your choice.

Part 2: You will then be asked to indicate who you believe should make the decision about whether you will receive the treatment. You will do this by responding to two questions. For example, you will be asked:

Who do you think should make the decision about your receiving this treatment?

Myself ☐

Others ☐ _____

(Please indicate who and this person'(s) relationship to you)

You will also be asked to explain in a few words why you chose a particular decision and person to make the decision.

You may now proceed to reading the actual scenarios and answering the questions. Do not hesitate to ask questions or clarifications at any point. Please proceed to the next page.

Section 1: Treatment and decision-maker preferences

Please read each of the two scenarios and answer the questions that follow.

Scenario 1: You are traveling in a car with a friend or family member who is driving the car. A drunken driver does not stop at a red light and hits the car on the side where you are seated. You sustain a severe head injury, which leads to a moderately severe stroke. One arm and leg are paralyzed. You have trouble speaking clearly but can write and understand when others speak. You rely on others for help with eating, dressing, bathing and using the toilet. In the opinion of your doctor, you have no chance of improvement and you are at high risk for another fatal stroke at any time.

Your doctor has indicated that there is likelihood that you will need artificial breathing support over time. Artificial breathing means the doctor puts a tube in your windpipe. Then a machine breathes for you through the tube. People on artificial breathing support cannot talk or take food or medicines by mouth. The length of time on the breathing machine varies from person to person and may range from a few hours to indefinitely. Without this intervention, one would usually die in a few hours to a day. Consider your condition as described in the preceding paragraph. If you stopped breathing, would you want to be on artificial breathing support? Circle the number below that indicates your wishes.

Definitely would not want this treatment	Definitely would want this treatment
1…………………….2………………….....3……………………..4……...………...5	

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Why did you make the above decision? (Please explain in a few words):

1. **Who do you think should make the decision about your receiving this treatment?**
   Indicate your opinion by marking an X next to one of the options below.

   Myself ☐

   Others ☐ _____
   (Please indicate who and this person'(s) relationship to you)

2. **Why did you choose yourself or another person(s) to make this decision? Please explain in few words.**

Scenario 2: You have lymphoma (blood cancer), which is in the final stages. You are tired and weak, requiring some help with household chores, dressing and using the toilet. Your thinking and memory are unaffected. You have constant pain that is currently controlled by medication. You also have chemotherapy sessions every six weeks. Chemotherapy makes you nauseous and weak and these side-effects last about one week after each treatment. In the opinion of your doctor, you have no chance of recovery and may have less than a year to live.

Your doctor has indicated that there is a likelihood that you will lose the ability to eat and drink through the mouth over time. Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. The food goes through a feeding tube. Usually the feeding tube goes through the skin into the stomach. Without this treatment, people usually die within 7-10 days. Consider your condition as described in the preceding paragraph. If your condition becomes such that you lose the ability to take in food or water by mouth, would you want artificial feeding and fluids? Circle the number below that indicates your wishes.

Definitely would not want this treatment				Definitely would want this treatment
1…………….……2………………....3……………………4……………....5				

Why did you make the above decision? (Please explain in a few words):

1. **Who do you think should make the decision about your receiving this treatment?**
   Indicate your opinion by marking an X next to one of the options below.

   Myself   ☐

   Others   ☐   _____
   (Please indicate who and this person's(s) relationship to you)

2. **Why did you choose yourself or another person(s) to make this decision? Please explain in few words.**

Section 2: Culture scale

There are differences in the degree to which people of different ethnicities assimilate into their host culture. Think about your culture and your adaptation to American (Western) culture. We are interested in your opinions about these cultural issues (Circle a number)

	Culture	Not at all Extremely often
1	I speak an Indian language.	1………..2………3……….4………5
2	I speak English.	1………..2………3……….4………5
3	I enjoy speaking an Indian language.	1………..2………3……….4………5
4	I associate with Caucasians.	1………..2………3……….4………5
5	I associate with Indian/Indian Americans.	1………..2………3……….4………5
6	I enjoy listening to Indian language music.	1………..2………3……….4………5
7	I enjoy listening to English language music.	1………..2………3……….4………5
8	I enjoy Indian language TV.	1………..2………3……….4……….5
9	I enjoy English language TV.	1………..2………3……….4………5
10	I enjoy English language movies.	1………..2………3……….4………5
11	I enjoy Indian language movies.	1………..2………3……….4………5
12	I enjoy reading in an Indian language.	1………..2………3……….4………5

13	I enjoy reading in the English language.	1………..2………..3………..4………5
14	I write an Indian language (e.g. letters)	1………..2………..3………..4………5
15	I write in the English language (e.g. letters)	1………..2………..3………..4………5
16	My thinking is done in the English language.	1………..2………..3………..4………5
17	My thinking is done in an Indian language.	1………..2………..3………..4………5
18	My contact with India has been	1………..2………..3………..4………5
19	My contact with the United States has been	1………..2………..3………..4………5
20	My father identified or identifies himself as Indian.	1………..2………..3………..4………5
21	My mother identified or identifies herself as Indian.	1………..2………..3………..4………5
22	My friends, while I was growing up were of Indian descent.	1………..2………..3………..4………5
23	My friends, while I was growing up were of Caucasian/European descent.	1………..2………..3………..4………5
24	My family cooks Indian food.	1………..2………..3………..4………5
25	My friends are of Caucasian/European descent.	1………..2………..3………..4………5
26	My friends now are of Indian descent.	1………..2………..3………..4………5
27	I like to identify myself as Caucasian.	1………..2………..3………..4………5
28	I like to identify myself as Indian American.	1………..2………..3………..4………5

29	I like to identify as Indian.	1………..2………..3………..4………5
30	I like to identify myself as an American.	1………..2………..3………..4………5

Section 3: Religious beliefs and rituals

There are differences in individual religious beliefs about how a dying person must be treated at the end of life. Think of your religious tradition and what you believe is important for a dying individual. We are interested in your opinions about those beliefs.

	Beliefs and rituals	Strongly Disagree Strongly Agree
1	It is important to read a holy text (the Bhagavad-Gita, for example) in the presence of the dying person.	1………..2………..3………..4………5
2	It is important to have the body washed by family members.	1………..2………..3………..4………5
3	It is important to have 10 to 14 days of mourning.	1………..2………..3………..4………5
4	It is important to have final rites performed by a male relative.	1………..2………..3………..4………5
5	It is important to have the dying person on the floor at death.	1………..2………..3………..4………5
6	It is important to wail, sob and cry in public at the death of a loved one.	1………..2………..3………..4………5
7	I believe that life and death are in the hands of God.	1………..2………..3………..4………5
8	It is important to have your ashes scattered on the River Ganges.	1………..2………..3………..4………5
9	It is important to have water from the River Ganges and a basil leaf put into your mouth at the time of death.	1………..2………..3………..4………5

10	It is important to have the body cremated or buried within 24 hours.	1………..2………..3………..4………5
11	I believe in reincarnation.	1………..2………..3………..4………5
12	I rely on prayer or invoking spirits, gods or forces to affect change.	1………..2………..3………..4………5
13	I believe in supernatural forces.	1………..2………..3………..4………5
14	I believe that suffering is caused by bad actions or deeds done in this or a past life.	1………..2………..3………..4………5

Section 4: Medical terms

Here are some medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing 4 possible words that could go there appear next to it. I want you to figure out which of those 4 words makes the sentence make sense. When you think you know which one it is, circle the word and go on to the next one. Once you finish this passage, go on to the second one on the next page.

Passage A

Your doctor has sent you to have a

| stomach |
| diabetes |
| stitches |
| germs |

X-ray.

You must have an

| asthma |
| empty |
| incest |
| anemia |

stomach when you come for

| is. |
| am. |
| if. |
| it. |

The X-ray will

| take |
| view |
| talk |
| look |

from 1 to 3

| beds |
| brains |
| hours |
| diets |

to do.

THE DAY BEFORE THE X-RAY

For supper only have a

| little |
| broth |
| attack |
| nausea |

snack of fruit,

| toes |
| throat |
| toast |
| thigh |

and jelly, with coffee or tea.

After

| minute |
| midnight |
| during |
| before |

, you must not

| easy |
| ate |
| drank |
| eat |

anything at

| ill |
| all |
| each |
| any |

until

after you have

| are |
| has |
| had |
| was |

the X-ray.

THE DAY OF THE X-RAY

Do not eat | appointment
walk-in.
breakfast.
clinic.

Do not | drive
drink
dress
dose | even | heart.
breath.
water.
cancer.

If you have any | answers
exercises
tracts
questions | , call the X-ray | department
sprain
pharmacy
toothache | at 616-4500.

PLEASE COMPLETE PASSAGE B

Passage B

I agree to give correct information to | hair
salt
see
ache | if I can receive Medicaid.

I | agree
probe
send
gain | to provide the county information to | hide
risk
discharge
prove | any

statements given in this | emphysema
application
gallbladder
relationship | and hereby

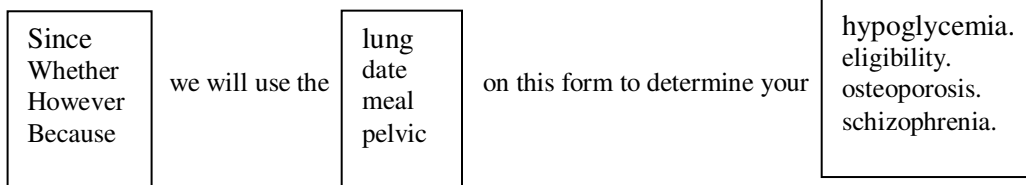give permission to the | inflammation
religion
iron
county | to get such proof.

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I
| investigate |
| entertain |
| understand |
| establish |

that for Medicaid, I must report any

| changes |
| hormone |
| antacids |
| charges |

in

my circumstances within 10

| (three) |
| (one) |
| (five) |
| (ten) |

days of becoming

| award |
| aware |
| away |
| await |

of

the change.

I understand

| thus |
| this |
| that |
| than |

if I DO NOT like the

| marital |
| occupation |
| adult |
| decision |

made on my case,

I have the

| bright |
| left |
| wrong |
| right |

to a fair hearing.

I can

| request |
| refuse |
| fail |
| mend |

a hearing by writing or

| counting |
| calling |
| reading |
| smelling |

the county

where I applied.

If you

| wash |
| want |
| cover |
| tape |

aid for any family

| member |
| history |
| weight |
| seatbelt |

you will have to

| relax |
| break |
| inhale |
| sign |

a different application form.

Since Whether However Because	we will use the	lung date meal pelvic	on this form to determine your	hypoglycemia. eligibility. osteoporosis. schizophrenia.

Section 5: Health scale

The following set of questions will help us understand how you have been feeling over the last few days. Please answer as accurately as possible.

1. In general would you say your health is (Check one)

    Excellent ☐   Very Good ☐   Good ☐   Fair ☐   Poor ☐

2. How much bodily pain have you had during the past four weeks? (Check one)

    None ☐   Very Mild ☐   Mild ☐   Moderate ☐   Severe ☐

3. For how long (if at all) has your health limited you in each of the following activities? (Check one box on each line)

Activity	Limited for more than 3 months	Limited for 3 months or less	Not at all
The kinds or amounts of vigorous activities you can do like lifting heavy objects, running or participating in sports.			
The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling.			
Walking uphill or climbing a few flights of stairs.			
Bending, lifting or stooping.			
Walking one block.			
Eating, bathing, dressing or using the toilet.			

4. Does your health keep you from working at a job, doing work around the house or going to school? (Check one)

    Yes, for more than 3 months ☐   Yes, for 3 months or less ☐   No ☐

5. Have you been unable to do certain kinds or amounts of work, housework or schoolwork because of your health? (Check one)

Yes, for more than 3 months ☐   Yes, for 3 months or less ☐   No ☐

6. For each of the following questions, please check the box for the one answer that comes closest to the way you have been feeling during the past month. (Check one box on each line).

Health in the past month	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1. How much of the time during the past month has your health limited your social activities (like visiting friends or relatives?)						
2. How much of the time during the past month have you been a very nervous person?						
3. During the past month, have you felt downhearted and blue?						
4. During the past month, how much of the time have you been a happy person?						
5. How often during the past month have you felt so down in the dumps that nothing could cheer you up?						

7. Please check the box that best describes whether each of the following statements is true or false for you. (Check one box on each line)

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
1. I am somewhat ill.					
2. I am as healthy as anybody I know.					
3. My health is excellent.					
4. I have been feeling bad lately.					

Section 6: Advance care planning

Please circle **Yes, No** or **Not Sure**

1. Do you know what an advance directive or living will is?

   Yes   No   Not sure

2. Have you completed an advance directive or living will?

   Yes   No   Not sure

3. Do you know what a Durable Power of Attorney for Health Care is?

   Yes   No   Not sure

4. Have you completed a Durable Power of Attorney for Health Care?

   Yes   No   Not sure

5. Have you discussed your wishes regarding end-of-life decisions with anyone?

Yes   No   Not sure

6. Do you know about the different legal end-of-life options available in your state?

    Yes   No   Not sure

Section 7: Additional information

Please provide us with some additional information about yourself.

1. Your age ☐

2. Years of education completed ☐
    (e.g., 8 years = 8th grade, 12 years = high school, 13 years = college freshman etc)

3. Male ☐   Female ☐

4. Your occupation ☐
    If retired, write "Retired" and give your occupation before retirement

5. Current Marital status:

    Never Married ☐   Married ☐   Widowed ☐   Separated ☐
    Divorced ☐   Other ☐

6. Number of children (please write 0 if no children) ☐

7. How long have you lived in the United States (in years)? ☐

THANK YOU VERY MUCH FOR YOUR TIME AND PARTICIPATION IN THIS STUDY.

APPENDIX B: Pilot study 1 – Evaluation

1. *Consider the head injury scenario. Please indicate on the following scales your opinions on the description of the illness and treatments.*

   To what extent did you find the scenario: (Please circle the number closest to your opinion)

   Realistic   1   2   3   4   5   Unrealistic
   Believable   1   2   3   4   5   Unbelievable
   Plausible   1   2   3   4   5   Implausible
   True to life 1   2   3   4   5   Fake

   To what extent do you think the injury will result in:

   Death   1   2   3   4   5   Recovery
   Negative health outcome 1   2   3   4   5   Positive health outcome
   Rapid health decline   1   2   3   4   5   Gradual health decline

2. *Consider the lymphoma scenario. Please indicate on the following scales your opinions on the description of the illness and treatments.*

   To what extent did you find the scenario: (Please circle the number closest to your opinion)

   Realistic   1   2   3   4   5   Unrealistic
   Believable   1   2   3   4   5   Unbelievable
   Plausible   1   2   3   4   5   Implausible
   True to life 1   2   3   4   5   Fake

   To what extent do you think the injury will result in:

   Recovery   1   2   3   4   5   Death
   Positive health outcome 1   2   3   4   5   Negative health outcome
   Gradual health decline   1   2   3   4   5   Rapid health decline

Were the questions on culture: Realistic   1 2 3 4 5   Unrealistic

APPENDIX C: Pilot study 2 – Evaluation

1. HEAD INJURY SCENARIO

To what extent did you find the head injury scenario: (Please circle the number closest to your opinion)

Unrealistic	1	2	3	4	5	Realistic
Unbelievable	1	2	3	4	5	Believable
Fake	1	2	3	4	5	True to life

To what extent do you think the head injury will result in:

Death	1	2	3	4	5	Recovery
Negative health outcome	1	2	3	4	5	Positive health outcome
Rapid health decline	1	2	3	4	5	Gradual health decline

2. LYMPHOMA SCENARIO

To what extent did you find the lymphoma scenario: (Please circle the number closest to your opinion)

Unrealistic	1	2	3	4	5	Realistic
Unbelievable	1	2	3	4	5	Believable
Fake	1	2	3	4	5	True to life

To what extent do you think the lymphoma will result in:

Death	1	2	3	4	5	Recovery
Negative health outcome	1	2	3	4	5	Positive health outcome
Rapid health decline	1	2	3	4	5	Gradual health decline

Were the questions on culture: Unrealistic   1 2 3 4 5   Realistic

APPENDIX D: Recruitment Flyer

PARTICIPATE IN A RESEARCH STUDY

Participants are required for a research study on decision-making at the University of Kansas.

PURPOSE: The purpose of this study is to understand how your culture and religion affect the way you look at medical decisions. This study will be very important in furthering our understanding of these issues in the Asian Indian community which is increasingly becoming an important minority presence in the United States. This study will take only about 20-30 minutes of your time and involves completing a questionnaire at a place of your convenience. All material collected will be kept confidential and no identifying information will be collected.

TO PARTICIPATE: If you are an Asian Indian Hindu between 18 and 35 years old OR 60 years and older and are interested in participating in this study to help in improving our knowledge of the role of religion and culture in decision-making, please contact:

Deepthi Mohankumar
913-768-7024
deepthim@ku.edu

Please also contact us if you know someone else who would be interested in participating.

Faculty advisor: Dr. Mary Lee Hummert
Vice Provost Faculty Development
Professor, Communication Studies
University of Kansas, Lawrence, KS 66045.

APPENDIX E: Interview Schedule

Treatment Preferences

1. Could you tell me a little more about why you made this decision?
2. Have you had any previous experiences with end-of-life decisions? How? When?
3. What are your expectations regarding the treatment about end-of-life?
4. Would you make the same decision if it involved your spouse/parents/children? Why or why not?
5. To what extent has living in the United States influenced your decision?
6. Has/How has your religion influenced your decision?
7. To what extent will/does your faith community support you in making these decisions?

Choice of decision-maker

1. Could you tell me a little about why you chose yourself / this person to make the decision for you?
2. Has your cultural background influenced this decision? How?
3. To what extent has living in the United States influenced your decision?
4. Has/How has your religion influenced your decision?
5. To what extent will/does your faith community support you in making these decisions?
6. Who do you think should make the decision for your spouse/parents/children?

Other issues

1. How are end-of-life decisions made in your community/religion/culture generally?
2. Are you aware of the end-of-life options available in the United States? Could you tell me a little about that?
3. Are you aware of the documents dealing with end-of-life preferences? Could you tell me your opinion about such documents?
4. Are you aware of hospice/assisted living/residential care facilities? Could you tell me a little about this?
5. What is your opinion on disclosing/not disclosing diagnoses to family members or others?
6. What is your opinion on disclosing/not disclosing to you, the diagnosis of a terminal illness?
7. What is your opinion on the role medical professionals should play in end-of-life decision-making?
8. What are your expectations regarding end-of-life from your spouse/other family members?

9. What will be important to you when you are dying OR what do you think are the important considerations at the end of a person's life?
10. Have you seen your parents or grandparents deal with these kinds of decisions? Could you tell me a little more about them?
11. What do you think are the generational differences in dealing with these issues? For instances, what differences do you see between yourself and your parents? Yourself and your children?
12. Is there anything about this topic in general that you would like to discuss?