AN EXPLORATION OF END-OF-LIFE DECISION MAKING WITHIN JAPANESE-AMERICAN FAMILIES

By

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ABSTRACT

TITLE: An Exploration of End-of-Life Decision Making within Japanese American Families

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This exploratory study addressed the experience of Japanese Americans (JA) with end-of-life decision making for a recently deceased family member. Given the rapidly aging JA population, increasing numbers of families face decisions about the use of life-sustaining treatments. Qualitative methods including a one-time, semi-structured interview were used to gather data from 16 JA family informants who described their experiences with the death of 22 family members. A grounded theory analysis led to the development of a model of a process that included four dimensions of family understanding. The four dimensions were: awareness of the seriousness of the family members' condition, decision-making about life-sustaining treatment, readiness for impending death, and experience of the dying process; each reflected a continuum from low to high understanding. Aware of Seriousness of Condition included lack of awareness, awareness with recovery, and awareness with no recovery. Decision-Making Process involved a decisional phase with no discussion, implicit knowing, and explicit discussion and an executional phase with others, informants, and deceased family members. Readiness for Impending Death consisted of surprised, ambivalence, and ready. Experience of the Dying Process included regret, prolonged grief, unsolved questions, resolution, and acceptance. The model also reflected the influence of health care providers' involvement and generational differences, based on age cohort rather than immigration group (e.g., Nisei), in adherence to traditional Japanese as well as Western values adapted through acculturation. The experience of most informants in making decisions within the context of the Patient Self-Determination Act was not problematic. The majority reported completion of advance directives by their family members even though these were seldom used in the actual decision making process. Overall, JA families reported experiencing less feelings of burden/responsibility and less conflict within the family than has been reported in previous studies of primarily White Americans, reflective of cultural differences in the decision-making process. The results suggest that nurses and other health care providers can impact the level of understanding within each of the dimensions in culturally sensitive ways and contribute to improving JA experience with end-of-life decision making.

TABLE OF CONTENT

TABLE OF FIGURES

LIST OF TABLES

CHAPTER 1

Introduction

The purpose of this dissertation research is to explore the experience of Japanese Americans with end-of-life decision making for a recently deceased family member, including the process used within the family to make such decisions. Ideally, a peaceful ending of life is "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassel, 1997). Quality end-of-life care depends in part on decision making, including the experience of families in this process and the role health care providers can play in supporting them (Teno, Casey, Welch, & Edgman-Levitan, 2001). However, studies have identified barriers to such a peaceful ending that arise from cultural differences in values, beliefs, and attitudes towards death and end-of-life care among related parties, including processes in decision making (Blackhall et al., 1999; Blackhall, Murphy, Frank, Michel, & Azen, 1995; Braun & Nichols, 1997; Hern, Koenig, Moore, & Marchall, 1998; Kagawa-Singer, 1994; Kagawa-Singer & Blackhall, 2001; Klessing, 1992; Koenig & Gates-Williams, 1995; Krakauer, Crenner, & Fox, 2002; Murphy et al., 1996; Orona, Koenig, & Davis, 1994). Currently, the National Institute of Nursing Research targets research funding toward end-of-life care and disparities in health outcomes in minority populations. This research agenda is crucial because of a continuously increasing aging and diversified population. In addition to responding to health needs, strengthening the research base responds to the awareness of health care providers of these demographic trends and their calls for expanded knowledge and relevant educational programs in these areas, including culturally sensitive approaches to end-of-life care.

Among minority populations, especially Asian Americans, Japanese Americans are one subpopulation increasingly faced with end-of-life care issues since most Japanese immigrated to the United States (U.S.) before World War II (WWII) unlike other groups (e.g., Vietnamese). Japanese Americans are the sixth largest Asian-American subpopulation in the U.S. and account for 800,000 people (Bureau, 2003). Of significance is that the Japanese-American population decreased by 53,000 from 1990 to 2000, in part because of mortality among its aging members (Bureau, 2002, 2003; Perot & Youndelman, 2001). These data further support the need to explain how Japanese Americans address end-of-life care issues within their families.

End-of-life decision making has been affected over the last several decades by changes in health care (e.g., more technological interventions) and the social and legal environment that influences health care decisions. Transformation from a paternalistic physician-centered decision-making model, predominant in much of the 20th century, to an informed or shared decision-making model involves participation of individuals and families in health care decisions (Charles, Gafni, & Whelan, 1999). The Patient Self-Determination Act (PSDA; 1990) is the primary legal bases for rights of individuals to make end-of-life care decisions in the U.S. or to appoint surrogate decision makers. Advance directives (ADs), consisting of living wills and durable power of attorney in health care, and advance care planning (ACP) are symbols of a patient-centered and individual-oriented decision-making model that has grown out of the PSDA in the U.S.

although ACP does include family participation. Central to AD and ACP is the consideration of the individual's wishes about withholding or withdrawing treatment at the end of life consistent with the ethical principle of autonomy (Hyun, 2003; Kuczewski, 2004).

In contrast, recent literature and research suggest that Japanese Americans favor a family-oriented decision-making model instead of an individual-oriented model in making end-of-life care decisions (Bito et al., in-press). This difference may reflect the influence of traditional Japanese cultural values about interdependence, familial obligation and the construal of the self as connected to others (Chan, 2004b; Markus & Kitayama, 1991). Japanese appear to construe self as being connected to others and interdependent in contrast to the view of self as separate from others and independent, a view traditionally held by most Americans and consistent with an emphasis on individual autonomy (Chan, 2004b; Sagara & Pickett, 1998). The construal of the interdependent self relies upon the group as its main point of reference. Others' expectations such as the family members direct proper responses and appropriate behaviors. Obligation as reflected in filial piety is another value central to the interdependent self. Therefore, the use of ADs and ACP which derived from a practice of an individual-oriented decision-making model may be at odds with cultural values of Japanese Americans. As such they may be a source of value conflict among Japanese-American patients and families and health care providers including nurses.

Inquiry into foundations of the cultural differences in decision-making practices has fascinated me for 15 years since I as a Japanese nurse decided to study abroad in the

U.S. I found when I arrived and began my studies that informed consent about treatment with veracity to patients about their illness or health conditions was a common practice in the U.S. as was self-determination of one's own dying process. The notion of the individual's right to make decisions about treatment at the end of their life or when dying was impossible for me to understand. In my country, it was a family matter to decide how a family member would die, in part to relieve the patient of the responsibility for making such decisions or knowing the truth about his/her incurable condition. My initial reaction was to reject the notion of ADs. Then my experience during a home-stay with a Japanese-American family raise questions for me about my own culturally based assumptions as well as the assumptions underpinning the use of ADs in the U.S. and the families' role in this process. I began to wonder how Japanese Americans would decide what to do when their family member faced the end of life given the potential influence of both Japanese and American cultural values on their lives.

Even though attitudes towards ADs among minority populations (e.g., Blackhall et al., 1995, 1999; Doorenbos & Nies, 2003; Eleazer et al., 1996; Murphy et al., 1996) and family perspectives, primarily of White-American subjects in end-of-life decision making (Jacob, 1998; Jeffers, 1998; Meeker, 2004) have been examined, perspectives of minority family such as Japanese Americans based on their actual decision-making experiences during the dying process and death of a family member have not been studied. Processes and outcomes of end-of-life decision making need to be described for the cultural groups comprising the U.S. population to reduce the misunderstandings and distress that arise from differences of values, beliefs, and attitudes among health care providers and patients and families, and to facilitate culturally sensitive care by nurses and other health care providers. Therefore, strengthening the knowledge base about minority family perspectives on end-of-life decision making is needed.

Aims of the Study

Given the cultural differences that may exist in decision making for Japanese Americans and preference for family-oriented rather than individual-centered end-of-life decision making (Bito et al., in-press), and the need for research to strengthen culturally sensitive care, understanding how Japanese-American family members actually reached end-of-life decisions to withhold and/or withdraw life-sustaining treatment for a family member, what they experienced in this process, and how they felt afterwards is warranted. Thus, the aims of this study are to describe: (a) the process that Japanese-American family members used to make end-of-life decisions for their recently deceased family members, including the influence of traditional values among the different generational groups; (b) their experience of making such decisions within the context of The Patient Self-Determination Act (PSDA) and the current U.S. health care system; and (c) their perspectives associated with the decisions after the family member's death, including the meanings that the decision, experience, and family member's death held for them.

CHAPTER 2

Review of the Literature

Overview

Exploration of the decision-making process for life-sustaining treatment at the end of life by Japanese Americans and its contextual factors drew on literature in three areas: the experience of end-of-life decision making in the U.S.; cultural and historical factors that influence the experience of Japanese-American families in decision making about end-of-life care; and research on cultural differences and family involvement in end-of-life decision making.

First, trends in decision making for end-of-life care were explored, including the historical background of and issues related to the PSDA and ACP in the U.S. Related values such as autonomy, individualism, and the independent self were explained. Then, research associated with family perspectives on the use of ADs was reviewed.

Second, the construal of the interdependent self arising from different cultural perspectives and the interrelationship of the self with family and society were examined as were spiritual and religious beliefs that affect the decision-making process in Japanese-American families. Additionally, historical events and cultural influences that have shaped the experiences of successive generations of Japanese Americans in this country were described.

Lastly, research and related literature associated with cultural differences in preferences for and use of ADs by individuals, including the appointment of surrogate decision makers to carry out one's wishes, and family experiences with end-of-life decision making for a family member was reviewed. A summary of the literature review and a rationale of the study were provided at the end.

Experience of End-of-Life Decision Making in the United States

Trends in Decision Making for End-of-Life Care

End of life is defined by the Institute of Medicine as "the phase in life when persons approach death in a trajectory inclusive of their families, friends, caregivers, and communities" (Bookbinder, Rutledge, Donaldson, & Pravikoff, 2002). Death in the U.S. was once accepted as a part of the natural cycle of life and typically happened at home with the dying person surrounded by family. During the last four decades, however, medical care in the U.S. has increasing been characterized by specialization of practice, early disease detection, increasingly complex treatments via surgery and medication, and application of life-sustaining technologies. As a result, health care in the U.S. reinforces a cure-oriented medical model. By 1949, 49.5% of deaths occurred in institutions; the rate increased to 74% in 1980 and was the same in 1992 even though hospice care had received more attention as an option (Field & Cassel, 1997). Thus, death in a hospital or other institution for a person still receiving treatment and care with advanced technologies and surrounded by unfamiliar faces became a common phenomenon. These changes have raised questions for both the public and health care providers about the circumstances under which an end-of-life decision would be made.

Historical background of the Patient Self-Determination Act. As the possibilities for prolonging life increased, questions also arose about the quality of life such approaches afforded. The situation of Karen Quinlan, a young woman in a vegetative but not terminal state, who had been kept alive with a respirator for a year, became a public issue when her parents requested to have the life support withdrawn. The 1976 New Jersey Supreme Court decision supported the parent's request and inspired the public with "the right to die." The court decision came to be the marker for the beginning of change from a physician-driven paternalistic decision-making model to an informed or a shared decision-making model for medical treatment (Charles, Whelan, & Gafni, 1999). The publicity surrounding this case, and the issues which the case highlighted, increased awareness on the part of the American public about the changing nature of medical care, including the prolongation of life through advances in treatment and technology, and the need for their participation in health care decision making about end-of-life care.

In 1983, the President's Commission for the Study for Ethical Problems in Medicine and Biomedical and Behavioral Research issued a report titled "Deciding to Forego Life-Sustaining Treatment" (Beauchamp & Walters, 2003, p. 207). Protecting dignity and independence at the end of life were highlighted. In 1987, another court case of a young woman in a vegetative state came to the forefront of public attention and professional debate. The parents of Nancy Cruzan, then 32 years old, after seven years without improvement in her condition from a motor vehicle accident, asked to withdraw her artificial feeding tube. Cruzan had voiced her desire not to be maintained in a persistent vegetative state, but her wishes were not documented. Contrary to the Karen Quinlan case, the U.S. Supreme Court (1987) refused the request. The majority stated that "its findings rest on a judgment by society that it is better to err in preserving life ... than to err through a decision that leads directly to death" (Beauchamp & Walters, 2003,

p. 114). However, the dissenting justices disagreed, stating that "Nancy Cruzan has a fundamental right to be free of unwanted artificial nutrition and hydration" (Beauchamp & Walters, 2003, p. 114).

Recently (2004-2005), another case attracted tremendous attention from the public because of judicial as well as political involvements in the family conflict. Again, with no documentation of her wishes, Terry Schiavo survived 15 years without improvement from a persistent vegetable state. Her husband and her parents disagreed about ending her life by removing her feeding tube. In a third ruling required by a bill passed by U.S. Congress and signed by the President, both the state and federal supreme courts upheld the previous decisions to remove the feeding tube (i.e., accepting her husband claims about his wife's wishes) and refused to review the case again. The much publicized case reflected different opinions about her mental state and her wishes, conflicts regarding her husband and parents' legal roles as surrogate decision makers, differing religious beliefs, and public opinion about political involvement in a civil issue.

In all three cases, the common issues were: what could be taken as legally binding, clear, and convincing evidence of the patient's wishes; and who had the right to serve as a surrogate decision maker. All three patients were incompetent in the sense that they could not speak for themselves (i.e., indicate their preferences).

The PSDA (1991) based in part on the Quinlan and Cruzan cases, emphasizes the importance of documentation of AD. An AD is a document that expresses one's will about end-of-life care (living will) and appoints a proxy (or surrogate, durable power of attorney for health care, attorney-in-fact, health care agent) to make decisions in case of incompetence. ADs allow individuals to refuse medical treatments, including the use of respirator, dialysis, and antibiotics as well as artificial nutrition and hydration. This law (i.e., PSDA) recognizes the patient's constitutional rights to self-determination.

Evolution of the concept of advance care planning and its issues. The goal of the PSDA is to clarify for patients, families, and health care providers the patient's preferences for end-of-life care and document these in a legally binding way; however, achieving the goals of the PSDA has been difficult. Surveys and studies of patients, families, and health care providers identified problems from the beginning. For example, only 10-30% of research participants surveyed in studies had completed ADs; hence, educational programs were developed for health care providers, patients and families, and the public to advocate implementation of ADs (Emanuel & Emanuel, 1992; Garas & Pantilat, 2001; Neuman & Wade, 1999; Nolan & Bruder, 1997; SUPPORT Investigators, 1995). The largest of these, the $28,000,000 five year and five center SUPPORT study, confirmed barriers to improving end-of-life decision making: (a) lack of communication between physicians and patients, especially physicians' understanding of patients' preference; (b) delay in deciding about a Do Not Resuscitate order and its relatively infrequent use; (c) poor pain management; (d) prolonged time spent in an intensive care unit; and (e) no reduction in use of hospital resources. Over all, these studies determined that focusing on ADs per se would not improve end-of-life care; rather improvement of communication between health care providers and patients and families would increase all parties' satisfaction and help with decision making (Kass-Bartelmes & Hughes, 2003; Teno, Stevens, Spernak, & Lynn, 1998).

ACP describes a more comprehensive approach, one where individuals are encouraged to discuss their ideas of a meaningful life ending with family members and health care providers. ADs and completion of a written document that was the initial focus of end-of-life decision making were reframed as only part of ACP (Teno et al., 1998). The major purpose of ACP is "to set the goals for medical treatment and for social, emotional and spiritual supports in all stages of a person's care from the time they face serious illness or decline until their death" (Field & Cassel, 1997). ACP encourages the public to be aware of health care environments and to think of just-in-case scenarios that might signal the end of their lives and those for whom they care.

The PSDA, AD, and ACP reflect individual autonomy, self-determination, and privacy as cultural values and support their realization. To understand meanings of these values, the terms of individualism and the independent self were briefly explored.

Evolution of Autonomy: Individualism and the Independent Self

The independent self is developed in a society of individualism. The ultimate dignity of the human being is the first core value associated with individualism (Christopher, 1992). An individualistic orientation is most closely identified with societies grounded in Western philosophic traditions.

In early Western culture and societies, each human being was not considered a unique individual with dignity. Until the Renaissance (the 14th to 16th century) and Reformation (the 16th century), "the individual did not exist for his own sake, but for the sake of the whole society" (Ullmann, 1966, p. 32, as cited in Christopher, 1992, p. 70). During the 18th century Enlightenment, ideas about man's capacity for reasoning and man's inherent dignity led to belief in the natural rights of man. For Kant, one of the great philosophers of the modern era, the significant and unique capacity of human beings is reasoning. He claimed that human beings are autonomous because they have an ability to reason, direct their actions, and take responsible for them, not heteronomous, that is, dependent on external forces or power (Kant, 1993/1785). Moreover, the idea of autonomy was formulated in his categorical imperative, emphasizing "treat[ing] every person as an end and never solely as a means" (Beauchamp & Walters, 2003, p. 16). It is this emphasis of respect for the dignity of the individual that makes human existence fully meaningful.

Autonomy is a second core value associated with individualism (Christopher, 1992). Agich (1993) argues autonomy is conceptualized as self-reliance, personal preference, and self-assertion, and Collopy (1995) considers autonomy in terms of decisional and executional acts. Both accept that the concept of self-determination derived from autonomy for decision making emphasizes "rational free-choice" without any external interventions (Agich, 1993, p. 3). Self-determination is a value and right, supported by law, in the U.S.

The third value, privacy, denotes "an area within which the individual is or should be left alone by others and able to do and think whatever he chooses" (Lukes, 1973, as cited in Christopher, 1992, p. 74). This conception of privacy overlaps partially with autonomy (Collopy, 1995). The uniqueness of privacy, however, derives from that aspect which rests in the minds of people; no one can access a mind directly except its owner.

Grounded in these three core values associated with individualism, the independent self is developed. According to the American anthropologist Clifford Geertz, a person in Western culture can be thought of as

> a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment, and action organized into a distinctive whole and set contrastively both against other such wholes and against a social and natural background (1983, as cited in Christopher, 1999, p. 142).

This boundary and distinction of self from others which reflects Agich's notion of self-reliance, personal preference, and self-assertion is at the core of the independent self.

Another characteristic of the independent self is control; Rothbaum, Weisz, and Shyder (1982) label it as "primary control" (as cited in Weisz, Rothbaum, & Blackburn, 1984, p. 955). Primary control is gained by attempting to influence existing realities, often through actions involving personal agency, dominance, or even aggression. Such actions are expressions of personal autonomy concomitant with independence.

In summary, the construal of the independent self endows the self with innate dignity. It is this orientation that underlies the cultivation and nurturance of the independent self in Western society and gives legitimacy to autonomy, self-determination, and privacy as crucial rights in societies that adopt such views. The PSDA, AD, and ACP are the reflections of these values.

The Use of Advance Directives and Outcomes

Even though completion of ADs emphasizes individual patient's self-determination, family perspectives on the use of AD is critical. The family inevitably is faced with having to make medical treatment decisions on behalf of the patient when he/she becomes incapacitated to make such decisions. Studies of such family experience reveal three major consequences of importance. One is the consequences for family members. For example, withdrawing life-sustaining treatment has been described as "the hardest thing they had ever had to do," evidence of stress experienced by family members when making such decisions (Tilden, Tolle, Nelson, & Fields, 2001, p. 110). Deciding for another when acting under a durable power of attorney for health care, or the health care decision maker by choice or by default, imposes an enormous responsibility since the choice between life and death is the ultimate decision in human life and relationships. The experience of a family member's death and feelings of guilt and burden regarding decisions made, motivated White Americans to fill out ADs for themselves (Nolan & Bruder, 1997; Sahlberg-Blom, Ternestedt, & Johansson, 2000). Since White Americans are likely to see life as controllable and think logically, family members might believe that there is a right decision to make for a loved one and feel pressured to do so. Therefore, completion of an AD by patients could alleviate family stress and pressure since this would provide a priori guidance for decisions (Tilden et al.).

The second consequence pertains to family-health care provider interaction. The existence of ADs did not affect the absence of a discussion of treatment options between health care providers and families in one study (Hanson, Danis, & Garrett, 1997). Also ADs are not always useful because the patients' conditions may not be seen as "absolutely, hopelessly ill," or family or the proxy "were not available, were ineffectual, or were overwhelmed" (Jeffers, 1998; Teno et al., 1998, p. 439). Hence, having ADs did not forestall or resolve all communication problems between families and providers.

Further, family experiences were not always improved even when health care providers discussed ADs with them and their family members. In a randomized controlled trial, Ditto et al. (2001) examined the accuracy of surrogate substituted judgment. None of the interventions that included discussion with patients and a review of the patient's ADs produced significant improvements in the accuracy of surrogate substituted judgment. The investigators concluded that the degree of discussion effectiveness might have been responsible for the level of surrogate accuracy. However, discussions about ADs improved surrogate's perception of understanding of patient's ADs and mutual comfort between pairs with end-of-life decision making when the patient had not completed an AD prior to the study. Another qualitative study supported this notion, in that discussions about ADs lessened the burden of the decision for the family (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001).

In conclusion, three points were clear regarding family perspectives on the use of patient ADs. First, ADs could be effective in reducing pressure on surrogate decision makers, most often family members, if they knew when to use the ADs. Second, ADs did not automatically lead to a discussion of treatment options between health care providers and families. Third, discussion within the family did not improve accuracy of family's judgment when enacting ADs in response to illness scenarios, but having ADs completed by patients in advance of end-of-life situations had beneficial effects emotionally (e.g., eased burden) for families who were involved in making decisions about withdrawing or withholding life support.

In summary, individual autonomy is still the heart of end-of-life planning in the U.S. However, a shift from a focus on the individual patient to family involvement in decision making has been occurring. More recently, some have advocated for family-oriented decision making instead of family involvement, but this approach is not yet the mainstream model in the U.S.

Cultural Aspects Influencing the Experience of Japanese-American Families in Decision Making about End-of-Life Care

In contrast to the experience of end-of-life decision making in the U.S., several critiques of the utility of an individual autonomous approach to end-of-life decision making have been published (Chan, 2004a, 2004b; Ikonomidis & Singer, 1999; Kuczewski, 2004). Some argue that such an approach ignores non-Western cultural values and practices predominant in much of the world. The traditional values of most immigrant-minority populations, especially from Asian countries, may not support individual autonomy and self-determination, questioning why only patient's wishes are of concern when family is the central societal unit.

The term "family autonomy" has been proposed by Fetters (1998) to illustrate the collectivist decision-making pattern of families. Based on his clinical experience (about 70% of his patients are Japanese expatriates) and research findings, Fetters described how culture influences notions about the morally correct role of the family in medical decision making. Fetters concluded that Japanese think "medical decision making can have more of an impact on the family than on the patient" (1998, p. 132). He supported the concept of family autonomy by referencing three aspects of how Japanese deal with a family member's death. First, Japanese hold the idea of reincarnation and have 25 to 50 years of ceremonies for the deceased, which implies death is not only an individual event, but also a family event for a long period of time. Second, Japanese think that it is the family, not the deceased, who have to continue their lives after the death with memories of how the deceased died and the impact of the dying process. Third, Japanese argue that it is the family, not the deceased, who deal with the financial implication based on primogeniture and obligation and responsibility for continuity of the family's name. Therefore, Fetters advocated for the family's direct involvement or participation in the decision-making process because of such obligations. He suggested that the ethical principle of respect for persons as conceived in Western cultures should include different interpretations of self, that is, interdependent as well as independent.

Additionally, Kuczewski (2004) argued for a "communitarian model" inclusive of surrogate judgment in end-of-life decision making, arguing that highly individualistic decision making is unrealistic. His logic assumes that decision making is a long process during which patients continue to gather information about illness experiences. These experiences include the feedback of significant others such as family members and the impact of the course of treatment on them. Thus, such shared experiences with families would be the basis for decision making rather than individual self-determination per se.

Because this study focuses specifically on Japanese Americans, construal of interdependent self and background on cultural aspects, especially religious and spiritual beliefs are essential for understanding the context of their decision making. Historical events that have shaped the experience and acculturation of various generations of Japanese Americans also contribute to the context serving as a backdrop for this study.

Interdependent Self

About 70% of the world's population lives in cultures characterized as non-individualist (Bruera, Neumann, Mazzocato, Stiefel, & Sala, 2000; Davis, 1999; Kagawa-Singer, 1994). Those who come from such cultures conceive the self differently. In non-Western cultures, one sees "self"

> as part of an encompassing social relationship and recognizing that one's behavior is determined, contingent on, and, to a large extent organized by what the actor perceives to be the thoughts, feelings, and actions of others in the relationship (Markus & Kitayama, 1991, p. 227).

Markus and Kitayama refer to these other non-individualistic senses of the self as interdependent. Those who are raised in non-Western cultures may not have a clear self-identity since the primary view of the self is in relation to others. For example, child-rearing customs, such as lying an infant down beside the parents and bathing together every night and giving a toddler the parent's selection of food and clothing, do not cultivate children's independence. Another example is seen in the discipline of a child. Japanese mothers use detachment approaches as punishment describing what could happen if their children's misbehaviors continue (e.g., Mother says, "If you do not behave, you might be kidnapped."). Rather than giving a time-out, shutting the misbehaving child out of the house is a common punishment. In other words, child-rearing customs emphasize the attachment to mother and to a household. This emphasis on social relationships nurtures interdependence.

Interrelationships with family and society. One of the characteristics for those with an interdependent self is that they act based on other's expectations; the source of their behavioral control is heteronomous, outside of the self. Concurrently, voluntary control of the inner self is considered to be a sign of maturity. This type of control is classified as "secondary control" and accommodates to existing realities, attempting to alter self-expectations, wishes, goals, perceptions, attitudes, interpretations, and attributes (Weisz et al., 1984). From the view of the interdependent self, an independent behavior such as asserting an opinion may be interpreted differently from the way it would be in Western culture. For instance, so called assertive behavior is frequently seen as being selfish or "pushy" in Japan. A person's strengths should not be emphasized by oneself; instead, people should wait for their strengths to be found by others. Such behavior patterns require that people be trained to recognize subtle cues of nonverbal communications and finely nuanced choice of words. In Japanese communication, the verb comes at the end of the sentence so that the speaker can adjust it to align with the listener's reaction. Thus, in non-Western cultures, social interaction is more central in directing people's way of life. Autonomy or individualism is not welcomed; rather it is suppressed. As a common Japanese folk expression puts it, "the nail that stands out gets pounded down."

Interrelationship with cultural values. Harmony may be the most important value for the interdependent self. A proverb, "A tall tree catches much wind," is used for child rearing. Avoiding conflicts, allowing others to "save face," keeping relationships, and interpreting nonverbal cues are aspects of keeping harmony. Solidarity and conformity are also closely related to harmony.

Obligation is another value to be created and fulfilled among those with an interdependent self. Especially in Asian cultures where Confucianism has been influential (e.g., China, Korea, and Japan), hierarchical or vertical relations (e.g., parent-child or employer-employee) are more important than horizontal ones (e.g., spouse-spouse or friend-friend; Christopher, 1992). Respect, deference, loyalty, trust, and obedience are closely related to obligation. Filial piety and primogeniture are examples of obligation and privilege associated with the hierarchical organization of families. To describe it, the eldest son inherits the family home and family business; in return, he and his wife are expected to provide care for his parents until their death, or vice versa (Fetters, 1998). Even very significant mutual undertakings outside the family context rely on obligation and social relationships for their enactment. For example, a verbal statement with handshakes can be enough evidence to be a contract without a written document; a statement of job appointment will not be issued until the first day at work.

With an emphasis on secondary control, those with an interdependent self tend to accept things as they are. Perseverance, reticence, tolerance, and obedience are expressions of secondary control. Primary control, such as attempts to make realities fit individuals' wishes, is discouraged (Weisz et al., 1984). Fate is acceptable to those with an interdependent self.

In summary, the construal of the interdependent self sees the self as being without a solid individual-identity but feeling comfortable as a part of groups. Others' expectations direct proper responses and appropriate behaviors. Deviation from the group could cause "social death," so harmony and self-control is emphasized. Thus, most values for those with the interdependent self include relational references.

Religious and Spiritual Beliefs

For this review, religious and spiritual beliefs focus on the meaning of death and the afterlife. Such beliefs may influence the willingness of Japanese Americans and other minority group members to engage in end-of-life care planning, including the use of ADs, and affect how family members make end-of-life decisions when called upon to do so.

Many Asian Americans believe in a natural life cycle; thus death should overcome human willpower (Bowman & Singer, 2001; Braun & Nichols, 1997), a fundamental Buddhist belief. According to Tsuchida (1998), traditionally Japanese had animistic reverence; nature, shizen, means "a force that transcends human control and follows its own course of changes or processes" rather than "the nonartificial, undomesticated state of nonhuman beings" in Western terms (p. 214). Thus, mechanical interventions to prolong one's life or recognition of a brain death without an arrested heart as a death may be difficult to accept for Japanese. To support this notion, some Japanese make pilgrimages to Buddhist temples believed to be efficacious in procuring a sudden death to pray for natural power.

The concept of karma or reincarnation, that one's conduct in a previous life affects the condition of the present life, is also part of the belief system of some Asian Americans (Braun & Nichols, 1997). Especially for Japanese, "one's identity and meaning of life are closely tied up with belief in ancestors' spirit ... [that] always be concerned about the welfare of the offspring" (Tsuchida, 1998, p. 212). Therefore, since death is viewed as a natural phenomenon, Japanese may share commonalties with acceptance of life as it comes and not be afraid of death as much as Westerners.

Another interesting point raised by Tsuchida (1998), citing earlier studies by Yanagita (1988/1945), is the Japanese belief that the most serious wishes of the dying are eventually realized after one's death. This belief is consistent with Samurai ethos that expects one to "maintain an attitude of indifference to the minutiae of their daily life [and] bravery and silent endurance [are] typical Japanese virtue" (Ohara, 2000). Because of a strong feeling of connection to offspring consistent with an interdependent self, implicit rather than explicit expression has more weight and value. A strong interrelated society makes it possible to let the dying go without knowing his/her wishes. Moreover, Japanese family members may accept the challenge of understanding the wishes of a dying person without explicit discussion since it is viewed as evidence of the closeness of their relationship. The words *ishin denshin* (mind to mind communication or thought transference) support this notion.

These cultural concepts may sound neither logical nor scientific, nor supportable by evidence, but are examples of non-Western beliefs that are significant to understand for health care providers to offer culturally sensitive end-of-life care. In the next section, the historical background of Japanese Americans and shifts that may have occurred in construals of the self with each generation among Japanese Americans are described.

Experiences of Japanese Americans

Generational distinctions among Japanese Americans. Japanese Americans included in this study comprised three groups based on place of birth and the number of generations in the U.S. represented by the reference person. The first group, called *Issei*, was born in Japan and came to the U.S. prior to World War II (WWII). Isseis who were born in Japan and came to the U.S. after the war are distinguished by the term *shin-Issei* or new-Issei (Bito et al., in-press). The second group, called *Nisei*, is the first American-born generation living in the U.S. The third group is called *Sansei* and represents children of the Nisei generation, born primarily after WWII. Later generations not included this study are called *Yonsei* and *Gosei*, the fourth and fifth generations respectively. Most all the Issei were born before 1900, while almost all the Nisei were born between 1915 and 1940 from Issei parents (interracial marriage was very uncommon). The Issei were prohibited from gaining citizenship or owning land by the Oriental Exclusion Act of 1924 (Spickard, 1996; Tomine, 1991). There is a clear generation gap between Issei and Nisei because of the Gentleman's Agreement (1907). This act prohibited Oriental (Japanese and Chinese) men's labor immigration between 1907 and 1924 although immigration of brides was allowed until 1924.

Among the various ethnic groups in the U.S, such a clear generational distinction among Japanese-Americans groups is not only unique but also meaningfully important (Fugita & O'Brian, 1991). This distinction highlights different characteristics of Japanese

Americans, including values and beliefs the immigrants from Japan brought with them, what they retained and passed on to their offspring, and the impact of historical events and laws on their experience and acculturation.

Acculturation defined as "culture change resulting from contact between two autonomous and independent cultural groups" (Refield et al., 1936 as cited in Berry, 1994, p. 211) affected each cohort differently. Berry identified four modes of acculturation as individual-level phenomena: assimilation, integration, marginalization, and separation. This classification was based on two factors: (a) whether "one's own cultural identity and customs are of value and to be retained"; and (b) "whether relations with other groups in the larger society are of value and are to be sought" (Berry, 1994, p. 212). Berry also identified four phases of acculturation: contact, conflict, crisis, and adaptation. Because immigrant Issei wanted to keep their Japanese identity and values and because some Japanese and U.S. values conflicted with each other, the acculturation of Issei can best be described as separation. However, the acculturation of the Nisei can best be described as marginalization given that conflict and crisis phases tended to mark their experiences. Feelings of alienation and loss of identity strengthened their affinity towards fellow Nisei. Cohesiveness, mutual aid, and a generally patriarchal set of authority relationships were maintained (Fugita & O'Brian, 1991). The acculturation outcome for the Sansei appears to be integration rather than assimilation even though they were more likely to have completed the acculturation process through the adaptation phase. Compared to other ethnic Americans, Sansei retained a higher level of involvement in their ethnic community, although the vast majority of them have become structurally assimilated into mainstream American life.

Historical events and cultural influences affecting Japanese Americans.

Issei experiences. The Issei represent the more typically traditional Japanese generation. Eighty five percent of Issei came to the U.S. to make a "fortune" and return to the homeland. However, because the fortune was seen as not large enough to go back with pride, many believed they had no choice but to stay. Life was not easy for the immigrants. Racial discrimination coupled with, and even as source of, economic and political problems, was unavoidable (Steiner, 1917). These, in addition to other factors such as their reluctance to permanently settle, contributed to Issei establishing voluntary associations and ethnic communities called *nihon-machi* (Fugita & O'Brian, 1991). The Issei worked to maintain Japanese culture and life style facilitated by the Japanese concepts of "peoplehood" i.e., seeing themselves collectively as a single people (Reischauer, 1981, as cited in Fugita & O'Brian) and homogeneity for structuring social relationships in Japan. On the other hand, their internalized values of hard work, sacrifice, thrift, trust, and deferred gratification contributed to success in establishing new lives in mainstream society.

The world of the Issei also was shaped by other values, ones more closely linked to Confucianism. According to Smith (1948), the guiding stars of the Japanese ethical system are four virtues: duty, gratitude, integrity, and loyalty (*giri*, *ho-on*, *renketu*, & *chuko* in Japanese, respectively). Subordinates must show these virtues to those in authority. In other words, these virtues were used to organize mutually dependent, hierarchical relationships, called *iemoto* or origin of the household (Fugita & O'Brian, 1991). For the Issei, acting in ways that preserve and promote respect for the family name, i.e., keeping up a front and preserving "face" was their duty. Moreover, they expected and depended on group harmony, supported by "meticulous norms of deference and self-effacement" (Fugita & O'Brian, 1991, p. 37). Additionally, Smith commented that "[b]enevolence and philanthropy are poorly developed in Japan because a man's obligations stop at the border of his family, his neighbors, and his employers" (1948, p. 96); however, in the special situation of being in a foreign country, this limit had expanded to "pseudo-kinship," much larger in scope than kin relations among Issei.

The Issei's experience of acculturation was complicated. Their economic success triggered anti-Japanese sentiment in the U.S. and prevented them from easily assimilating into the U.S. mainstream. On the other hand, the military successes of Japan (China in 1885 and Russia in 1905) gave Japanese, including the immigrants to the U.S., inflated ideas of their own importance, laudable ambition, and a bold assertion of their rights (Steiner, 1917). In the beginning, almost no assimilation with mainstream American culture occurred. Examples of this ethnic isolation include Japanese language schools, Buddhist churches, self-employed traditional occupations such as farming, and daily customs like diet, bathing, clothing, and the use of leisure time (Smith, 1948). In contrast, other characteristics of Japanese culture facilitated some assimilating, for example, the value that culture is "'socially sensitive' in that it is desirable [for an individual] to fit into whatever social setting one finds oneself" (Fugita & O'Brian, 1991, p. 94). Moreover, the Japanese culture encourages a flexible and low key approach to religion such that Buddhism, Confucianism, and Shintoism can co-exist in an individual Japanese, and different religious affiliations (e.g., Buddhism and Christianity) are acceptable within a family (Yoo, 2000). This "situational morality" encouraged Issei to adopt the attitudes and behavior of the host society and thus facilitated at least some degree of acculturation. Moreover, officials at the Buddhist headquarters in Japan had instructed Buddhist ministers in the U.S. to educate Japanese immigrants to be good American citizens and to modify their preaching to be suitable to an American life.

The Issei experience of internment was devastating and further mitigated against acculturation. They lost everything they acquired in the U.S. except one bag of belongings each. The Issei and their families showed their loyalty to the U.S. by moving out of their homes without much resistance and with acceptance of their situation. There is not much recorded regarding Issei's thoughts about internment. Rather, their attitudes, such as *gaman* (patience, endurance, or perseverance) and *shikata ga nai* (it can't be helped; what happened has happened; need to move on), were described by the Nisei generation (Harth, 2001). After WWII, the Issei did not have energy to rebuild their lives again physically and psychologically. Daily decision-making responsibilities were shifted to the Nisei.

Nisei experience. The Nisei have lived in two different worlds from their childhood on, but often felt marginalized. One world was an American life at public school where they saluted the flag, sang national hymns, and learned freedom, equality, and justice. The other was a family life in the Japanese community where they went to Japanese language school after public school to learn not only Japanese language but also the culture, such as Japanese social and moral values, discipline, and history (Dubrow & Graves, 2002; Fugita & O'Brian, 1991). Being forced to master both cultures left less than positive memories for most Nisei, as did incidents of racial discrimination.

Nisei were confronted with the hard task of preserving an inner harmony as a practice of secondary control, which is voluntary control of the inner self to meet others' expectations, while making their adjustment to two cultures. The common values (e.g., honesty, courage, and courtesy) did not create conflict, whereas the different values (acceptance and submission versus questioning and standing up for one's own rights) produced trouble (Smith, 1948). For instance, Nisei struggled with traditional marriage expectations (e.g., whether to support mother or wife when conflicts arise between them and roles of man vs. woman) and choices of occupations (e.g., staying in the community to avoid racial discrimination vs. seeking jobs elsewhere). Robert Park first described the Nisei as "marginal men" in 1926; in a later publication, Everett Stonequist (1937) expanded the idea as follows: "the marginal man is the key personality in the contacts of cultures. It is in his mind that the cultures come together, conflict, and eventually work out some kind of mutual adjustment and interpenetration" (as cited in Smith, 1948, p. 383).

Moreover, as for the Issei, World War II and the experience of internment caused great upheaval, compounding identity issues for the Nisei. "We are Americans by every right, birth, education and belief, but our faces are those of the enemy" (Tajiri, Pacific Citizen, June 11, 1942, as cited in Yoo, 2000, p. 95). When they were forced to move from their homes, they felt betrayed, angry, resentful, bitter, and disappointed about their treatment by the U.S. government even though many Nisei men served in the war in the American Armed Forces, fighting against Japan. At the same time, they internalized such experiences as shameful. Their choice of expression was, therefore, reticence. Along with the physical hardships, the psychological challenges were considerable: "the loss of homes, property, livelihood, [and] freedom as well as the stress of captivity and the uncertainty of the future" (Yoo, 2000, p. 103).

Sansei experience. The Sansei generation after WWII is significantly different from the Nisei. The Sansei still live in dual cultural worlds, but their lives are much more American than Japanese. The amount of discrimination the Sansei have faced is significantly less, and the opportunities for education and occupations are much wider. However, the acculturation outcome of this generation appears to be integration rather than total assimilation into the majority U.S. culture.

Comparison of the Nisei and Sansei indicated points of difference and similarity (Fujita & O'Brian, 1991). Sansei perceived more differences between Japanese and White's behavior in the four social environments of business, social, church, and family than did Nisei, especially with regard to business and family. Fugita and O'Brian concluded that "social boundary become[s] more prevalent among [the Sansei] as their structural assimilation increases," despite less discrimination (1991, p. 167). However, Nisei and Sansei's perceptions about the characteristics distinguishing Japanese Americans from other Americans were similar. Greater work ethic (43.5% and 39.3%, respectively), more reserved interactional style (32.1% and 32.5%), and physical characteristics (27.8% and 22.9%) were the top three categories the participants chose.

From research conducted earlier, Connor (1974) concluded that the Sansei retain certain core Japanese traits. These include: a sense of closer family ties; a greater sense of duty, obligation, and deference; less need to dominate; a greater tendency to affiliate; less aggressiveness; a greater need for succor and order; and a greater fear of failure in social role performance than other Americans (as cited in Fugita & O'Brian, 1991). When Nisei and Sansei were asked about the differences between their two generations, they also answered similarly, responding negatively to changes and erosion of ethnicity. Both perceived a loss of their distinctive interactional styles and other cultural characteristics, such as modesty, conservativeness, obligation to family, family closeness, respect for elders, work ethics, and honesty.

Most Sansei appeared to regret the loss of connection to the Japanese culture and language. They thought of the internment as an important factor which accelerated their loss because of the cessation of Japanese language schools, the inability to return to pre-internment homes, and Nisei's discouragement of Sansei's ethnic identity (Dubrow & Graves, 2002; Harth, 2001). The Sansei carried feelings of Nisei's sadness and anger, and with their own regret, some Sansei tried to keep in touch with ethnic community organizations and pass on some Japanese traditions to their offspring. Ethnicity for Sansei was more likely to revolve around issues of personal identification and "fitting in" with the majority culture (Fugita & O'Brian, 1991).

The majority of Nisei and Sansei (83.0% and 83.7%, respectively) reported that it is at least somewhat important to be a part of the Japanese community (Fugita & O'Brian, 1991). The identified reason was the legacy of peoplehood. Ethnic community organizations such as long-term care services established and expanded by the Nisei and maintained by the Sansei are example of eclectic values and culture between traditional Japan and the majority of the U.S. (Young, McCormick &Vitalino, 2002). For this reason, with respect to Berry's model of acculturation (1994), the Sansei appear to reflect the integration mode rather than assimilation. Increased intermarriage among Sansei (50% among men and 60% among women; Fugita & O'Brian, 1991) and dispersed residency, however, suggested that it might be difficult to pass on aspects of Japanese tradition and ethnicity to future generations. Nevertheless, as long as Japanese Americans do not lose their construals of interdependent self, the legacy of 'peoplehood,' and traditional values and beliefs, Japanese heritage will be continued to some extent.

Research in End-of-Life Care Decision Making

In this section, studies focused on cultural difference in acceptance and use of ADs and the experience of families with end-of-life decision making will be reviewed. Research on cultural differences associated with ADs primarily is limited to studies that included Asian Americans, with particular attention to Japanese Americans as a subgroup of Asian Americans. Unless otherwise stated, statements use White Americans as the reference group for comparisons. Research on families' experiences with end-of-life decision making includes: explanatory studies of factors affecting family's experiences and descriptive studies of family's experiences with decision making at the end of a family member's life.

The terms related to “family” decision making need to be clarified since the extent of family or family members’ involvement in decision making is a question in this study. However, the literature provides limited explanation of what terms such as family-centered actually involve (Hyun, 2003). In this study, family was defined as persons related to the patient or deceased family member by blood or marriage, or who can be designated as a legal surrogate. For a clear distinction, in this study "family" does not include the patient or deceased family member unless specifically identified. Similarly, a family-oriented model by Bito et al. (in-press) was defined as decision-making by a consensus among the physician and family members, and at times, the patient. A family-centered model was defined as "the sole responsibility of the family to hear bad news about the patient's diagnosis and prognosis and to make the difficult decisions about life support" (Blackhall et al., 1995, ¶ 23).

Cultural differences in Acceptance and Use of Advance Directives

Studies examining cultural differences in acceptance and use of AD published in the last 10 years are summarized in Appendix A. Results of these studies indicate that knowledge, attitudes, and reasoning related to ADs and actual completion rates of this end-of-life care planning document are different for various ethnic populations in the U.S. (e.g., Blackhall et al., 1995, 1999; Doorenbos & Nies, 2003; Eleazer et al., 1996; Hopp & Duffy, 2000; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Murphy et al., 1996; Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002; Voltz, Akabayashi, Reese, Ohi, & Sass, 1998). In general, evidence from comparative studies supports that the attitudes and experiences of minority Americans differ from those of White Americans. For example, White Americans have higher completion rates of ADs than do African Americans, Mexican Americans, and Asian Americans as well as persons in many other countries (Blackhall et al., 1995; Voltz et al.). An important decision is choosing a proxy empowered to make health care decisions when one cannot do so for oneself. African Americans often choose a relative other than a spouse or child as a key person in decision making (Hornung et al., 1998). Because it might destroy family harmony, difficulty in designating only one person as the proxy may occur for those from non-Western cultures (Bowman & Singer, 2001). Consistent with the concept of filial piety in Asian families, adult children are considered to have an obligation to decide on older parents' care to relieve parents from the responsibility for decisions when they are ill (Blackhall et al., 1999).

The value place on autonomy and self-determination in different cultures may help explained the differences found among groups in completion of ADs. Because individual autonomy is not valued as much in non-Western cultures as it is in Western cultures, those from non-Western cultures may associate self-determination with being isolated, lonely, and abandoned. Similarly, the exercise of influence by others may be seen as coercive or oppositional in Western culture, while it is often considered a desirable norm in non-Western cultures.

Asian Americans' preference for end-of-life care. The research on attitudes and preferences of Asian Americans found variation among groups from different countries and cultures of origin. Three apparently paradoxical sets of findings and speculations were identified from studies that used primarily Chinese Americans, Korean Americans, and Asian Indian Hindus living in the U.S. First, compared to White and Mexican Americans, Korean and Chinese Americans were least likely to believe in individual autonomy and more likely to accept life support but less likely to want it (Blackhall et al., 1995; Eleazer et al., 1996). This apparent paradox was explained by a theme that emerged from in-depth interviews of 20 subjects in each of four ethnic groups in Blackhall et al.'s follow up study. Namely, Korean Americans indicated that they personally would not want to be kept alive on life support, but consider the decisions as up to their family and not theirs to make. So they would accept life support at the family's wishes.

A second apparent paradox was the relatively high prevalence of recorded health care wishes for end-of-life care, including ADs and health care proxies, for a primarily Chinese sample (79%) of Asian Americans in Eleazer et al's study (1996). Asian Americans traditionally value recognition of a verbal contract instead of formal documentation, hence, hypothetically leading to low completion rates of ADs. Moreover, Asian-Americans' wishes to avoid family conflict by not naming just one person as a proxy would support low completion rates of health care proxies by this group (Bowman & Singer, 2001). These cultural values may have been outweighed by the effects of education and acculturation for the study sample. Therefore, preference for not using life support would be an overriding concern, leading to higher completions rates of ADs and naming health care proxies (Braun & Nichols, 1997; Eleazer et al.; Vaughn, Kiyasu, & McCormick, 2002). Moreover, the inclusion of verbally expressed wishes recorded by staff in the records as a category of health care wishes about end-of-life care in Eleazer et al.'s study may also have confounded the findings. Verbal expression of wishes is consistent with traditional practices and not a usual way of "counting" AD completion.

The third paradox was the mixed preference for use of life support expressed by Asian Indian Hindus in a recent study (Doorenbos & Nies, 2003). One group objected to the use of life support, saying that it interfered with karmic fate, while another group supported it, explaining it as a part of karmic fate.

Japanese Americans' preference for end-of-life care. Although Japanese Americans were not well represented in the published studies of Asian Americans cited above, generally end-of-life care preferences among Japanese Americans have been found to be similar to those of other Asian Americans (Okuno, Tagaya, Tamura, & Davis, 1999; Orona et al., 1994; Paton & Wicks, 1996). In a recent qualitative study using focus group interviews, the experiences of three groups of Japanese persons (Japanese in Japan [n=28], Japanese-speaking Japanese Americans in the U.S [n=29], and English-speaking Japanese Americans [n=65] in the U.S.) were compared to examine acculturation trends in end-of-life care decision making (Bito et al., in-press). The majority of participants were men over 65 years old in all groups; the youngest group was English-speaking Japanese Americans. All three groups expressed negative feelings towards living in adverse health states and using life sustaining treatments. Bito et al. found that Japanese in Japan were somewhat accepting of ADs but only in an informal fashion since they thought a written AD was intrusive. Japanese Americans accepted ADs because they thought it would prevent family conflicts and reduce family burdens, reasoning that was similar to that of White Americans (Vaughn et al., 2002; Voltz et al., 1998).

All three groups were found to prefer that bad news be presented first to the family, not to the patient. Japanese in Japan would rarely tell the bad news to the patient regardless of the patient's wishes; however, the frequency of truth telling to the patient increased with the acculturation of Japanese Americans. Customarily, Japanese justify the use of false hope because of their concern with disrupting the "internal world" of the patient in order to maintain hope (Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998; Orona et al., 1994).

All three groups also preferred a family-oriented decision-making model (Bito et al., in-press). The difference was that Japanese in Japan practiced paternalism with a family decision-making style (i.e., without the patient's participation), while among Japanese Americans in the U.S., the frequency of patient participation within the family-oriented decision-making model increased with acculturation. Additionally, a similar study found that most Japanese Americans preferred *group* surrogate decision making. English-speaking Japanese Americans had more positive attitudes toward foregoing care, ACP, and individual autonomous decision making (Matsumura et al., 2002).

The review of characteristics and values of Japanese Americans appears to support the results of Bito et al.'s study (in-press). However, two methodological drawbacks of the study may have affected the results. First, validity might have been threatened by the focus-group approach used because of social desirability, especially since "keeping face" is important for Japanese and their descendants. Second, the participants were not in the situation of making end-of-life decisions for another (even though some might have experienced it). Perhaps a sample chosen to reflect experience with end-of-life decision making would have provided a stronger basis for understanding the process.

In conclusion, the findings of Bito et al.'s study (in-press) supported the role of acculturation among Japanese subgroups. However, of particular significance is that although English-speaking Japanese Americans were younger than the participants in the other two groups, even second- and third-generation Japanese Americans appeared to preserve traditional Japanese values in their preference for a family-oriented end-of-life decision making model.

Summary. The values of Asian Americans support family-oriented decision making for end-of-life care, although their preferences for ADs varied across studies and subpopulations. Moreover, acculturation level, family interaction, education, and experience affected decision making. For all Asian-American groups, paradoxes reflecting competing values and degree of acculturation appeared to influence the use of ADs and end-of-life care decision making. What is not known is how and to what extent a family-oriented decision making model is used when Japanese Americans actually face the impending death of a family member and to what extent conflict is experienced within the family, or between the family and health care providers, because of different culturally based values guiding their actions.

Explanatory Studies of Factors Affecting Family's Experiences

Despite the intense interest of health care providers, bioethicists, and others in the involvement of patient's families in decision making, few quantitative studies examined factors that affected family involvement or experiences. Two key studies found are summarized in Appendix B. As part of the SUPPORT study, Baker et al. (2000) focused on family satisfaction with end-of-life care. They found that satisfaction with care decreased if the patient died after discharge from hospital whereas support provided by staff during the process of a patient's dying in the hospital or at home increased it significantly. Two other factors were recognized as important although the results were not statistically significant. A Match with Patients' Preferences at the end of life tended to increase family satisfaction levels while the Use of Life-Sustaining Treatment tended to decrease family satisfaction levels.

In another retrospective study, Tilden et al. (2001) interviewed 74 families involved in deciding to withdraw life-sustaining treatment for a family member in the ICU setting. Fourteen family members (19% of the participants) were minorities (8 African, 5 Asian, and 1 Native American). Three factors that affected the level of stress experienced by families were absence of ADs, being an ethnic minority, and a longer commute distance from the hospital. Although these two studies identified critical factors affecting aspects of family experiences with end-of-life care (satisfaction and stress), they did not fully examine in depth the experience of families involved in end-of-life decisions for a family member, especially from a minority group, the focus of this dissertation.

Descriptive Studies of Factors Affecting Family's Experiences

Four qualitative studies that described family perspectives of end-of-life decision making were found and are summarized in Appendix C. These studies are described in some depth here because they provide a deeper understanding of family experiences, similar to the focus of this dissertation. Jacob (1998) examined the experiences of 17 families involved in decision making for their 15 seriously incompetent ill family members in the ICU in order to understand such experiences. Interviews were conducted from 1 week to 5 years after the ill family member's death.

Three major themes using a grounded theory approach were identified to describe the process of decision making: Arriving at a Judgment, Moving in Concert versus Disharmony, and Looking Back and Going on. The first theme involved consideration of the patient's condition and the patient's preference about treatment. Variation occurred in how knowledge of the patient's condition affected family's judgment. Information variation included its availability, family's perception of the amount of information needed, and certainty attached to information as well as their judgment and decision. The patient's preferences about treatment were discerned by the family objectively through mechanisms such as written ADs (5 out of 15 patients completed), and subjectively through "just knowing." Other considerations undertaken to Arrive at a Judgment included concerns about prolongation of life, doing what was the best for the patient and effects of choices on the family.

The second theme, Moving in Concert versus Disharmony, described interactions and relationships with health care providers. Connecting with health care providers occurred when providers took time to show their caring and were available to the family and supportive; all these were fundamental attributes of Connecting for the family and key to Moving in Concert. Care shown, information sharing, and attention to the mutuality of treatment goals were other attributes described by the family that were critical to Moving in Concert. On the other hand, examples of attributes of interactions that resulted in Disharmony for the family were: being misunderstood or ignored, lack of caring shown, without attention to the mutuality of treatment goals.

Looking Back and Going on was the final phase of the process for families. Family members expressed positive feelings about their involvement in decision making, although the emotional burden of the responsibility was also a common theme in their experience.

Jeffers (1998) used a phenomenological approach in interviews with 11 family members who had been involved in decision making at least a year ago (14 months to 15 years) of a hospitalized incapacitated family member. Four major themes described the non-linear experience of surrogates in making treatment decisions for their family member: Contextualizing the Decision, Actualizing Agency, Reviewing and Resolving, and Transcending.

Contextualizing the Decision involved surrogate's perception of the terminal nature of the present illness within the context of the past, present, and future health and quality of life of their family member. Gathering Information was a key way in which the surrogate decision maker tried to make sense of the present illness within the context of the patient's health trajectory. Health care providers were not always informative during this process.

Actualizing Agency reflected the experiences and feelings of the surrogates as they made end-of-life treatment decisions. They felt that they shouldered the key responsibility and burden for decisions even when others were involved. Being Alone characterized their experience of Actualizing Agency.

Reviewing and Resolving were composed of the expression of feelings of regret or guilt regarding treatment decisions, although most surrogates expressed that "they had done the best they could" under the circumstances by the end of the interview. The presence of ADs and prior treatment discussions did not ease the decision making or mitigate negative feelings associated with decisions. Transcending denoted surrogate's strength from having faith, the support of others, and using their experience as a way of reaching out to others in similar situations.

Meeker (2004) investigated family surrogate's experiences in decision making at the end of the life of a family member who had cancer. Meeker interviewed 20 family members within 3 months to 8 years of the death of their family member. A grounded theory approach guided the study and the analysis. The study found that family surrogate's experiences were an ongoing, basic social process of Seeing Them Through with Care and Respect, interwoven with the other activities of their lives. Core values of caring for their family member and respecting their family member's autonomy were essential to guiding this process.

During Learning the Diagnosis as the entry point into the process, family continuously sought information even when shocked by the possibility of the diagnosis. Next, two major surrogate roles that characterized the activities of the surrogates were identified: Standing With and Acting For the ill family member.

The first major surrogate role, Standing With, included the categories of Active Presence (i.e., being supportive and vigilance for the patient) and Respect for the Person (i.e., knowing and learning about the patient's wishes; understanding and empathizing with the patient; and discerning meaning in the events). The second major surrogate role, Acting For, was comprised of Advocating and Protecting. Advocating included surrogates' effort to ensure access to and continuity of care and honoring of the patient's choice while they felt like they had “hit-the-wall” about the patient's care when they encountered difficulties. Surrogates described Protecting patients from health care providers by Treading Lightly or Taking patients’ wishes over those of other family members or health care providers.

Brokering Information and Working with Family were recognized as gating (transitional) categories, situated in between two major surrogate roles, Standing With and Acting For, and facilitated or impeded decision making. Brokering Information described surrogates' activities in Seeking and Receiving information from the health care providers and in conveying or providing information to other family members. Another gating category, Working with Family, illustrated surrogate’s experiences and interactions with other family members during the decision-making process.

Taking Leave described activities near the time of the patient's death but subsequent to it. Knowing/Preparing for pending death and Honoring the life of the ill family member were its subcategories. Finally, Outcomes represented consequences of having been the decision maker and included emotional reactions such as Persisting Concerns or Satisfaction.

In their study of 30 family members of 16 critically ill patients (14 White Americans and 2 African Americans), Swigart, Lidz, Butterworth, and Arnold (1996) found that "letting go" of the patients involved three interrelated preparatory processes for the family in reaching decisions about withholding or withdrawing treatment: Seeking and Understanding information about the critical illness of the patient; Reviewing the life story of the patient and Seeking the meaning of the patient's life; and Struggling with family roles and relationships.

In the first process, Seeking and Understanding, family members moved toward accepting death as imminent when they believed they had done all that was possible and recovery was improbable. In the second process, Reviewing the life and Seeking meaning, family members were able to conclude that the patient would not want life support given the illness circumstances. In the last process, Struggling with family roles and relationships, family members were often supportive of each other in reaching agreement about the "right thing to do." They worked toward fulfilling their decision-making responsibilities about life support in a way that would preserve family relationships. Families who worked through these processes successfully were able to rework and reframe issues within the context of the critical illness experience. The researchers concluded that having a consistent and trusted confidant among health care providers who could explain and clarify the seriousness of the illness situation was key to providing families with timely knowledge that facilitated their movement through these processes.

All four studies above presented a somewhat linear process of families' experience of decision making along the patient's illness trajectory. Understanding the nature of the patient's illness through information gathering was the first phase or process. This was followed by phases that involved dynamic interactions both within the family and with health care providers as well as intrapsychic work for individual members. Acting on behalf of the ill family member was paramount in the middle phases. Feeling responsibility and burden or making sense/finding meaning within the context of the illness and decisions were the most frequently expressed themes. Near the end of the ill family member's life or afterwards, surrogates eventually reached closure if they felt they had honored the wishes of their family member, or done the best they could in the situations, and maintain intact family relationships.

The settings of these studies, however, influenced family experiences. The studies of Jacob (1998), Jeffers (1998), and Swigart et al. (1996) in critical care settings made decisions about life-sustaining measures time sensitive for families. In contrast, Meeker (2004) described interactions among the terminal ill patient with cancer, family, and health care providers in a longer process of reflection and decision making, including preparation for the death.

The focus of the study also influenced the presentation of findings. For example, Jacob (1998) emphasized the interactions with health care providers whereas Swigart et al. (1996) focused on interrelationships within the family and connection with the ill patient. Additionally, Swigart et al. employed a concurrent study method to focus on decision-making process to withhold or withdraw life-support treatment. Jeffers (1998) described a more "alone" lived experience of being a surrogate decision maker for a hospitalized patient. In summary, each study examined family experiences in decision making in a limited range of situations (i.e., critically ill ICU patients, hospitalized patients, terminally ill cancer patients). In contrast, this dissertation research focused on family members' experience in decision making across a broader range of setting and conditions.

A limitation of the studies conducted to date is that the samples consisted mainly of White Americans, a major concern given the demographic trends reflecting increasing numbers of minorities in the U.S. population. Even though attitudes towards ADs among minority populations have been examined, minority family perspectives based on their actual decision-making experiences during the end of life of a family member have not been studied in and of themselves. This dissertation study addressed theses limitations by focusing on the actual decision-making experience among Japanese Americans.

Summary and Conclusion

Changing health-care circumstances in the U.S. have helped to shift decision-making at the end of life from a paternalistic physician-centered model to a patient-centered model in which decision making is shared. This shift has seen supported by legislation and enactment of the PSDA, emphasizing the use of ADs and surrogate decision makers when a family member is incapacitated. Although family members are increasingly involved in end-of-life decisions about withholding or withdrawing life sustaining treatment, research on families' experience with decision making is limited. To date, most studies conducted in the U.S. have focused on family stress or satisfaction or experience with decision making for critically ill, incapacitated patients in ICU or other critical care units in hospitals. Moreover, samples and respondents in these studies are predominantly White Americans; few minorities have been included. Because of the changing demographics in this country and the increasing number of immigrants from non-Western cultures, it is essential that their experiences be examined also. This is especially important since cultural values that support a less individualistic and more family-oriented decision-making style continue to influence many minority groups, especially those from Asian countries such as Japan. Given the unique experiences of Japanese Americans in this county and the rapidly aging Japanese-American community, knowledge about their experience is especially important. Such knowledge is needed to ensure that health care providers have information essential for providing culturally sensitive care to Japanese Americans and similar minority groups when a family member is dying. Thus, this dissertation study addressed the gap in our knowledge base for practice by focusing on the experience of Japanese-American families with end-of-life decision making for a recently deceased ill member.

CHAPTER 3

Method

Design

The research questions and aims for this study focused on the process used by Japanese Americans to make end-of-life decisions for a recently deceased family member, including their perceptions of the situation, how the decision was made, what influenced this process, and how they felt about the experience afterwards (i.e., the meaning the experience, decision, and family member's death held for them). A descriptive design using qualitative methods was undertaken to explore these questions and aims.

Grounded theory methodology (Glaser & Strauss, 1967) was used to describe the process of decision making and experiences, feelings, and meanings associated with making end-of-life decisions for family members. Its purpose is to "generate theory from systematically collected data" in order for relevant predictions, explanations, interpretations, and applications of social phenomena (Baker, Norton, Young, & Ward, 1998, p. 547). According to Charmaz (2000), the foundations of grounded theory are three-fold: Glaser's strong positivistic methodological training in quantitative research; Strauss' "pragmatist philosophical study of process, action, and meaning into empirical inquiry"; plus, symbolic interactionism (Baker et al., 1998, p. 512).

Symbolic interactionism used as a framework provided the philosophical underpinnings for the qualitative approach and methods. Symbolic interactionism was well suited for this study since the approach and the methods associated with it allow the researcher to analyze the experience of the participants as well as their perceptions of the interactions among the self, their family members, and health care providers within the social context in which end-of-life care decisions are made.

The purpose of symbolic interactionism in guiding research is to understand the cause of human action (Charon, 1989). Symbolic interactionism is characterized by three basic premises: (a) an individual acts toward things on the basis of the meanings that the things have for that individual; (b) meanings are derived from, or arise out of, the social interaction; and (c) meanings are handled in, and modified through, an interpretive process used by the individual (Blumer, 1969). For example, social factors (e.g., social structure, culture, and values) and affective psychological factors (e.g., motives, attitudes, and feelings) might influence individual actions; however, such factors in symbolic interactionism are considered to set conditions for the action but not to determine the action (Blumer). The determinant of the action is the individual's cognitive processes, in which the individual identifies or defines the situation, interprets others' actions, and decides on his/her own action.

Setting and Sample

The sample was recruited from a metropolitan area in the northwestern part of the U.S. The majority of Japanese-American participants derived from two generational cohorts: Nisei and Sansei. Sansei were included because the subjects in two studies of Japanese Americans in a county in the same northwestern state whose data were collected in 1994 were 88% Nisei, with an average age of 71 (Graves et al., 1999; McCormick et al., 1996). Since 11 years have passed, the number within this cohort would be further diminished. Moreover, including the Sansei should more accurately reflect family perspectives of the deceased over-60 population since Sansei themselves are aging and are increasingly involved in end-of-life decision making for their parents and spouses. Interviews occurred at a place of the participant's choice, including their place of residence or any location mutually agreeable to the participants and the researcher.

Inclusion Criteria

Inclusion criteria included: (1) U.S. citizenship; (2) English speaking; (3) self-identified as Nisei and Sansei Japanese Americans with both parents Japanese Americans; (4) over 40 years old; (5) having a deceased family member 60 years old or older who died more than three months previously but less than five years ago; and (6) having experienced decisions making about withholding and/or withdrawing treatment for the deceased family member. A Shin-Issei (means new Issei) who immigrated to the U.S. after WWII was originally excluded from this study. However, the researcher with consent of her committee and Oregon Health and Science University (OHSU) Internal Review Board (IRB) approval included the Shin-Issei in the study since she had lived in the U.S. over 40 years.

Most inclusion criteria were set to establish a certain level of homogeneity, to reflect family perspectives, and to avoid extraneous analysis. The time frame of 3 months to 5 years after the death was selected based on other researchers' experience and recommendations (Hansen, 2002; Lee, 2001; Suzuki, 1997; Tilden, Drach, Tolle, Rosenfeld, & Hickman, 2002). As part of their tradition, Japanese hold weekly grievance ceremonies until the 49th day after the family member's death. The 49th day is considered the day the deceased moves on to the next life, and Japanese family members feel their responsibility has been carried out. Interviewing Japanese participants after the 49th day would appear to be an appropriate timeframe. However, investigators in a previous study reported that even 60 days after the death of a family member, surviving family members were still too vulnerable to be interviewed; a 49% refusal rate by those who lost their family member one-to-two months earlier confirmed this view (Tilden et al., 2001).

Recruitment of Study Participants

After approval by the dissertation committee and OHSU IRB, formal recruitment began. Personal contacts with community leaders and other associates, advertisement on bulletin boards in Japanese-American community organizations, visits to health care facilities, and churches and temples in the Japanese-American communities were carried out (see Appendix D). One member of the dissertation committee with research experience about the Japanese-American community in the area assisted with contacts, and two members provided indirect personal contacts. A Japanese-American community organization that focused on the provision of a continuum of culturally appropriate long-term care service for Japanese Americans was contacted. The organization services include a retirement home, assisted living, nursing home, meal programs, adult daycare, and intergenerational daycare in which Japanese culture influenced the care given, including activities, meals, and the language spoken. In all cases, the researcher made initial contact with key informants and potential intermediaries (e.g., directors, managers, social workers, and religious leaders in Japanese-American communities) by phone and regular or electronic mail (see Appendix E). She then spent six days in the area visiting community facilities to recruit potential participants. Snowball sampling (referral by study participants) was also used.

Screening Potential Participants

Ideally, potential participants who saw advertisements about the study would initiate contact with the researcher because of their interest. However, in reality, the researcher more often identified and contacted potential participants through key informants, personal contacts, and organizations. A master list, which included the name, telephone number, and address of possible participants, eligibility criteria check boxes, and codes was constructed (see Appendix F). Potential participants were initially contacted by phone or mail, whichever seemed most appropriate. The researcher introduced herself and explained the referral source to each potential participant. She then described the study and informed them that the information gained from the interview would be used to describe the process and experience of Japanese Americans who have made end-of-life decisions for a recently deceased family member in hopes of improving culturally sensitive care by health care professionals. If the potential participant expressed interest in the study, study eligibility was determined by telephone screening using the inclusion criteria (see Appendix G). During the screening, the researcher realized that it was difficult for the family member to determine what withholding and/or withdrawing of life-sustaining treatment means and limiting the treatment decision only to those the researcher chose as examples would not reflect the purpose of this exploratory study. For example, hospice was not included in the criteria, but choosing a hospice program means to withhold life-support treatments. In addition, some families chose to have I.V. therapy under hospice care. Oxygen therapy and blood transfusion were other examples. Since treatment decisions varied and this was an exploratory study, an "other treatments" section was additionally created.

All those contacted by telephone met study criteria and wished to participate. Hence, they were told that an interview would be set up either in their place of residence or in an alternative mutually agreeable location that allowed privacy. Written consent would be obtained prior to the interview (see Appendix H). Participants were forewarned that the interviews might evoke painful emotions, assured that they could withdraw from the study at any time, and told that if they needed to debrief or be referred, their preferred resource or community agency would be contacted for counseling. Participants who completed interviews for the study were thereafter referred to as informants.

Data Collection

Design in the grounded theory approach consists of four components: theoretical sampling; coding with constant comparative analysis, emergence of themes, and saturation of data (Creswell, 1998). In grounded theory, data collection and data analysis occur simultaneously. After initial sampling and data collection, the researcher's concerns and questions arise from the initial data analysis, which lead to the selection of the next subjects who will be able to answer these concerns. This is called theoretical sampling. Data collection ends when responses become redundant, that is, saturation of data occurs since the unit of analysis is concepts associated with a phenomenon, not individuals or groups.

A semi-structured interview, constructed with consultation with dissertation committee members, was used to guide the interview with participants (see Appendix I). Prior to data collection, sample questions were pilot-tested, discussed with committee members and community key informants, and revised to ensure appropriateness. A one-page questionnaire completed by the researcher was developed to record demographic data gathered from each participant.

Qualitative data about end-of-life decision making were collected using open-ended semi-structured interview questions. The initial semi-structured interview questions with initial participants were broad. Questions about the end-of life decision-making experience became more specific as the study progressed and the research problem was better understood. Along with qualitative data, demographic data such as age, gender, and religious affiliation of both the participant and his/her deceased family member, participant's generation and relationship to the deceased; the date, cause, and place of death of the deceased; and the types and the length of the deceased family member's illness were collected to understand contextual factors within the situation (see Appendix J).

Data Collection Procedure

A one-time interview for up to 1-1.5 hours was the primary method used to collect data. Because of the sensitive nature of the topic, the researcher made every attempt to maintain privacy within the location selected by the participant. Interviews were audiotaped with the consent of the participants. After obtaining written consent, interviewing began with an open ended question related to the substantive focus of the study. Four focus areas included experience and process around decision making, the use of ADs, perspectives about the decision made, and comments to health care providers. Each participant was asked to share his/her experience of what it was like to be a family member when the deceased family member's health was failing and death appeared imminent. If not covered by the participant, probes were used to elicit further description. Probes included questions about what made the decision easier or difficult to make, and what was the role and involvement of the family members, including the deceased family member, in making decisions. Participants were specifically asked about the use of ADs to guide decisions about withholding or withdrawal of treatment at the end of life if ADs were not mentioned. Next, participants were asked about feelings they experienced when the decision was made to withhold and/or withdraw treatment, when the decision was implemented, at the time of their family members' death, and at the present. Before ending the interview, the researcher asked if the participants had any advice for health care providers. Lastly, she checked to be sure all demographic data information was recorded. In addition to data obtained by interview, participant observation and researcher reflection on the interview were included as data in the analysis (see Appendix K).

Since data collection and analysis occurs concurrently in this qualitative method, the researcher's questions that arose from an initial data analysis of interviews contributed to the selection of subsequent participants who would likely be able to address these questions (i.e., theoretical sampling). However, concurrent data collection and analysis was modified since the researcher lived at a considerable distance from the data collection site. A set of interviews instead of an individual interview were analyzed together. The researcher's concerns and questions that arose from this initial data analysis became questions for the next set of subjects. Data collection continued until data saturation occurred; in other words, when data were redundant or did not include new information, data collection ended.

Protection of Human Subject

As described previously, approval of the research protocol by the OHSU IRB was obtained prior to recruitment of participants. Written informed consent was obtained from each participant prior to being enrolled in the study. Each participant was informed of the study purpose, procedures, potential risks and benefits, confidentiality, contact information, and the voluntary nature of participation, including the right to withdraw from the study at any time. Participants were forewarned that the interviews might evoke painful emotions and that they could choose not to respond to specific questions if they wished. Confidentiality was maintained by removing identifying information from the interview transcripts and other data sources and by using number codes for participants. All the material used for interviewing, screening sheets, recorded tapes of interviews, and transcriptions of the interviews were kept in a locked file cabinet. Data entered into the computer for analysis were password protected. To insure confidentiality, the master list of participants' names associated with code numbers was kept separately from all interview materials and other data. The screening sheets, recorded tapes of interviews, and the master list of participants were destroyed upon completion of the study.

Data Analysis

Descriptive statistics (e.g., percentages) were used to describe the characteristics of the participants in this study. Demographic data also were used to facilitate comparisons of recently deceased family members and health situations related to end-of-life decisions.

Audiotaped interview data were transcribed verbatim for analysis by the researcher and two medical transcriptionists. Japanese words were translated when needed to clarify meaning. Since English is the second language for the researcher, one of her committee members double checked her transcription for accuracy. After each transcript was verified and read repeatedly to grasp a sense of the story, theoretical memos with persistent observations were organized. Then, transcribed data from the interviews were entered into the QSR NUD-IST version 6.0 software program to facilitate data analysis. Substantive (open) coding, close to line by line method (the unit of analysis was words and phrases) was exercised. Half of the data and a coding book with definitions were shared with the committee members to ensure dependability of the data. Examples of the codes were "patient characteristics" and "decision." All coding of data was done by the researcher. With monthly discussions with the committee, the first model was shaped tentatively. Based on the categories chosen in the first model, theoretical coding was employed. This time, the unit of analysis became sentences and paragraphs. Elements within the situation were isolated and described (e.g., this is an instance of this element, and that is not), descriptive statements about each element in a situation were formed, then such descriptive statements were applied to other instances within the data (Blumer, 1969; Charon, 1989). The relationships between elements were analyzed and described. Looking for similarities, differences, and patterns in the codes, focusing on end-of-life decisions to withhold and/or withdraw life-sustaining treatment in data, and alternating inductive and deductive approaches to data were emphasized. Extraction of the significance and characteristics from data and weekly discussions with two methodologists on the committee enabled the researcher to develop the second model. Examples of the codes were "decline in patient health" and "factors affecting decision." Finally, the unit of analysis became concepts, and higher level conceptualization and parsimony led to developing the model presented in this dissertation.

Methodological Rigor

Employing specific research evaluation criteria in designing and conducting the study increases methodological rigor. For example, data analysis approaches aimed at ensuring credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1994) were employed.

Credibility. Prolonged engagement and persistent observation with participants verified the quality of data. Member checks confirmed trustworthiness and promoted fairness and authenticity. For this purpose, permission to contact participants again at a later date was included in the informed consent in case a second interview was needed to verify data obtained in the study. In addition, the researcher was credible in this culturally sensitive study since she is Japanese and has had exposure to both Japanese and American cultures and experience in health care setting as a clinical nurse.

Transferability. Rich, thick description of one minority Asian-American population with a wider range of illness type and sample enabled readers to decide if the results of this study would be applicable to other minority populations regarding end-of-life decision making. However, this study is limited to the extent that the study was undertaken in one location in the U.S.

Dependability. For research within the symbolic interaction perspective, a document was considered to be subjective as an account of human experience as well as objective as a record, enabling others (i.e., committee members) to have access to the data and encouraging the researcher to return always to them. By so doing (called audit trail or external audit), dependability is more likely established (Blumer, 1969). The dissertation committee participated in the process of data analysis to ensure dependability by peer review and debriefing (Guba & Lincoln, 1994).

Confirmability. This point in part overlaps with dependability. Using peer review or debriefing increased an objective view of the researcher. Debriefing sessions were instrumental in clarifying the researcher's bias, identifying analytical weaknesses, and stimulating thinking about the data and further conceptualization of the model.

CHAPTER 4

Results

Sample

Recruitment

A total of 18 participants were identified and contacted by the researcher or intermediaries over a five month period. Of the 16 who agreed to participate, 6 were obtained through religious leaders, 5 through snowballing, 3 through personal contacts, and 1 each through a community organization and poster advertisement. One potential participant contacted by a participant (i.e., snowballing) declined to participate since it was too early for her to talk about the deceased (five months after her mother died). Another potential participant identified through personal contact cancelled the interview because she did not feel she had anything to offer since her mother died so suddenly.

An interview was arranged with the 16 eligible participants either in their place of residence (5) or in an alternative mutually agreeable location that allowed privacy (8 cases in a private room of public building such as church, nursing home, and library; 2 cases in restaurants; and 1 case in a park).

As shown in Table 1, there were 22 cases of a family member's death described by the 16 participants. This included 1 case that occurred less than 3 months prior to interview and 3 cases that occurred more than 5 years ago. The expansion of the time frame of 3 months to 5 years after the death as described in inclusion criteria occurred unintentionally. All the participants met inclusion criteria; however, they spontaneously shared experiences about other deaths of family members in addition to the target

Table 1

Years since Family Member's Death and Number of Cases Described by Informants

Years since family member's death	Number of cases
< 1	3
1 - < 2	4
2 - < 3	6
3 - < 4	2
4 - < 5	4
> 5	3

deceased member who met sampling criteria. The researcher decided data about all 22 cases were relevant to include for three reasons. First, the expansion occurred naturally in that participants shared information that they viewed as relevant to the research spontaneously. It would have been awkward to stop the participants from sharing this information during interviews. Secondly, the stories were recorded so that discarding relevant information would have been a waste of the informant's time and contrary to the underlying principles of the methodology. Finally, the researcher and her committee members agreed that the data were pertinent to the aims of the study.

Family Informants (Informants)

A combination of purposive and convenience sampling strategies were used to assure that the sample would include informants with a broad range of blood relationships with the deceased family member, generations, and experiences in decision

Table 2

Generational Groups and Age of Informants at Interview

	Generational Group							
	Shin Issei		Nisei		Sansei			
	Gender		Gender		Gender			
Age	M	F	M	F	M	F	Total	%
<70	0	1	1	0	2	4	8	50
≥70	0	0	2	5	1	0	8	50
Total	0	1	3	5	3	4	16	
%	0	6.3	18.8	31.3	18.8	25		100

making. The sample (n = 16) included 10 females (62.5%), and 6 males (34.5%). Informants' age ranged from 40-89 years old. Generation by immigrant status included 1 Shin-Issei (6.3%), 8 Niseis (50%) and 7 Sanseis (43.8%) as shown in Table 2. A Shin-Issei (means new Issei) who immigrated to the U.S. after WWII would originally have been excluded from this study. However, because she had lived in the U.S. for over 40 years, this criterion was amended. The researcher with her committee's consent obtained approval from the IRB at OHSU for this change.

Deceased Family Member (Family Member)

A total of 22 cases were described by 16 informants (two informants were relatives of one deceased family member). Six informants lost more than one family member. The cases included 12 females (54.5%) and 10 males (45.5%). As shown in Table 3, generations included were: 4 Isseis (18.2%), 1 Chinese Issei (4.5%), 15 Niseis

Table 3

Generational Groups and Age of Deceased Family Member at Time of Informant's Interview

	Generational Group									
	Issei		Chinese Issei		Nisei		Sansei			
	Gender		Gender		Gender		Gender			
Age	M	F	M	F	M	F	M	F	Total	%
70's	0	0	0	0	5	1	2	0	8	36.4
80's	0	0	1	0	1	6	0	0	8	36.4
90's	0	3	0	0	1	1	0	0	5	22.7
100's	0	1	0	0	0	0	0	0	1	4.5
Total	0	4	1	0	7	8	2	0	22	
%	0	18.2	4.5	0	31.8	36.4	9.1	0		100

(68.2%) and 2 Sanseis (9.1%). Their ages ranged from 71 to 102 years old. Table 4 shows characteristics of the cases of deceased family members. According to informants, the major causes of death included 9 cases of mutli-system failure (40.9%), 5 cases each of cardiovascular disease (22.7%) and cancer (22.7%), 3 cases of cerebro-vascular accident (13.6%) and one case of iatrogenic cause (4.5%). The places of death were: 9 cases in the hospital (40.9%), 8 cases in a nursing home (36.4%), and 5 cases at home (22.7%). Hospice care was provided in 7 cases (31.8%). Among the 22 cases, 17 deceased family members had ADs; 13 cases decided by themselves in either a living will

Table 4

Characteristics of the Cases of Deceased Family Members

	Categories	Deceased Family Members
Relationship of the deceased family member to informant	Husband	5
	Father	4
	Mother	9
	Mother-in-law	1
	Aunt	2
	Brother	1
	Sister	1
Place of death	Hospital	9
	Nursing Home/Hospice	8/5
	Home/Hospice	5/2
Cause of death	MSF	9
	CVD	5
	Cancer	5
	CVA	3
	Iatrogenic cause	1

MSF=Multi System Failure (aging, infection), CVD=CardioVascular Disease,

CVA=Cerebro Vascular Accident

or power of attorney for health care, or both; 3 cases deferred to informants or other family member verbally; and in the case of a person with dementia, he verbalized his wishes and his family completed the AD on admission to the facility.

The relationship of the deceased family member to the informants were husband in 5 cases (21.7%), mother in 9 cases (39.1%) and mother-in-law in 1 case (4.3%), father in 4 cases (17.3%), aunt in 2 cases (8.7%), brother in 1 case (4.3%), and sister in 1 case (4.3%). One case was described by two related informants.

Findings

The aims of this study were to describe: (a) the process that Japanese-American family members used to make end-of-life decisions for their recently deceased family members, including the influence of traditional values among the different generational groups; (b) their experience of making such decisions within the context of the PSDA and the current U.S. health care system; and (c) their perspectives associated with the decisions after the family member's death, including the meanings that the decision, experience, and family member's death held for them. In this study, end-of-life decisions included decisions to withdraw or withhold life-sustaining treatment at the end of the family member's life and were inclusive of hospice.

Introduction of the Model: The Four Dimensions of Family Understanding in End-of-Life Decision Making among Japanese-American Families as Influenced by Generational Values and Health Care Providers

Figure 1 shows the relationships among the four dimensions of family understanding, and influence of generational values and health care providers, in end-of-life decision-making experiences of Japanese-American families. The dimensions, influencing factors and relationship will be described and illustrated in this section.

The process that Japanese-American families used to make end-of-life decisions for their family members was characterized by four dimensions of family understanding. Each of these dimensions occurred along a continuum from low understanding to high understanding. The first dimension of family understanding, Awareness of Seriousness of Condition, was associated with the illness or aging trajectory, indicating a degree of the informant's awareness of the deceased family member's serious health condition. The second dimension of family understanding, Decision-Making Process, was about the deceased family member's wishes. In the end-of-life decision-making process, two significant factors were identified. These factors were a level of clear discussion about the deceased family member's treatment including the wishes of both the deceased family member and the informant, and who implemented the decisions. The third dimension of family understanding, Readiness for Impending Death, was the informant's readiness to accept the family member's death. The final dimension of family understanding, Experience of the Dying Process, involved the informants' experiences of the family member's dying process. Additionally, these four dimensions were influenced by both health care providers and generational values of the informants. These dimensions of family understanding occurred along a continuum. Even when categories were found and named, family experiences would locate at some point on the continuum.

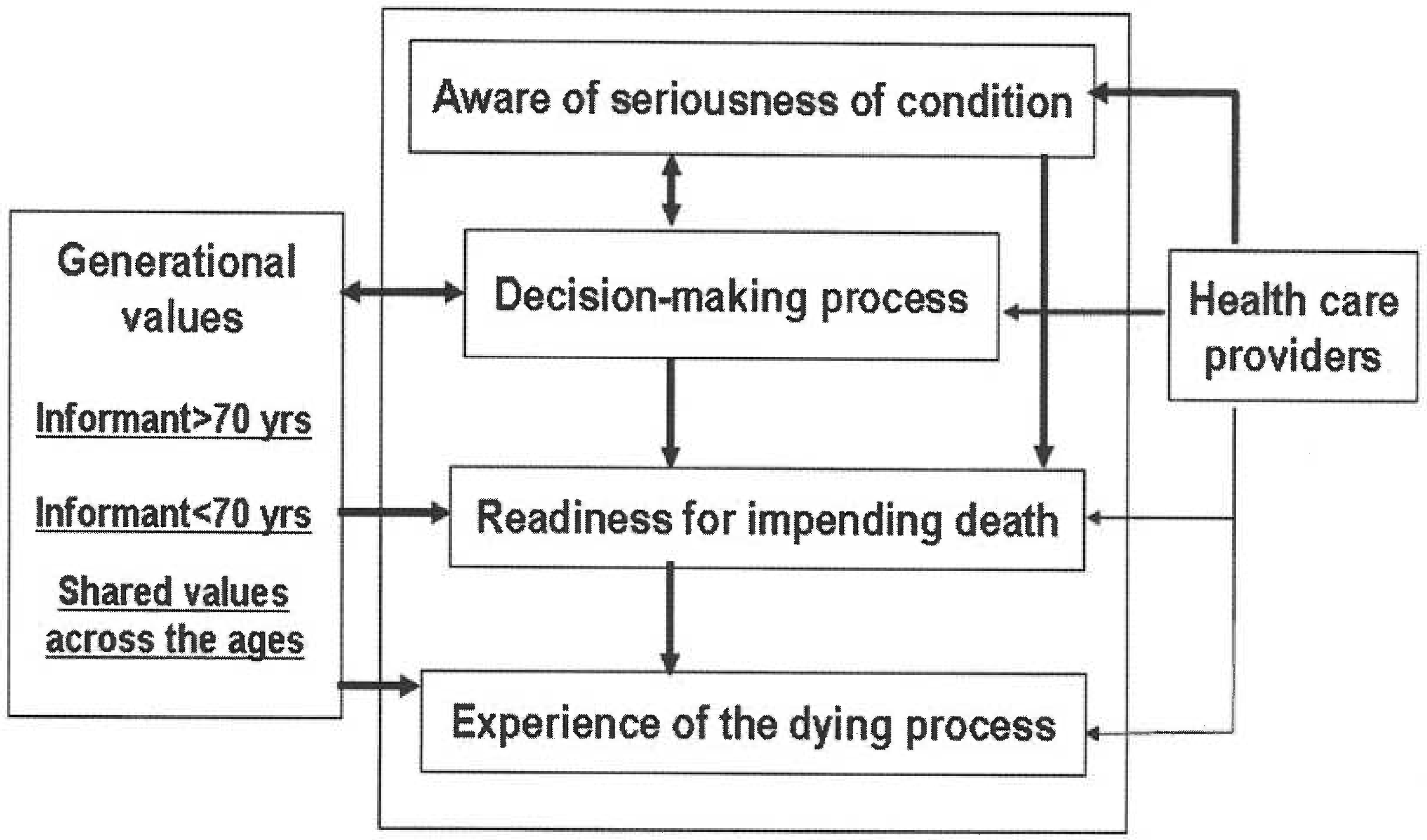

Figure 1. The four dimensions of family understanding in end-of-life decision making among Japanese-American families as influenced by generational values and health care providers

Dimension One: Awareness of Seriousness of Condition

Definition

Informant's awareness of the deceased family member's seriousness of condition was a preceding condition for the decision-making process and was defined as the informant's level of awareness that the family member would die within a week. Their awareness depended on their judgment about their family member's physical or mental condition.

Continuum of Awareness of Seriousness of Condition

The lack of awareness and awareness of declining health comprised the continuum of Awareness of Seriousness of Condition.

Lack of awareness. Lack of awareness occurred when informants were not aware of the family member's illness condition. The situation was described as "sudden death."

> C: The very day that I was ready to go to Germany, my sister and brother called me, and told me that my father wasn't feeling good. So he ended up going to the hospital. … So I asked [mother], "Did you want me to come home?" She said "Yes." So I made arrangements for my ticket to be changed to go from Boston to Denver instead of Boston to Frankfurt. … When I took a flight back to Denver … my brother picked me up at the airport. That's when he told me my father passed away.

Awareness of declining health. Awareness of declining health was further divided into two aspects: recovery expected and no recovery expected.

Awareness with recovery expected. When a family member was alert at the last visit, the informants expected the family member to recover or that the family member would have lived longer. As a result, the family member was brought to a hospital to receive treatment.

> N: It was not the worst thing so far, as difficult breathing I've seen, but in her condition ... she needed to be seen. So I wanted to have her checked. And … I certainly didn't think it was her last [hospitalization].

Awareness with no recovery expected. Some informants were fully aware of the family member's declining health and no recovery was expected. Perceived forewarning signs included no recognition of informants, no communication ability, and no swallowing ability. This awareness was especially clear when an aged (over 80 years old) or chronically ill family member had a change in their physical or mental condition.

> D: Last two weeks you could see how … she's getting weaker and weaker and weaker and … last few days she can hardly get out of the bed, … So there're a lot more forewarning that end is near. So we were all kind of around. … pretty much whole time last few days … all her sons and families and stuff.

Dimension Two: Decision-Making Process

Definition

Decision-making process was defined as a systematic series of actions directed to an ending or conclusion including execution of the conclusion. How family member's wishes were expressed; how informant's wishes about the family member's treatment were expressed; who would be involved; who was a key person for making decisions; and who implemented the decisions illustrated the family interactions and dynamics of the decision-making process.

Continuum of Decision-Making Process

Decision-making process consisted of two phases. The first phase was decisional phase, to make a decision; the second phase was executional phase, to implement the decision. Both phases involved a balance between informant's perceptions of the deceased family member's wishes and the informant's wishes in treating the family member.

Decisional phase. In the decisional phase, three types of family discussions were identified based on the communication style between a deceased family member and his/her informant. Three types of family discussions were no discussion, implicit knowing, and explicit discussion.

No discussion. Informants perceived no discussion ever occurred when they could not communicate verbally with the family member or when they did not feel that they had understood the family member's thoughts or wishes. Several reasons were given for no discussion, including the family member's refusal of discussion, the informant's difficulty in bringing up the topic, or distance.

S: He wasn't ever discussing that he's going to die. He never discussed it.

Implicit knowing. Implicit knowing/communication style was characterized as no open or direct discussion among the family about a family member's wishes, but informants felt that they understood the family member's thoughts or wishes without discussion or written words. Reasons given for this approach included language barriers, the "Japanese way," and refusal or no initiation of discussion.

> Z: We ... no we never ... we just had an understanding we would not use life support. We never discussed it.

Another example was that of a Sansei male faced with the decision of withdrawing life support. He described the non-verbal communication he used in his decision making.

> G: … facial expression or body language or … maybe unspoken type of feeling, because you can feel that.

Explicit discussion. Explicit style, on the other hand, denoted that a family member and his/her informants exchanged opinions, thoughts, and wishes. Thus, the informants felt that they understood their family member's wishes through words. All family members using this type of discussion had AD.

> I: … so we … had always just been talking about it. So it wasn't like a major decision that had to be made at one time. I think we all knew what direction we were going in, and we were all really united in our thinking.

Implementation phase. The second phase in the decision-making process was to implement the decision made. Three types of key persons identified were others, informants, and family members.

Others as a key person. A Shin-Issei female faced a "no alternative" situation when a physician refused to place a dialysis line in her disoriented husband. Neither the family member's wishes nor the informant's wishes were considered in this case.

> P: … But the third time (hospital visit). Ah … hospital doctor refused to [place a dialysis line]. "[Gee] this patient!" They know, he … moves around. [So the doctor] can't do [it] … So [at last … he] didn't [do it]. … Just [he said,] "I can't do that." Like that (mimicking the doctor's action to take a look back quickly). It's really awful [of] doctor's attitude. Yeah.

Informant as a key person. Most of the informants implemented the decisions. Three such cases were a) a decision maker was an informant; b) a family member deferred authority to the informant and c) a family member became mentally incapacitated near the end.

In the first case, when an informant was a decision maker, he/she also implemented the decision. This case involved only adult children of a deceased family member. Two types of balance between the family member's wishes and the informant's wishes about treatment were recognized. The two types of balance are to weigh more an informant's wishes than the family member's and the other way around. The following was an example when an informant weighed his wishes more than the deceased family member.

> Z: The Japanese don't need verbal communication. We say we understand that which is not said. The trouble is I was too American. I wanted to talk about it and I changed my mind. I should have [done] what we understood. My mother wasn't going to go along with life support system. She didn't want it.

When a Sansei male was faced with making a decision to withdraw life support, he and his siblings weighed their own interests and hopes at first. Then they reconsidered and weighed the family member's best interests.

> G: … And the doctor told us, "Do you wanna remove …?" Initial thought was yeah let's - let's keep the life support on. … let's keep it on and see what … if she can get through it; maybe things get better ... But that was into the first half one hour. You know at that time, the consensus of thought was yeah we keep it on. … keep it on. But then … the doctor came in again and said … there is nothing right now that he can do to alleviate the pain. … So … we had to decide that for her, not in our best interest but for, in her, in her best interest. … And so after about two hours, you know we yeah … we both said, "Yeah, yeah OK. We have to take the life support off and let and let her go."

In the second case, a family member expressed her deference for decision-making authority to the informant.

> Q: … I think towards the later part of her life, … to her anything was fine, … whatever, to her it was okay. "Yeah, that's fine."

In the third case, a family member became mentally incapacitated to exercise executional autonomy near the end because of advanced illness, stroke, or medication induced coma.

> F: ... because that was her desire. All I did was implement it. I didn't make any decisions for her. She made all those decisions herself. The only decision I made was probably the ... the [pain] patch. And I just felt like she wasn't going to do it and I didn't want her to go in pain and she would have ... the Japanese gaman (patience)? She would have done that I think and I didn't want her to have to do that. So that is probably the only decision I made.

Deceased family member as a key person. The deceased family member's wishes were carried out either with or without input from the rest of the family. When a husband of a Nisei female was dying, she didn't know his wishes. She figured it out through health care providers' behaviors.

> U: … So I don't' know what he wrote it in medical thing when he went to, but I kind of think he said he didn't want anything prolong for him … So that wouldn't be him [to prolong his life]. And so, but I don't know but because I only know by the way the hospital staff react.

Dimension Three: Readiness for Impending Death

Definition

Readiness for impending death was defined as the informants' level of readiness to face the family member's death within a day.

Continuum of Readiness for Impending Death

Surprised, ambivalence, and ready composed the continuum of informants' readiness for the family member's impending death.

Surprised. "Surprised" was used to categorize informants' readiness when they did not expect the death.

> N: Yeah. So … yeah … they (nurses) do say sometimes right before they (patients) get stronger … they do say that. But ah she was excited because she had a lot of people but I didn't think she was remarkably stronger and more alert. I don't think it was that remarkable a change. Otherwise, I would have been suspicious ... because I fully intended to be there. …Yeah, I would [have been] there. …

Ambivalence. Ambivalence was expressed by informants who decided to withdraw life support intentionally or unintentionally (forced to withdraw it by default with no alternative choice) or decided to use life support. Their feelings expressed were complex, but they believed it was the right thing to do or shikata ga nai (cannot be helped)

> G: But … at the time … when you see her there, and to recall the memories … and times past, it's very difficult. But, ah, when you take away your selfishness … because that's what it is. … You've been selfish you wanna keep her; ah, you don't wanna let her go. … you remember too many good things about her, but now you have to think about her first. … what's gonna be the best for her.

Ready. Informants were "ready" to accept the family member's death when he/she could not communicate with them and his/her recovery was not possible. When informants were "ready," they described the family member's condition objectively rather than emotionally and letting him/her go would be his/her wishes with dignity.

> F: … But, it was a peace ... it was peaceful. He wasn't contorted. It wasn't like … he was hurting, but Ru (nurse) also came in almost hourly on the hour and gave him morphine.

A Nisei male described the difficulty of being with his mother who experienced distressed breathing in the end. It was suffering for him. Letting her go quickly was his wish.

> O: While she was in a coma … near the last day or two, she was having a lot of respiratory distress, … When people are dying they breathe really difficult, and I was thinking it would be more comfortable for her if it went quickly, … so, even if I wasn't there and they called me, she had passed, I felt relief for her. Yeah. … distressed breathing. And it's not something very nice, and being with them (friends passed away) at that time it's very difficult for me, and my mother was going through that, too. In all three cases I thought, "Gee, it would be nicer … they could be at peace." And … I think I thought better that all three did pass. It's the exact same breathing, … When they stop breathing, there's no hope

> anyway; it's a good thing. Maybe they are not suffering, but it seems when I'm there, it looks like they are suffering. …

Dimension Four: Experience of the Dying Process

Definition

Experience of the dying process was defined as the informants' perspectives after the family member's death in terms of their experience of the family member's dying process including decision-making process and the death itself.

Continuum of Experience of the Dying Process

Informants' experiences of the family member's dying process were categorized based on the stage (levels and types) of the informants' emotional state and their conceptualization about the death. Five categories identified were regret, prolonged grief, unresolved questions, resolution, and acceptance.

Regret. "Regret" about the whole situation was a central consequence when life support was used intentionally or unintentionally despite the family members' wishes. Informants realized that there was no second chance in end-of-life decision making. They would do differently if they could but it was final.

> Z: … Because I knew that that period of time we went through this reversal ... it didn't accomplish anything for my mother. In fact, it was worse. She didn't need to go through that. And the few more months that she survived, ultimately it was not meant for me either. It was bad for both of [us] ... it was obviously a poor decision, but my mother went along with her son's stupid decision.

Prolonged grief. Grief is part of the natural human response to loss, but some informants expressed their unresolved feelings. An unexpected death especially made it tougher for them to accept their family member's death. Feelings of missing and difficulty letting go were expressed.

> C: … Because it was sudden, and I didn't have a chance to … say good-bye while he was [alive] … right now it still hurts. … I had not to 100% to let go because I didn't have specific chance.

Unresolved questions. Perplexed feelings were expressed when a younger brother died earlier than the informant and when another informant questioned whether her late husband's wishes were carried out although she felt no regret about her care of him.

> P: Satisfaction yeah, I think so. But … for him [I wonder] this is good or not … because [he had] pain, pain, pain; then it'[d been] long time. [I] just [wonder] … if I [would not have] take[n] care of [his] diet … maybe he passed away earlier [and he hadn't needed to be suffered so long time].

Resolution. Resolution was defined as the creation of a personal meaning based on the informants' experiences to make sense of the family member's death. The experience included a deceased family member's denial of death, an informant's decision to withdraw all life support from the family member, and another informant's decision to go against the original mutual agreement with the family member and use a feeding tube. Informants searched for meaning of the death in spiritual or religious beliefs. Believing another dimension and searching self-identity were described. A common religious theme encompassing all three informants' experiences was summarized in the last informant's rationalization.

> Z: … my mother left me the legacy in her death what I never understood all her life. … I believe that that moment after death, even those who are not religious, turn to the more religious. … And that's a very interesting phenomena for me because as I understand Buddhism, Christianity, I have no problems because they all treat death as something good … Right? I mean ... better ... you're no longer old ... everything is better.

Acceptance. Informant's acceptance of the family member's death was expressed as being a blessing, something merciful or a relief. Satisfaction with decisions made or care provided, willingness to share the experience with others, unity of family, completion and a sense of a smooth transition, and dying with dignity were also expressed. Acceptance of death arose at the deathbed.

> F: So in that sense also when he went, it was a blessing for him. … At the end ... when he could no longer walk nor talk nor function and he wanted to go ... uh ... it was probably a blessing to let him go.

Alongside acceptance, expression of deep sadness related to the loss and reflection on one's own death were described. While hoping her mother found peace, a Sansei female described her deep feeling of loss.

> I: Oh, you know I think no matter how much you want them to go just for their own peace, I think, … there's just a real … sadness … it is just very, very sad. … And it gets sadder and sadder as you call people and tell them about it, … I'd call my brother, and then I'd call my children, and it just got sadder, and sadder, … And it's … it's hard, …

Some informants extended the acceptance of the family member's death to reflect on their own deaths. Those who were over 70 years old, tended to accept their own death.

> G: … I'm thinking … if I die today … I'm not going to see them any more, but … that's ok. I'm going to the pure land … So I don't worry about passing on. I mean sure you gonna miss a lot of things, but so what …

Those who were younger than 70 years old, however, expressed hesitation to accept their own death.

> I: … and I think it's hard for us to realize that we're the older generation now … Like my mother was the last of … my children's grandparents … And to all of a sudden realize, we're the oldest generation. So there's a lot of different feelings, I think.

Health Care Providers (HCPs)

HCPs influenced all four dimensions either to lower or heighten the family informant's understanding. However, the impact of HCPs on the four dimensions was not as strong as the relationship among the four dimensions except for the relation between HCPs and Awareness of Seriousness of Condition. The relationship between HCPs and the four dimensions will be discussed in the following sections.

Relation between HCPs and Awareness of Seriousness of Condition

HCPs affected the informant's awareness of the seriousness of family member's condition through medical diagnoses, treatment options, and prognoses by physicians, comments and suggestions by nurses and residents, and hospice services. When HCPs did not increase the informant's awareness, the informant's understanding of the family member's seriousness of condition stayed low. The following quote exemplified such a case.

> U: … I talked to him (surgeon). … He said, "It's really; if I open him at all. That would be it. I cannot." He tried to explain. And so I thought, "Well … he refused." That, that, that was that. … And it was three or four hours later, he (husband) was gone.

When HCPs enhanced the informant's awareness, the informant's understanding of the family member's seriousness of condition increased. Once the informant's awareness of the family member's seriousness of condition was raised, the decision-making process started.

> G: … last couple of hours doctor came and he said, "You know there is really not much hope. Ah … I don't wanna sugar coated or anything. Ah but you have to determine, you have to tell me, do you wanna keep life support system on?" And so I said, "How much time do you need?" He said, "We need to know in an hour or two."

Relation between HCPs and the Decision-Making Process

HCPs influenced the decision-making process by sharing their medical knowledge and information. Such an interaction directly affected the informant's implementation of a decision. An extreme example involved HCPs acting as an excutional decision maker so that the informant did not have a say. However, HCPs usually interacted with the informants. When medical knowledge and critical information for the end-of-life treatment was not shared appropriately, the informants' understanding of what should be implemented for their family member was poor. As a result, they missed an opportunity to decide and implement. A medical meeting with a Sansei female failed when she did not get a better picture of her father's condition. She remained in a state of confusion.

> K: ...So we had a meeting there in the hospital with one of these doctors and it was me, my two brothers and their wives, and so ... ah let's see ... I guess we wanted to know ... what was the prognosis. I mean, was he going to recover maybe, or was ... is this the way he was going to be or ... was he going to die soon or what ... And of course, ... I don't think he could say ... he didn't say. And my sister-in-law who ... has been a nurse for years, and I'm sure she has seen many people ... anyway she was asking the doctor something about a ... what was she asking him? ... Something about a morphine drip or something ... and he said, "Oh, yeah, yeah, we can ..." And then we were trying to find out what he was being given in the I.V. ... But I guess I was very confused as to what the real situation was. Because sometimes it seemed that he might recover, you know, and other times it seemed, "Well, maybe not" ...

On the other hand, the informant's understanding of what should be implemented for their family member was clear when medical knowledge and critical information for the end-of-life treatment was shared appropriately.

> O: ... I thought, "Well, maybe because her mouth is dry that maybe we should give her I.V. fluids." And the Hospice nurse was very helpful ... next day, the

> Hospice nurse came and she says … "If you give a person in a coma I.V. fluid and they already have distressed respiratory problems, you could cause pulmonary edema, and they will be not comfortable." And she said it's up to us but "You might take that into consideration." So that was real good advice. And then … her doctor's nurse … nurse practitioner also came and said the same thing. So we decided that we're no'gonna do anything. Yeah. And so, since the decision had been made, now reflecting back, it was not difficult. It was already decided … it was her decision.

Relation between HCPs and Readiness for Impending Death

HCPs could assist the family informants to accept their family member's imminent death by explaining his/her critical condition objectively. When HCPs could not give a clear purpose of the treatment, the informant's understanding of readiness for the family member's impending death was ambivalent.

> K: … And I remember talking to, um, one of the nurses … "Isn't that sugar water keeping him alive?" … And "Isn't that considered life support?" And it's sort of like … they said, "No, it's not life support, it's just something that …" I don't know. But I think what he was getting was probably life support. It was probably keeping him alive.

To be ready themselves for their family member's impending death, the informants depended on HCPs' medical knowledge and experiences. Timing of HCPs' action became crucial for the informants' readiness. The following quote illustrated that HCPs successfully informed the informants about a family member's impending death by a telephone call.

> F: … at six o'clock in the morning I got a telephone call from Ru, the head nurse, and he said, "F, I think you might want to come today. I think your husband's going to go today." So I called my daughter and I called … H only had one brother ... one living brother. And so I called T and I said, "Ru just called and he said he thinks your brother is going to pass on today."

In contrast, timing of information was not optimal in some instances.

> D: … he was … weak and not feeling very good, so nurse came and "Oh your blood pressure is very low. So you need to go the ..." So he went to the hospital, and yeah the doctor said, "You need to get some fluid,“ and … he was receiving the second bag and … Actually I think because he was doing jerking or stuff like that, nurses were thinking he might be passing away so she did try to call us … (cough) So that we were, my brother and I were driving back, driving to the hospital, and then he, by the time I got there, he was already passed away. So it was too late, yea, but then he never regain consciousness either, so we were never able to talk to him. So yeah, .. (cough) … So it was kind of shock … so all of us got phone call from my mom from the hospital … but …

Relation between HCPs and Experience of the Dying Process

Unfortunately some HCPs failed to support the informants in accepting their family member's death. A Nisei female who suddenly lost her husband described her situation.

> T: I was told by various people that I would be put in contact with the counseling circles, but I never was. … After he died, they said they would send me names, but I never received any names of people who had grief counseling or grief groups; I don't know what they are called. … Oh, absolutely, I think that [I am an outsider], but I don't think I am alone. I think that if they neglected to let me … to give me a list of people to contact, I think other people are treated the same way. I don't think I am an exception. … They mean well, when they say "We will give you names," but they forget. I don't think it's a top priority … I think I am still grieving for him. But I think I had to accept his death right away.

On the other hand, an informant denied the need for any support from outside, suggesting that not all individuals desire referrals from HCPs for their grieving process.

> G: Well I don't think any input from outside would help. … I think it's soul searching … that you have to look into within yourself. I don't think if it's any outside input other than doctor's saying there is no hope. … The doctor said there is no hope; I mean what would you [want] to do? I mean just keep prolonging agony and pain?

Generational Values

Definition

Generational values were defined as the social principles, goals, or standards held or accepted by the specific generational cohort.

Components of Generational Values

Two grouping methods were examined to compare which group would reflect better generational differences derived from data: immigrational group such as Nisei and Sansei versus age cohort. Interview data supported values that were expressed differently by two age cohorts rather than by two immigrational groups. Because the values of the informants were influenced by their living environment and historical events, there appeared a distinguishing line at 70 years of age. The living environment and historical events did not accurately reflect value differences between the two immigrational groups as anticipated. Therefore, the informant's age, whether over 70 or younger than 70, was used for classifying generational values.

Informants older than 70 years old. The values illustrated by the informants who were older than 70 years old included homogeneity of Japanese society, filial piety and obligation, obedience, and paternalism. Each value will be explained in more detail in the following sections.

Homogeneity of Japanese society. Homogeneity of Japanese society reflected a common environment while growing-up, emphasizing Japanese traditions for the older cohort. The following quotes illustrated its essence.

> Z: … There are certain understandings when you're homogenous. And we were homogenous at the beginning because my parents lived in a ghetto of Japanese

> people and my friends were of Japanese background. … Japanese people live by community.

> This Nisei male further elaborated what it was like to be a growing up Nisei.

> Z: But I'm a firm believer that maybe even if my mother and father and I had a better communications of language, I don't know if we would have communicated that much better, because we're still coming from two different ... cultures. And it might have been much more divisive, much more argumentative because I'm certain they expected their son and daughter to do what we were told. In America that's very difficult. … If it's good or bad, I'm not saying. I'm just saying that's my culture, that's my background, my peer local. Now, I think all of the Japanese-American Niseis, we were confused. So, you know? Some of them denied our culture … My parents' culture. So, if my parents made me musubi (rice ball) for school to eat, I threw it away. I wanted peanut butter sandwiches which I don't like. That wasn't American. So, in many funny ways we didn't speak the language because that wasn't American. But that wasn't true for Chinese. But we were put away during the war. So we wanted to be American. Okay? So I was embarrassed on my mother and father because they couldn't speak English like my friends, my Hakujin (White) friends could. So all these things I had to overcome in America.

Filial piety and obligation. Filial piety and obligation were well depicted by a Sansei male who had given direct care to his parents for 12 years.

> G: … And my friend was saying, "You know G, you're spending all your time taking care of your parents." I said "Why? I think … when I was a little child, they took care of me. So now it's pay back time." So I didn't mind ten, twelve years that they took out of my life because they had to devote their life when I needed, when I was not able to take care of myself. Even when we were internment during World War Two, in camps, you know, they took care of me. So I didn't mind it …. So but looking back and retrospect, I am very fortunate that I was able to do that.

Obedience. Obedience was reflected in a willingness to carry out authoritative orders by elders.

> U: … And somebody that might a been a mother or father have overridden whatever they said; "So we're gonna do this way." [Then children would have] no feel[ing against] it. That, that would be natural …

Paternalism. Paternalism is the belief that another person would know what is best or can make decisions for another individual.

> N: … One thing I regret is mom say, "Why do you just talk to him (physician)? Why doesn't he talk to me?" … And I didn't really think much about it. She wanted to know what is going on. She pretty much could tell, but sometimes because doctors always kind to her before and afterward, but all the medical kinds of things he would talk to me; she didn't like that (laugh) … But I didn't want to spend ... that much extra time for doctor. That's why I told her, "It takes so long." Yeah … then she didn't say anything (laugh) … Later I thought I should have you know … That thought came to me one time, a couple of years after … "You know I should have" (laugh).

Informants younger than 70 years old. The younger cohort grew up in a more heterogeneous society beyond the homogeneity of traditional Japanese communities and valued individual autonomy and quality of life.

Heterogeneity of society. Heterogeneous society was described as being an open society, having a "really strong support system" outside the family, their friends being "more Caucasian than Japanese," and "talking more" about family affairs without the shameful feelings that more traditional Japanese like Isseis might have.

Individual autonomy. The younger cohort valued individual autonomy, particularly the right to know, respect of individual independence, and respect of individual decision making.

> D: … I think it's just general, United States people like to know, even it's hard they like to know. Because it is easier to … deal with.

> O: … I think a lot of it was based on trust between she and I … I always told her the truth and I never hid anything from her and I always gave her a choice. I never made her do anything and … but I would … if she asked me, I would give her my opinion, and I think she respected my opinion and generally, 90% of the time, she was always very cooperative, yeah.

Quality of life. Quality of life was the second most emphasized value by the younger cohort.

> F: … at the end he wanted to go. He had no quality [of] life. He was very vibrant. He did all these things in his past, and he couldn't do anything and he was being diapered and ... he couldn't even go to the dining room because they had to lift him in a hammock with and he doesn't like height and so he couldn't even sit in a wheelchair without being lifted … at the end he also was not happy with his quality of life and he wanted to go.

Shared values across the ages. Four values were described in both groups: language, power relationships within the family, no complaints, and not to be a burden. The last two values were derived from the informant's perception of the family member's values.

Language. Daily communication between parents and children was a concern for some family. Most of Niseis and Sansei were fluent in English but not in all the cases. The communication between Isseis and Niseis for some families was a bigger concern.

> O: …it was typical Nisei language. My mother and I, we spoke a mixture of English and Japanese all mixed together. And I spoke English with a Japanese accent. That's the way my mother spoke English. It was … I think it's typical of Issei-Nisei relationships, and also, my mother used like Meiji Japanese.
>
> Z: But I don't think in my culture of my parents, of myself, we ever discussed anything ... and I think not because we weren't able to ... I think it's because we lost our ability of language. I never had a father-son or a mother-son talk. Never. Because we could not communicate. Because I had not enough Japanese and they had not enough English, so we only talked simple things … We understood many things that we never talked about. It's not because it's Japanese, we lost the ability to communicate.

Power relationships within the family. All informants described several types of family dynamics. Two major power relationships within the family related to decision making involved "being the first son" and "being an in-law."

All the male informants (n =6) were the only son or the first son. Two of them had an elder sister, but being the first son meant to the informants having responsibility and a special relationship with their mother.

> C: … both my parents are typical Japanese, so I don't think they have any type of living wills or any type of things set [up]. So we pretty much had to decide everything … because even though my sister is older than I am … I was the first born male. So everything pretty much … stay with me for making more decisions even though I was away.

> Z: … she would not listen to my sister. … I don't think if my sister had made that decision it would have been that simple. She would argue or resist my sister. She never did that to me …

> O: … I think there is a special bond between Japanese mothers and their son, maybe the way the mothers look at their sons.

Being an in-law was another theme derived from interviews. Except for three families, in-laws excused themselves from direct involvement in family matters in order not to create animosity.

> U: I think I will still do the same because she would go with [her own children] ... If it was my husband, that's different. She would have gone with it. But he would have gone what I woulda said. But ah with the rest, ah since there was some old family ties with that doctor and the family which I never had ... And so I think I still woulda backed down even today because that's the family wanted, right?

No complaints. Many informants characterized the deceased family member as not being a complainer. All deceased family members were over 70 years old so that this could be interpreted as an exercise of traditional Japanese values such as maintaining harmony, patience, and following a traditional proverb ("with age, you must obey your children,") or just their personalities.

> Q: … they always said "She was such a nice person, so easy going", and she didn't complain. Never complained.

Not to be a burden. Many deceased family members expressed wishes "not to be a burden" in any way or wished to continue "living an independent life." These expressions implied a desire not to place a physical burden upon the children. In addition, two family members did not reveal their cancer diagnoses to their sons at the beginning of the illness trajectory, due to their concern about a psychological burden. It took 6 months and 2 years, respectively, for the family members to reveal their illness to their spouse and children. Physical strain or an emergency surgery forced them to do so.

> G: Ah ... I said, he was a very private person very quiet and very reserved so ah and I don't know if it's going back to the Japanese you know background he kept to himself for I would say almost 6 months. Until one day when he had to go hospital and he had to be fed with the one of these bags, or he had to urinate into the bags systems just I guess bypass his normal system and he hated that, you know he'd had to wear oversized coat to disguise the bag he had to carry with him.
>
> D: … And actually he didn't even tell us about that. The kids. Because I guess he didn't want to worry that maybe Japanese thing, he didn't want to worry us or whatever, so … I think… about at that time, usually if you catch bladder cancer early, then if it's contain within a bladder, you remove the bladder, then you'll be ok. So that's they are hoping. Then two years later, it showed up again. So …

Relationships among the Constructs of the Model

Relation between Awareness of Seriousness of Condition and Decision-Making Process

The first dimension, informants' understanding of awareness of their family member's illness condition, included a continuum from being unaware to aware. The second dimension, their understanding of the decision-making process, was divided into two phases: the decisional phase and the executional phase. The decisional phase was further categorized into no discussion, implicit knowing, and explicit family discussion types whereas the executional phase was comprised of others, informants, and family members as the key person to implement the decisions.

The decision-making process did not begin when informants lacked awareness of their family member's illness condition. Even when informants were aware of their family member's declining health but expected him/her to recover or anticipated that he/she would live longer, the informants tended to pursue life support treatment or override his/her treatment wishes. Those informants comprised both implicit and explicit approaches to discussion. For example, a Nisei male knew that his mother wanted no treatment at the end of her life; however, he did not understand her illness trajectory after her stroke. Consequently, he reversed their previous understanding and placed a feeding tube.

> Z: … I should have left that alone because that was what we understood… What I'm saying is that prolonging of her life was my selfishness to not let my mother go… And the one thing I didn't ever make clear, my mother was never going to get better than she was. That's a hard fact to accept. And it's even harder to know it was going to get progressively worse.

More than a half (15 cases) of the family members and the informants had made end-of-life treatment decisions for family members when they were healthier or before their final hospitalization or treatment. In 10 out of 15 cases, the informants understood no recovery was expected when the final end-of-life treatment decision was implemented. These informants followed their original decisions. A Sansei female illustrated her implementation process of the decision.

> I: … And then at the very end she had a stroke, and we had already made arrangements with the nursing home. I had met with the people on the board there and told them … if she had something like this happen; that we did not want her life prolonged; that our family had already discussed it, and we didn't want

> her to be placed in the hospital; but that she could stay in the nursing home and just be kept comfortable. So, that was kind of … our situation ... at the end.

Relation between Awareness of Seriousness of Condition and Readiness for Impending Death

The third dimension, informants' understanding of readiness for their family member's impending death was classified into three categories: surprised, ambivalence, and ready. Informants who were confronted with an unexpected family death and unaware of the seriousness of the family member's illness experienced surprise or complete shock as described in the section on *Lack of awareness.*

Relation between Decision-Making Process and Readiness for Impending Death

In this sample, the informants who were not ready had also not discussed end-of-life treatments with their family members, or knew about the treatment preference implicitly. A lack of understanding of their family member's wishes might have affected their readiness for the family member's impending death. Because a lack of understanding of what to do could lead informants to have less confidence to make or implement a decision, they could not reach a high level of readiness. A Sansei female who did not have an open discussion with her father could not implement his wishes. She said she was "confused … and regret the whole situation" and was not ready for his death. As another example, a Nisei male did not have an explicit discussion with his mother after her stroke. However, it was understood between them that no life support would be used. When she faced her death, he could not refuse the use of life support. His ambivalent feelings and conflict about what to do were expressed after her passing.

> Z: … there [were] a lot of things I could have done, but I didn't have the ability or the courage to do it. … I think I could have helped my mother in her death much more than I did. I didn't want to be a part of it.

In contrast, there was clear evidence that informants were ready for the impending death of a family member when they had had an explicit discussion with that family member. They understood their family member's wishes and implemented them with confidence. In situations where a family member's communication was impaired or he/she was in a coma, the informants' readiness was enhanced.

> F: Considering her health and her condition and her age ... and since that was her decision and she wanted to go, I think we were all in favor of allowing her to go with dignity. You know, you can always put them on life support ... there is life support and feedings by a tube, and no quality of life ... I think she wanted to go with dignity and we allowed her to do that.

> O: Well, when she had the stroke and we came to visit her ... The next day when the nurse and the Hospice nurse came and talked to us about alternatives … I think at that time I was already comfortable with my mom's decision not to do anything. And in fact, knowing my mother, I would think that the faster she died, she would be happier. She didn't want to last a long time, I don't think.

Interestingly, informants' perceptions of the family member's mental condition near death affected them most in how they faced their family member's impending death. The types of family communication did not prevail over this observation. When a family member was alert during the last visit, the informants did not believe the family member would die soon or within a day. Thus, the informants were surprised when the family member passed away.

> S: … actually his diagnosis was, he had cancer of the lung. And so he was getting weaker and weaker, and we knew that he would not last very long. But then when he died within a month, it was very unexpected because we thought he would last maybe three to six months.

Therefore, the informants' perception of the cognitive state of the family member during the last visit appeared to impact the informants' readiness for the family member's impending death more than the decision-making process, the types of communication or the level of understanding of the dying person's wishes.

Relation between Readiness for Impending Death and Experience of the Dying Process

Five categories comprised the fourth dimension, informants' understanding of their experience of a family member's dying process: regret, prolonged grief, unresolved questions, resolution, and acceptance. Informants who were surprised about a family member's death experienced less resolution about the death. In half of the cases (n=11), informants were surprised when their family member passed away. In these cases, informants experienced prolonged grief.

> U: ... so as far as my reaction and such, I was in shock all the time so I [didn't] do any other plan. Everybody else did everything … I've never resolved it so like ... I guess what you call depression because I was … [so sad.] … Sometimes when you are too well taken care of, and I stayed in shock for a long time.

Five of the 11 cases included deceased family members who were younger than 80 years old. For their informants, a shift from the initial feeling of being surprised to acceptance of the death was more difficult. For example, a Sansei male who suddenly lost his younger brother had unresolved questions. Another Sansei male whose father was in denial about his own impending death struggled to reach a state of resolution after his father died. Contrarily, when the deceased family member was over 80 years old, about a third of the informants (4 cases) were able to shift from their initial feeling of being surprised to acceptance of the death more readily.

> B: ... when she's 98 there's not too much saki (future, ahead) in front of her... So shoganai yo (cannot be helped; laughs). That was my attitude. Maybe that's not the right attitude, but by the same token I wish she had been alive until I got home. But then ... I guess when you think about it, it doesn't make that much difference ... already 98 and half dakara (so that) one or two more days, just until I got home ... that doesn't make any sense. I mean, when her time came she was gone. So, I don't know if you call that fatalistic or what, but it's not up to me (Laugh).

When informants were in an ambivalent state while facing a family member's impending death, they did not accept the family member's death easily. Their experience of the dying process reflected regret, having an unresolved question, or a struggle to reach a state of resolution. On the other hand, when the informants were ready for the family member's impending death, they were able to accept the death more easily.

> L: She said she'll wait; when time is here, she is ready to go. So it was a lot easier to accept... So I think she was wanting to go and [it] was time to be released.

Relation between Generational Values and Decision-Making Process

The older informants' cohort, age over 70, tended to have no discussion or an implicit knowing style with their family member. This relationship was more likely influenced by the homogeneity of the Japanese society they had lived in and its concomitant values, close family relationships, and language issues between them. As a result, the informants' decisions reflected paternalism, and they played a key role in implementing those decisions.

Members of the younger informants' cohort, on the other hand, had open, explicit discussions with their family members, and their understanding of the family members' wishes were clear and mutual. Heterogeneity of the society they had lived in and the value of respecting individual autonomy likely facilitated this communication and decision-making process.

In the decision-making process, informants conveyed four shared values identified across the ages: language, power relationships within the family, no complaint, and not to be a burden. The first shared value, language as a communication tool, affected the informants' understanding of their family member's wishes. Except for two cases, informants did not perceive a primary language barrier with their family members. In two exceptions, the informants perceived poor understanding of their family member's wishes. The exchange below illustrated the important role of communications in decision making.

> U: … they just talk to their mother in English... I asked her, "Do you understand?" She said, "Not really. But I get the general gist of them, you know." But when she talked, she talked Japanese... When they get to that nitty-gritty, I don't know how ... they could say to their mother without a translator, you know because their Japanese very very limited, very limited.
>
> Z: … So, though it's hindsight, the agony of my saying no … is very difficult because my mother had to also agree, so we had to get an interpreter there. We had to get a lawyer ... everything had to be done … and that's the law today in America. This is where American culture is very difficult.

The second shared value, power relationships within the family, revealed a ranking system in the decision-making process. The first son held the most powerful position in the family and being an in-law implied an outsider status. Yet two aspects deviated from these relationships: a close relationship between a mother and her daughter and long distance between a family member and his/her first son. For example, family dynamics shifted when the wife of the first son who lived at a distance from his mother interjected the informants and her sister's views.

> Q: My sister actually … was the more in control in terms of what should happen, and she would communicate with my brothers down in California, too, but we didn't really give them a lot of say, only because we were the ones that were responsible for taking care of her, making sure everything was okay with her so … They would interject their comments and stuff, but my sister, being the most responsible one … would tell them "this is the way it is going to be unless you want us to send her to you." This was her statement. "We will send her down to California and you could take care of her the way you want to do." … my older brother, he has a wife that is more … interjection, "tell them to do this, tell them to do that" kind of wife. Yeah. And see they … maybe a year or so after my mother had her stroke, my brother … had stroke. He was only 57, so he recovered mentally and everything, but he lost the use of his hand. Well, shortly after that his mother-in-law had a stroke… So then they brought her into their home and were taking care of her in their home. So they're thinking that we should do the same thing. That she would get better care and … It was a different thinking there, thinking "why put mom in N (nursing home in the Japanese-American community) when one of you should take care of her." And my sister says, "Well, you want to take care of her, we'll send her down."

The third shared value, no complaint, derived from the informants' perception of their family member's personality or response to the decision made. Those family members appeared to be influenced by a traditional proverb "with age, you must obey your children." They were Isseis or older Niseis (age over 80 who grew up in a homogeneous Japanese society). Most of the informants took their family member's no complaint as an agreement or positive response to a decision made.

> N: … But finally towards the end, she's really kinda getting pretty bad … and in her Japanese way she would ask, "Does this mean I don't have a choice?" And I would say in a Japanese way, "Yes, that's about how it means, what it means." So she said "Oh, OK." She never complained.

The last shared value, not to be a burden, was the family member's value from the informant's viewpoint. Some family members verbalized their feeling not to be a burden; however, the informants' response to the verbalization and its degree of influence on the decision-making process were not clear.

> D: … she didn't wanna be, she didn't like to be burden on, ... in case ...we have family and then we have young kids so takes time and so she didn't wanna be ... burden on the family.

Even though a family member did not verbalize a wish not to be a burden, the informant detected this value from the family member's personality and/or their relationships.

> G: ... she would wanna be prolonged and to keep life support system on, I don't think she had ever said that. I think being a sensitive person that she was, she would say, "No … I don't want you guys to worry. I don't want you guys to go through all this again. … Just take everything off." She wasn't able to say that…

Relation between Generational Values and Readiness for Impending Death

None of the older informants' cohort was ready when they faced their family member's impending death. A possible reason could be their close feelings towards their family member based on filial piety, obligation, and paternalism. An informant described it as "bonding." Such bonding might have prevented them from being ready for the impending death. Consequently, they ended with being surprised or ambivalent when their family member passed away. A 79-year-old Nisei female described her feelings towards her late 102-year-old mother.

> N: She had very good life … She would have lived more if she didn't … and healthier and all … Other people say "over and beyond" but nothing was over and beyond between us, for us as far as we were concerned.

The younger informants' cohort, on the other hand, was more likely to be ready. They respected individual autonomy and quality of life, which led them to agree with their family member's wishes. Thus, when the family member's wishes were no treatment at the end of his/her life, respecting his/her wishes enhanced informants' readiness for the impending death.

Relation between Generational Values and Experience of the Dying Process

Acceptance of the death was difficult for both cohort informants when their family member died unexpectedly (11 cases). The older age of a deceased family member, however, helped a third of those informants accept the death easier. When the family member died at age 80 or older, the informants were able to come to a closure about their family member's life as "his/her time was over." Nevertheless, the older informants' cohort among the other two-thirds tended to have unresolved feelings about the death of their family members. They expressed prolonged grief, had unresolved questions, or struggled to reach a state of resolution. Their feeling towards the deceased family member, such as familial affection based on filial piety and obligation or bonding between them, might have prevented the older informants' cohort from accepting their family member's death easily.

On the contrary, the younger informants' cohort accepted the death of their family member with less discomfort. Similar to the *readiness for impending death* section, the fact that informants respected individual autonomy and quality of life might give them greater satisfaction that family member died as he/she wished.

Summary of the Model

The process that Japanese-American families used to make end-of-life decisions for their family member was characterized by four dimensions of family understanding and was influenced by generational values and health care providers, including nurses.

Each of these dimensions occurred along a continuum from low understanding to high understanding. The first dimension of family understanding indicated the degree of the informants' awareness of the family member's illness condition. The second dimension represented the end-of-life decision-making process, focusing on the types of communication between the informants and their family member and the persons who implemented the decisions. The third dimension described the informants' readiness to accept the family member's death. The fourth dimension of family understanding was associated with the informants' experience of their family member's dying process.

HCPs, generational values, and the four dimensions influenced each dimension directly or indirectly in positive and/or negative ways. Informants' increased awareness of their family member's declining health triggered the process of decision making, deciding end-of-life treatment options and implementing the decision. When informants possessed a clear understanding of the family member's wishes, they were ready for the family member's impending death. However, when informants expected family members' recovery, their readiness was negatively affected. The level of the informants' readiness for the impending death influenced the informants' experiences of their family members' dying process.

Two extreme cases will be summarized briefly. The first case illustrated the higher end of family understanding in each dimension. It was six months after the father died of cancer when an ER visit revealed that the mother had an advanced stage of cancer and poor prognosis. All family members including the mother and her three sons discussed the situation with her physician and each other and understood her wishes; she chose hospice care right away. The family observed her weakening and was able to anticipate her dying. Four months later, all the sons and their families were at her deathbed and accepted her death as something merciful.

In contrast, the second case took an opposite course. When a father's prognosis after a heart attack was unclear, three children and their spouses struggled. All knew the father's written wishes that there would be no extraordinary measures at the end. Yet, no discussion took place between the father and his children either before or after the heart attack, leaving his definition of extraordinary treatment unspecified. A medical meeting with a physician did not clarify his prognosis or treatment. Their ambivalence was reflected in the mixed messages they gave to their father, saying, "You can go dad; you don't need to hang on," and then, "No, no. You need to keep it on," when he tried to take his oxygen mask or IV line off. Contradictory approaches to the father and unused hospice care were perceived as keeping him alive uncomfortably. He was found dead with the oxygen mask taken off. The whole situation resulted in regret.

Recommendations for HCPs

All informants were asked for any recommendations from their experiences. From physicians, they expected accurate diagnosis, a clear presentation of treatment options with research data, and accurate prognosis as well as a professional manner, especially humane sensitivity towards patients and their families. From other health care providers including nurses, informants wished for an explanation of the illness or aging trajectory, including personal view from one's professional experiences. Other requests included a clear presentation of the definition of life support and discussions about end-of-life treatments with HCPs as well as within families. Introduction and use of hospice care were strongly recommended. To the general public, informants recommended completing an AD and funeral plans, writing one's own eulogy or obituary, and living and doing as one wished in order not to have regrets. Finally, the Japanese Community's long-term care facilities were highly utilized and praised as a culturally sensitive and comfortable place for the family members.

CHAPTER 5

Discussion

This chapter was organized into five areas: a discussion of study findings and comparison with previous research on end-of-life decision making; strengths and limitations of the study; implications and recommendations for practice and nursing research; and summary and conclusion.

A Discussion of Findings and Comparison with Previous Studies

This study found that the end-of-life decision-making process used by Japanese-American families involved four dimensions of family understanding and was influenced by HCPs and generational values. Each dimension was composed of a continuum that represented increasing levels or degrees of understanding and acceptance of a family member's end-of-life situation and death. The dimensions were related to each other and together described a decision-making process beginning with an awareness of the seriousness of a family members' declining health or illness and ending with resolution, or not, of a family member's death. Extrinsic factors (e.g. HCPs' responses and information) and intrinsic factors (e.g. age-cohort generational values) influenced Japanese-American families' experience of the process. Both traditional Japanese values about family relationships and the effect of acculturation were evident in families' experience of decision making. Even though their interaction with HCPs was not dominant in the data, they engaged with HCPs at critical points in decision making.

Comparison of End-of-Life Decision Making Processes and Experiences among Studies

Table 5 compares the findings from this dissertation with processes discussed in four previous studies of families' end-of-life decision-making experiences. Four major characteristics were: an understanding of the seriousness of their family member's condition as the initial phase; the decision-making process as the middle phase; a phase focused on anticipation/preparing for the impending death; and a final phase of coming to terms with the actual death of the family member.

First, all studies found that the process for families started with an understanding of the seriousness of their family member's condition even though the experience is described differently depending on the focus of the study, for example, learning the diagnosis (Meeker, 2004) and understanding the critically illness (Swigart et al., 1996). The context of their family member's deterioration of health set the stage for decision making about life-sustaining treatment. Compared to findings from this study, gathering information about the condition during the initial phase was emphasized more in other studies, most likely because of the acute nature of illnesses and critical care setting requiring time sensitive decision about ending treatment in those studies.

Second, all studies describe the actual decision-making process as the middle phase of the process of family informant's experience although in quite different ways depending on study focus. The nature of family involvement in decision making depended on the settings in which decisions to withhold or withdraw life support were made. The findings from this study were consistent with those of previous studies in which an intense and rather short-term involvement of the family in an acute setting

Table 5

Comparison of Findings for Four Published Qualitative Studies with Findings for Dissertation

	Jacob (1998)	Jeffers (1998)	Meeker (2004)	Swigart et al. (1996)	Colclough (2005)
Processes	Arriving at a Judgment (patient's condition, preference)	Contextualizing the Decision Informing and Gathering Information	Learning the diagnosis Continued seeking, shock, living fully in the interim	Seeking and understanding information about the critical illness of the patient	Awareness of Seriousness of Condition Lack of awareness, awareness with recovery expected, awareness with no recovery expected
	Moving in Concert vs. Disharmony (relationship with health care providers)	Actualizing Agency Alone/ presenting	Standing With Active Presence (Supporting, Vigilance) Respect for Person (Knowing/Learning the family member's wishes, Empathizing/Understanding the meanings)	Reviewing the life story of the patient and seeking the meaning of the patient's life	Decision-Making Process Decisional phase (no discussion, implicit knowing, explicit discussion) Implementation phase (others, informant, deceased family member)
			Gating (transitional) categories Brokering Information Working with Family		
			Acting For Advocating (Accessing care, Continuum of care, Hitting the Wall, Honoring choices) Protecting (Treading lightly, Taking over)	Struggling with family roles and relationships	
			Taking Leaving Knowing/ Preparing for the death, Honoring the life)		Readiness for Impending Death Surprised, ambivalence, ready
	Looking Back and Going on (positive about involvement and burden of responsibility)	Reviewing and Resolving Transcending	Outcomes Persisting Concerns, Satisfaction, Learning	(Struggling with family roles and relationships)	Experiences of the dying process Regret, prolonged grief, unsolved questions, resolution, acceptance

(Jacob, 1998; Jeffers, 1998; Swigart et al., 1996) and a gradual and long-term involvement in community-based and long-term care settings (Meeker, 2004) were found. Differences include the theme of burden/responsibility that emerged in several studies but not in this study; the degree to which the patients wishes were considered; experience of family conflict; and centrality, or lack thereof, of HCPs involvement. Each of these differences will be discussed in more detail in the next section.

Third, only this study and Meeker's study (2004) identified a phase focused on anticipation/preparing for the impending death following the actual decision-making phase. Such a phase may occur when death is not as imminent following decision making about life-sustaining treatment or when the chronic nature of an illness provides more impetus for its occurrence. Reflection on the impending death of a family member may not be as central to informants' experience when the decision to withhold or withdraw life-sustaining treatment is the paramount concern in critical illnesses/care situation (Jacob, 1998; Jeffers, 1998; Swigart at el. 1996). Fourth, all studies included themes related to a final phase of coming to terms with the actual death of the family member.

Although similarities were found in the overall processes described by families in this and other studies, key differences were also found in the experience of Japanese-American families compared to other families. These differences occurred primarily in the decision-making phase and were as follows.

The theme of burden/responsibility. Feelings of responsibility and burden were strongly expressed by families in the previous qualitative studies (Jacob, 1998; Jeffers, 1998; Meeker, 2004; Swigart et al., 1996) as well as in Tilden et al.'s study (2001). However, informants in this study seldom described such feelings. Only one case in which the mutual decision not to use a feeding tube at the end was reversed did the informant express feelings of responsibility and burden in making the end-of-life treatment decision. In this case, he perceived that his sister "played traditional Japanese culture," putting him in the position of making all the decisions. This intriguing finding may be attributed to two different factors: how the designated surrogate role was enacted in Japanese-American families and the broader range of health related situations explored in this study in which death of a family member occurred.

Even though some Japanese-American informants in this study were designated as surrogate decision makers, all cases except for one involved other family members equally in decision making about end-of-life care. Therefore, the "designated" person within these Japanese-American families did not necessarily feel all of the responsibility for making decisions. In contrast, surrogates in previous studies of predominantly White Americans appeared to carry sole responsibility for such decisions and described feeling "alone" and burdened in making decisions for their family members (Jacob, 1998; Jeffers, 1998; Meeker, 2004; Swigart et al., 1996). The previous studies, however, focused on surrogate decision making for incapacitated ill family members in critical care settings in which such a decision was final and needed to be made in a relative short period of time while most decisions described in this study did not immediately result in the family member's death.

Two cases in this study were exceptions in that they involved a family member's immediate death after informants made their decisions. One case required a decision about applying cardiopulmonary resuscitation (CPR) when a husband collapsed. Although his wish was for no extraordinary treatment, his wife (the informant in this study) thought that he might have been revived if CPR had been applied soon enough. In the other, the informant and his siblings made a decision together, without their mother's AD and a discussion about her wishes, to withdraw all the life support after 13 days in the ICU. They did so within two hours after a physician asked for the first time for a final decision. Even though the situation described was similar to those in other studies, the informant did not describe feelings of responsibility and heavy burden although the decision was "very difficult" to make. His attitude towards decision making may be explained by the Japanese value of filial piety, that is, he believed end-of-life decision making to be the children's responsibility on behalf of their parents. Supportive of this value, he verbalized that somebody would do the same thing for him as he did for his mother. Thus, for these Japanese-American family informants, the decision-making process may have been characterized by feelings of less responsibility and burden because of the influence of traditional Japanese cultural values.

The degree to which the deceased family member's wishes were considered. An unanticipated finding was that 16 out of 22 cases in this study had ADs (72.7%) prior to an incapacitating illness. In contrast, 33% of the patients in Jacob's study (1998) and 36% in Jeffer's study (1998) had completed ADs (the other two studies did not report these data). The ratio in this study of Japanese Americans is very high compared with previous reports for the general population (10-30%), but similar to other studies of Asian Americans (Braun & Nichols, 1997; Eleazer et al., 1996; Vaughn et al., 2002). Even though traditional Japanese culture does not favor written documentation, acculturation and immersion in American society, attorney services in the community, recognition of the importance of legal documentation in the U.S., and increased public awareness of the importance of AD through the media may have motivated Japanese Americans to complete ADs. Although not addressed in the study, their HCPs may have encouraged completion of ADs also.

Practical use of AD, however, appeared low in this study. A few informants verbalized that they actually used ADs in their decision making when the deceased family member was incapacitated and could not make his/her wishes known. Usually, ADs were used to confirm the wishes of the patient to HCPs, but not actually used when deciding on and executing end-of-life decisions. Several reasons are considered. First, the lack of reliance on ADs even when they existed may reflect Japanese-American informants' certainty about understanding their family member's wishes. Second, most of the deaths occurred in non-acute care settings rather than in critical care settings where technology is used to prolong life. So no proof was necessary to show the deceased wishes. Third, ADs may have given the deceased and informants peace of mind or provided a safe guard for a just in case scenario, similar to what was found in Ditto et al.'s study (2001). Thus, understanding a family member's wishes rather than documenting them per se with an AD seemed to be the more salient point for these informants, regardless of whether the understanding resulted from implicit knowing or explicit discussion. Also less conflict within a family or between a family and HCPs did not necessitate the use of the family member's AD. However, it is also possible that the interviewer did not probe sufficiently to uncover a deeper description of the use of ADs in actual decision making.

Moreover, informants' decisions about life-sustaining treatments appeared to carry more weight than the family member's wishes whether implicitly or explicitly expressed. This phenomenon may represent difficulties families have in applying and translating ADs in a real situation. This finding is neither consistent with characteristics of a family-centered decision-making style in minority population (Blackhall et al., 1995) nor what was found in the four previous studies in which "accuracy" or "a right thing to do" was a common theme expressed by their informants. "Family-centered" model defined by Blackhall et al. emphasizes the sole responsibility of the family to make a decision and does not seem to aptly describe the processes used by informants in this study. Most informants in this study appeared to be influenced more by their perception of what would be in their family member's best interest (i.e., their well being) rather than the wishes of the deceased or their own wishes or interest. In addition, ill family member appeared not to be bothered by paternalistic approaches. Therefore, the term "family-interdependent model" might be a better descriptor of the process found in this study.

Experience of family conflict. In the previous studies of primarily White Americans, conflict among family members involved in end-of-life decision making was found to be an issue (Jeffers, 1998; Meeker, 2004; Swigart et al., 1996). However, Japanese-American informants in this study seldom described family conflict as an issue.

One reason could be that those who were directly involved in decision making in this study were immediate family members such as sons, daughters, or spouses; siblings of the deceased or in-laws were usually not involved in decision making. Therefore, minor conflicts may have been more easily resolved.

However, unspoken conflicts between some informants and their deceased family members occurred in a few cases. In these cases, the ill family member usually conformed to the wishes of the informant. In one case, an informant's mother needed to agree with him since he said she would have a feeding tube and signed the document through an interpreter because of language difficulties. In another case, the informant firmly believed as surrogate decision maker that the use of pain medication for her aunt, who held the Japanese attitude of "tolerance" of pain at the end, was the "right thing to do." Thus, less open conflict within Japanese-American families also may reflect traditional Japanese values such as altering one's own wishes in order to maintain harmony, solidarity within the family, and conformity.

Involvement of HCPs in decision making. In contrast to previous studies, informants in this study did not emphasize the involvement of HCPs in decision making. The reasons could be that this study did not focus on decision making when an incapacitated family member was hospitalized or over the course of a life-threatening illness such as cancer compared with the focus of previous studies (Jacob, 1998; Jeffers, 1998; Meeker, 2004; Swigart et al., 1996; Tilden et al., 2001). Instead, interviews addressed family members' experience in a range of situations leading to the death of a family member. When HCPs were mentioned, the situations described were usually those that immediately preceded death or during the final hospitalization. For the most part the descriptions of HCPs involvement were positive. Only a few examples of conflicts between informants and HCPs were described.

The results suggest that the key role of HCPs was to help family members face the awareness that their family member was nearing the end of life. HCPs' communication facilitated or impeded an informant's understanding regarding the seriousness of their family member's health condition and informant's readiness for the impending death of their family member, two key aspects of their experience. The Decision-Making Process dimension itself, especially the executional phase, would not begin without awareness of how much the family member's health was failing. Similarly, without readiness for the impending death, acceptance of the death could not occur. Although the concepts are described slightly differently, a similar relationship between Awareness of Seriousness of Condition and Decision-Making Process in this study was found in previous studies (Jeffers, 1998; Meeker, 2004; Swigart at el. 1996). This accumulation of evidence supports the critical role HCPs play in family member's initiation of end-of-life decision making and execution of such decisions.

Nurses were sometimes mentioned as helpful in the Decision-Making Process and Readiness for Impending Death dimensions of family understanding. Advising consideration not to use I.V. fluids for a family member with distressed respiration, a timely call to informants about a family member's nearing death, and explaining about one's own experience of losing a family member to imply that such a possibility may come soon were examples of how nurses utilized their expertise and helped informants implement decisions or prepare for an impending death.

Influence of Generational Differences and Acculturation

Although it was anticipated that immigration group (e.g., Nisei, Sansei) would distinguish generations of Japanese Americans, this was not born out by the data. Instead, age cohort (older or younger than 70 years old) emerged as a more relevant determinant of generational differences especially in how acculturation affected informants' experience. For example, the youngest informant in the older generation was 71 years old, and the oldest in the younger generation was 65 years old even though both were Niseis. From a historical viewpoint, they were 8 years old and 3 years old respectively when interred during WWII. Because of the age difference, their awareness of this and other life experiences growing up in the U.S. may have affected their acculturation (e.g., adherence to Japanese versus American values) differently.

Generational differences were a key factor that influenced families' experience of three of the four dimensions of family understanding: the Decision-Making Process, Readiness for Impending Death, and Experience of the Dying Process. Communication style differences between the generations were reflected in their experiences. Since most deceased family members of the younger generation informants discussed end-of-life issues with their family explicitly, the informants were more likely to accept family member's declining of health, impending death, and the death itself. In contrast, most of the older generation did not have explicit discussions with their ill family member but relied instead on implicit knowing. Such a style could have resulted in their failure to notice a critical point in a family member's declining health preceding death and in their greater difficulty in accepting the death afterwards.

Furthermore, the informants' Readiness for Impending Death and Experience of the Dying Process appeared complex, especially for the older generation. Religious affiliation, either Buddhism or Christianity, did not seem to make any difference in their view. Their experience cannot be explained by the traditional Japanese view of death either, that is, beliefs of death as a part of the natural life cycle, as becoming an ancestor's spirit, or as reincarnation.

One speculation is that a special relationship existed especially among the older generation informants and their family members (or Issei and Nisei), perhaps related to immigrant status and in part to historical events. Informants confirmed that Isseis lived for their children, and that a special bond existed. The interconnectedness with the deceased family member may have affected the older informants' experiences of the dying process. In contrast, the younger informants were more concerned about quality of life and loss of the ability to perform activities of daily life for older ill family members, consistent with perspectives of Western culture such as autonomy and independence. Thus, the model illustrated that the older generation was influenced by not only traditional Japanese values and beliefs such as filial piety and obligation, but also by the nature of their relationship with the deceased family member such as paternalism and a special bonding.

This study supports that understanding differences in values and communication styles among Japanese-American generations is especially important. The differential effect of acculturation on the older versus younger generations is evident in their experiences with end-of-life decision making. As Young et al. (2002) observed, "eclectic" nursing services based on both traditional and new values and beliefs would satisfy the needs of minority populations.

Strengths and Limitations of the Study

An empirical design that employed in depth interviews with family members who had actual experiences with end-of-life decision making is a strength of this study that led to empirically based findings about the dimensions of family understanding. The focus on a culturally different group and a wider range of health conditions that resulted in death across various illnesses and settings added new information to the existent knowledge about end-of-life decision making. Moreover, the bicultural viewpoint of the researcher was advantageous in the data collection and analysis.

On the other hand, this study may be limited to the extent that the researcher's interview technique and communication skill (English as a second language) affected data collection. Furthermore, this study is limited to the extent that in part a convenience sample of informants from one Japanese-American community was used even though five informants grew up in other states. Modified theoretical sampling, even though data were saturated, was also a methodological limitation. In addition, a retrospective study based on informants' recall of the decision making may not have accurately represented what they actually experienced at the time. Time from the death to the interview varied from 2.5 months to 15 years although most were within 5 years. Accurate recall of some events and feelings associated with the experiences might have been challenging.

However, a concurrent study design similar to one employed by Swigart et al. (1996) contains high risk regarding recruitment, time, and manpower. The feasibility of using such a design in a study within the Japanese-American community is unknown.

Implications and Recommendations for Clinical Practice

The findings in this study support that HCPs can play a critical role in end-of-life decision making although their centrality to the process will vary by the nature of the illness and setting in which end-of-life decision are made. Most of all, HCPs must provide accurate and timely information about the illness trajectory and deteriorating health to increase family members' awareness of the seriousness of the condition of the ill member and to support decision making in a professional and compassionate manner. This is the paramount task in which HCPs can utilize their professional knowledge and expertise to help families face the impending death of a loved one.

Data in this study also support that explicit discussion in decision making could improve end-of-life care. After understanding each patient and family member's values, nurses could facilitate discussion about end-of-life care as well as help families understand how death could approach an ill or aged family member in a gentle but realistic manner without giving false hope. It is important for both patient and family together to reach at a comfortable level of openness about end-of-life care/treatment.

How a family member died affected informants' perspectives on their family member's dying process and alternately their acceptance of the death and resolution of issues related to it. Thus, HCPs need to be especially vigilant about family expectations related to the impending death of a family member. It is at this critical time that HCPs can use their experiences, knowledge, intuition, and expert judgment to help family's face that death may be imminent. Nurses especially need to be aware of their own sensitivity to impending death gained from experience and recognize that this may be the first death experience for a family. Alerting family members that the end is near in a sensitive and professional manner (i.e., gently but clearly communicate to family members their insights) would enable family members to be present with their loved one when death occurs.

To help with resolution after a family member's death, informants recommended writing one's own obituary ahead of time and discussing end-of-life issues within the family and with HCPs while the recent experience is still foremost in mind. In addition, when HCPs offer support with grief work, they need to follow through with their commitments. Especially, introducing hospice care and support groups should occur in a timely manner.

Even though the choice of a long-term care facility was not a focus in this study, this context had a significant meaning to informants and their family members in this study. The Japanese-American community in which the data were collected has reliable long-term care facilities developed by a Japanese-American organization. The high utilization of the facilities by this study's participants further emphasizes the importance of and need for culturally sensitive care.

Implications for Future Research

This dissertation study is a first step in a program of research aimed at contributing to nursing science through increasing knowledge about end-of-life care among culturally diverse groups within the U.S. A future qualitative study using similar methodology could be undertaken to explore the experience of the Japanese-American families whose health care is provided outside of the Japanese-American community to see if the same model emerges, especially related to the role of HCPs. This might further help tease out dimensions of culturally sensitive care. Moreover, a comparison study to explore the experience of other Asian-American populations or other ethnic minority populations such as Native Americans could further expand our knowledge about end-of-life decision making in diverse groups and the experience of families in this process.

Furthermore, based on this study's findings, an assessment tool for patients, their family, and HCPs to prepare for a peaceful ending such as culturally sensitive end-of-life care could be developed and tested for its utility. Designing and testing nursing interventions to promote awareness of the seriousness of the condition, preparedness for decision making, and preparedness for impending death of a family member could further contribute to culturally sensitive end-of-life care and nursing science.

Summary and Conclusion

The process that Japanese-American family members used to make end-of-life decisions for their recently deceased family members was depicted in a model that included four dimensions of family understanding along a continuum from low understanding to high understanding. These were: Aware of Seriousness of Condition, Decision-Making Process, Readiness for Impending Death, and Experience of the Dying Process. The dimensions were related to each other and together described a decision-making process beginning with understanding the seriousness of their family member's condition and ending with their reflection on their family member's death.

The model in this study was influenced by traditional Japanese values as well as Western values adapted through acculturation. Moreover, a generational difference clearly existed, based on age cohorts rather than immigration groups, and was a salient factor in differentiating experience. Nonetheless, the experience of most informants of making decisions within the context of the PSDA and the current U.S. health care system did not appear to result in noticeable conflict for them. Japanese Americans adjusted well to expectations of the majority culture as evidenced by a higher completion rate of ADs and a few events of dissatisfaction with HCPs.

Overall, Japanese-Americans' perspectives associated with the decisions after the family member's death were influenced by their values and how the family members died. In some cases, culturally unique community-base, long-term care facilities supported their family member's end of life in a reliable and comfortable manner. The informants' experiences of the dying process ranged from regret to resolution, impacting their attitudes towards life and death religiously and spiritually.

The results support that HCPs including nurses can play a critical role in facilitating family understanding of each dimension in the process described in this study. This study suggests that clinical approaches that take into account the cultural values and communication styles of families, including the ill family member, are essential to improving end–of-life care and Japanese-American families' experience of decision making. Acculturation and the influence of traditional Japanese and Western values reflected differently in successive generations are especially relevant to consider. The goal of end-of-life care is "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassel, 1997, p. 4). To the extent that this study enhances our understanding of cultural aspect of end-of-life care for one minority group in the U.S. and provides guidance for HCPs working with Japanese American families, it has contributed to this goal.

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LIST OF APPENDICES

Appendix A

Studies Examined Cultural Differences in Acceptance and Use of Advance Directives

Bito, S., Matsumura, S., Kagawa-Singer, M., Meredith, L. S., Fukuhara, S., & Wenger, N. S. (in-press). Acculturation and end-of-life decision making: Comparison of Japanese and Japanese-American focus groups.

Sample	Description	Results	Comments
18 focus groups with 122 Japanese participants in 3 groups: 28 Japanese in Japan (JJ, 71% over 65, half male); 29 Japanese-speaking Japanese American in the US (JJA, 84% over 65, 79% male); & 65 English-speaking Japanese American in the US (EJA, 52% over 65, 60% male).	Purpose: to understand and compare the end-of-life decision-making models of Japanese living in Japan and Japanese Americans (JAs). Design: focus group interviews using a grounded theory, qualitative approach.	Identified themes related to: presenting bad news, end-of-life care attitudes, preferred decision-making model, & ADs. All three groups indicated similarities in 3 areas. They preferred presenting bad news first to the family. Then, JJ rarely would tell bad news to the patient with or without the patient's wishes. The frequency of truth telling to the patient increased with acculturation of JAs. Also all preferred sudden death & less family burden (*meiwaku* in Japanese); JJ indicated strong duty to care for family members, but it became less with acculturation. ADs were acceptable for JJ only in an informal fashion, but the two JA groups accepted ADs to relieve family conflicts created by family responsibility to sustain the dying patient (*kazoku no jo*). Preferred decision-making model indicated differences among the groups. JJ preferred a paternalistic model with a family decision-making style. Family would be a main factor for JAs. Family would be guided by the physician's professional advice for the JJA group, and patient participation would be an important role for the EJA group.	EJAs were younger (38 Nisei & 20 Sansei, and 52% over 65) than other two groups but traditional Japanese values appeared to be preserved in end-of-life care and decision-making process. However, acculturation was an influencing factor on JA. How they retain such values while being born and living in a different culture is unknown. Participants' backgrounds such as their health, experience, age, gender, occupations, religion, etc. were not described.

Blackhall, L. J., Murphy, S. T., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *Journal of American Medical Association, 274*(10), 820-825.

Sample	Description	Results	Comments
200 subjects: 100 male & 100 female for each ethnic group (White American [WA], African American [AA], Mexican American (MA), or Korean American [KA]), aged 65 years and older.	Purpose: to study differences in the attitudes from different ethnic groups toward disclosure of the diagnosis and prognosis of a terminal illness and toward end-of-life decision making. Design: survey (Attitudes Toward Advance Care Directives Questionnaire) administered at 31 senior citizen centers.	In truth telling about the diagnosis of metastatic cancer to a patient, 87% of WA and 88% of AA were supportive vs. 47% of KA and 65% of MA. About a terminal prognosis, 63% of EA and 69% of AA supported vs. 35% of KA and 48% of MA. In decision making about the use of life-supporting technology, 61% of WA, 65% of AA, 28% of KA and 41% of MA indicated it's a patient's responsibility to decide. KA and MA tended to believe that the family should make decisions about the use of life support. All differences between WA vs. KA and MA were significant. Also the statistical test indicated that the primary factor related to attitude was ethnicity. The years of education was the second most important factor for the truth telling but not decision making.	Authors concluded that KA and MA were more likely to hold a family-centered model of medical decision making rather than the patient autonomy model favored by most of the WA and AA. They also stated that "autonomy is not viewed as empowering, rather it is seen as isolating and burdensome to patients who are too sick and too ignorant about their condition to be able to make meaningful choices" (¶. 23). "Belief in the ideal of patient autonomy is far from universal. ... Simple progress from an uninformed paternalism to a more enlightened and respectful attitude towards patients. ... The high value placed on open expression of emotion and on the rights of individuals to control their destiny was not necessarily shared by all segments of American society" (¶ 24).

Blackhall, L. J., Frank, G., Murphy, S. T., Michel, V., Palmer, J. M., & Azen, S. P. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine., 48*(12), 1779-1789.

Sample	Description	Results	Comments
Follow up from the previous study of 1995; 20 subjects each group	Purpose: to examine whether permissible to withhold life support under certain circumstances, and the underlying reasons why participants held these beliefs and the context within which these beliefs took shape. Design: In-depth ethnographic interviews	KAs are least likely to believe individual in autonomy and more likely to accept but less likely to desire life-support; paradox is that the person would not want to be kept alive on life support, but it would not be her decision to make (p. 1784). MAs believe in individual autonomy and are more likely to accept and desire life-support even though stating "If there is no hope, why prolong the suffering?" (p. 1785); they tend to rely on the doctor's judgment when making decisions about forgoing medical care. So they think if there is no hope at the beginning, the doctor should not start life support; once it gets started since it means there is hope, then why stop later? But they are less likely to complete ADs. AAs believe in individual autonomy, are less likely to accept life-support but desire to "try it". "Try me on the machine. If it worked, let me stay on" (p. 1786). They are less likely to complete ADs. WAs believe in individual autonomy, are least likely to accept and desire life-support but complete ADs to avoid "burden" & "vegetable" state.	Authors concluded that (a) ethnicity is strongly related to attitudes toward and personal wishes for the use of life support in the event of coma or terminal illness, and (b) this relationship was complex and in some cases, contradictory. Also they suggested that "studies looking at end-of-life decisions should include a qualitative component to help clarify and prevent misunderstanding of data collected in other ways" (p. 1787).

Bowman, K. W., & Singer, P. A. (2001). Chinese seniors' perspectives on end-of-life decisions. *Social Science & Medicine.,* *53*(4), 455-464.

Sample	Description	Results	Comments
40 Chinese seniors 65 years of age or older in Chinese community center in Toronto, Canada	Purpose: to examine attitudes of Chinese seniors towards end-of-life decisions Design: qualitative survey; face-to-face interviews were conducted in Cantonese Data were analyzed by modified grounded theory, using three coding techniques, but no theory was generated.	Seven influential factors were hope, suffering & burden, the future, emotional harmony, the life cycle, respect for doctors, & the family. Respondents rejected ADs. Respondents' attitudes toward end-of-life decision making can be understood through the lens of values from Confucianist, Buddhist & Taoist traditions. Examples were: life cycle should take over human's will; negative outcomes can result from negative thoughts; death is an event in life; they believe in/trust children & physician as an expert so that no struggle with their decisions; burden may derived from the Buddhist value of justice and destiny; moral reasoning is based on context; suffering is the transitive and impermanent aspects of life; Confucianism teaches that a child who agrees to a parent's refusal of Tx would be violating the principle of filial piety; AD is impossible, unnecessary, and even unwise; durable power of attorney for health care limits the opinions of family members not so named & impedes collective family decision making.	Studying a non-assimilated group limits the influence of acculturation since the authors assumption is that acculturated individuals "may more closely approximate the Western health care practices" (p. 456). Authors' view appeared to be dichotomous; they failed to consider that any conflicts exist in apparent acculturated groups. Identified influential categories are not described; they don't convey meanings well. Explanations or examples would have helped.

Braun, K. L., & Nichols, R. (1997). Death and dying in four Asian American cultures: A descriptive study. *Death Studies, 21*(4), 327-359.

Sample	Description	Results	Comments
34 respondents in Hawaii, 2 key informants for each group and 5 – 8 people per focus group of four Asian Americans: Chinese, Japanese, Vietnamese, and Filipino.	Purpose: to explore cultural variations in the process of dying and grieving Design: six broad areas of interview questions: the underlying philosophy or religion influencing death and dying in the culture; burial, memorial services, & bereavement; suicide & euthanasia; ADs & organ donations; changes in beliefs & practices over time; & advice for health care professionals working with members of that ethnic group.	Differences were influenced by date of immigration, age, acculturation, economic status, & educational levels. Japanese were older and second generation while Chinese were youngest. The three other groups were all recent immigrants. The more educated and acculturated were more likely to have thoughts about living wills, organ donations, & euthanasia. Among the differences was a more open attitude toward suicide among the Japanese, despite sharing a common Buddhist heritage with the Vietnamese and the Chinese. Similarities among the four groups included respondents' willingness to discuss experiences with death.	Useful table 1 (Summary for key informants and focus group participants) & 2 (A summary of responses, by ethnicity) and the section of "brief history of immigration" for each group.

Doorenbos, A. Z., & Nies, M. A. (2003). The use of advance directives in a population of Asian Indian Hindus. *Journal of Transcultural Nursing, 14*(1), 17-24.

Sample	Description	Results	Comments
45 Asian Indian Hindus from an U.S. community, including 31 female (69%).	Purpose: to examine the completion rate of and related factors to ADs Design: descriptive exploratory survey; 47% returned out of 100, then 2 eliminated for incomplete. Survey questionnaire was developed after qualitative study (3 focus groups and 5 interviews with key informants); 3 identified themes were a belief in fate or karma, family involvement in all end-of-life care, & the importance of maintaining religious death and dying rituals during the end-of-life process. Univariate, bivariate, & stepwise multivariate analysis were used.	Being female and having an individualistic decision-making style were significantly positively correlated with AD completion. Having strong religious affiliation and a family decision-making style (n=31) were significantly negatively correlated with AD completion. Only 9% had a living will, but only 4% responded that they had no desire to complete ADs. The result indicated that 87% of respondents would have completed ADs if some situation support them to do so (p. 22)	Authors stated that Hindu cultural literature is rife with themes of the pain and punishment inevitably suffered by those who try to defy their karma. Two interpretations of the use of life-prolonging machines emerged. The avoiding group thought of it as “interfering” with karmic fate; therefore ADs should be used to avoid the potential use of life-prolonging machines. The supportive groups thought of it as the doctor is the tool of karma carrying out what is fated (p. 19).

Eleazer, G. P., Hornung, C. A., Egbert, C. B., Egbert, J. R., Eng, C., Hedgepeth, J., et al. (1996). The relationship between ethnicity and advance directives in a frail older population. *Journal of the American Geriatrics Society, 44*(8), 938-943.

Sample	Description	Results	Comments
1193 frail older adults for nursing home level of care in PACE (Program For All Inclusive Care Of The Elderly), including 385 non-Hispanic whites, 364 blacks, 156 Hispanics, and 288 Asians (79% were Chinese).	Purpose: to assess the relationship between ethnicity and health care wishes, including ADs. Design: retrospective chart review. PACE is a comprehensive managed care demonstration program serving frail older participants at 10 sites across the nation. Measurements: presence or absence of ADs, type of health care wishes selected including living will, durable power of attorney, and health care proxy.	Blacks are more likely to prefer aggressive interventions (OR1.6; 95%CI=.96-2.52 vs. White=1.00) but less likely to utilize written instruments for expressing wishes. Whites are more likely to utilize written instruments for AD. Asians are less likely to prefer aggressive interventions (80% of no code; OR 2.74; 95%CI 1.86-4.03; White=1.00) and are unlikely to use written ADs. Possible explanations were illiterate in English and the honor of the spoken word and verbal agreements. But, nearly all of the Asians had recorded their health care wishes 6.48 times more likely than whites and blacks and 50 times more likely than Hispanics, so did the use of a health care proxy by Asians to other groups. Durable power of attorney preference was completely in opposite direction (OR 0.04; 95%CI 0.01-0.19; White=1.00). Hispanics are less likely to utilize all advance planning and least likely to express their wishes for code situation.	Authors indicated that the result could be related to a study location (San Francisco) where AD and health care planing have high public discourse because of the HIV epidemic. Definitions of durable power of attorney and health care proxy are not clear. Asian's high completion of AD and health care proxy might be based on their preference for no life support. Recorded documentation as measurement, not including verbal expression of wishes, however, may not have reflected individual true wishes, especially Asians.

Hopp, F. P., & Duffy, S. A. (2000). Racial variations in end-of-life care. *Journal of the American Geriatrics Society, 48*(6), 658-663.

Sample	Description	Results	Comments
540 proxy respondents included 454 White Americans (WA) and 86 African Americans (AA), whose relatives died between 1993 and 1995.	Purpose: to identify differences in ACP and end-of-life decision-making between whites and blacks elders. Design: interview at home by telephone (n = 444) or in person (n = 95) based on the Asset and Health Dynamics Among the Oldest Old (AHEAD) study, a nationally representative survey of adults who were aged 70 and older in 1993. Data were analyzed with logistic regressions.	WAs were significantly more likely than AAs to discuss treatment preferences before death (p=.002), to complete a living will (p=.001), and to designate a Durable Power of Attorney for Health Care (DPAHC; p=.032). The treatment decisions for whites were more likely to involve limiting care in certain situations (p=.007) and withholding treatment before death (p=.034). In contrast, the treatment decisions for AAs were more likely to be based on the desire to provide all care possible in order to prolong life (p=.013). Logistic regression models revealed that race continued to be a significant predictor of ACP and treatment decisions even after controlling for sociodemographic factors.	The results were the same as scenario based studies so that it could be evidence of validity for scenario based studies. The strength is to have examined racial differences among persons who are currently facing EOL issues even though half of proxies misconstrued hospitalized patients' wishes. Authors discussed that in-person interviewees were less likely to withdraw Tx than telephone interviewees (social desirability bias?), and children are more likely to withhold Tx than relatives. Timing of interview is not stated. Authors recommended (a) to engage in discussions with blacks and (b) to use triangulation: family, patient, and other members (health providers).

Matsumura, S., Bito, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa-Singer, M., et al. (2002). Acculturation of attitudes toward end-of-life care: A cross-cultural survey of Japanese Americans and Japanese. *Journal of General Internal Medicine, 17*(7), 531-539.

Sample	Description	Results	Comments
539 English-speaking Japanese Americans (EJA, 92% response rate, mean age=62.8, 61% male), 340 Japanese-speaking Japanese Americans (JJA, 82%, Mage=74.3, 36% male), and 304 Japanese living in Japan (JJ, 91%, Mage=64.3, 47% male)	Purpose: to know about how and to what extent acculturation changes attitudes toward end-of-life care and ACP. Design: self-administered questionnaire in English and Japanese. Data were analyzed using Pearson χ_2 test and logistic regression.	Few subjects (6-11%) had discussed end-of-life issues with physicians, while many (EJA, 40%; JJA, 55%; JJ, 54%) desired to do so. But 18% of EJA, 16% of JJA & 23% of JJ did not want to do so. Most subjects preferred group surrogate decision making (EJA, 75%; JJA, 57%; JJ, 69%). After adjustment for demographics and health status, desire for informing the patient of a terminal prognosis using words increased significantly with acculturation (EJA, OR=8.8; 95% CI, 5.4 to 14.3; JJA, OR=2.8; 95% CI 1.8 to 4.4; JJ, OR=1.0). EJA had more-positive attitudes toward foregoing care, ACP, and autonomous decision making. 1/3 of JJ preferred to withhold the terminal prognosis from the patient while 31% of JJ & 23% of JJA preferred nonverbal communication to be informed about the terminal prognosis.	This study analyzed data by scenario based questionnaire but may reflect well reality of these societies. JJA are older, more female, widowed, living alone, less income, less working, more Issei, less acculturation score & more hospitalization in past 6 months. JJ are less religious and less likely to have a regular doctor. EJA are more educated, Nisei or Sansei, and likely to have experienced an ICU visit. Without knowing their reasoning, it is difficult to analyze their background meaning correctly. What does it mean by "nonverbal communication" as a method of informing? Acculturation as a factor is supported

Morrison, R. S., Zayas, L. H., Mulvihill, M., Baskin, S. A., & Meier, D. E. (1998). Barriers to completion of health care proxies: an examination of ethnic differences. *Archives of Internal Medicine, 158*(22), 2493-2497.

Sample	Description	Results	Comments
197 subjects aged 65 years or older. African Americans (AA; n = 65), Hispanic (n = 65), or non-Hispanic White (WA; n = 67) at an outpatient clinic in a New York City hospital.	Purpose: to examine barriers to completion of health care proxies. Design: Questionnaires were developed from the literature and from focus groups. Logistic regression analysis was used.	Significant predictors of proxy completion included knowledge of health care proxies, availability of a health care agent, exposure to mechanical ventilation, age, and self-reported health status as fair to poor. Hispanics were less likely to believe in the necessity of the proxy and less likely to have a family member to be their proxy (make a decision for them; 54% vs. 93% of WAs and 92% of AAs; ¶. 13). A possible reason was that they were more reluctant to ask a relative to serve as their agent than were WAs or AAs (¶. 19). They were less comfortable talking about end-of-life care with physician (46% vs. 81% of WAs and 71% of AAs) (¶. 14)	Authors concluded that lack of knowledge and the perceived irrelevance of ADs were potentially reversible barriers through education of both health care providers and patients. They also stated a possible reason for knowledge seeking behavior would be a differential motivation resulting in different knowledge levels (¶. 17). “Familism dictates that one’s family is central, requires obligations to one’s family member before outsiders, and emphasizes family unity” (¶. 18). Authors concerned that ADs are perceived as an unnecessary and overly formal approach to decisions that have traditionally rested with family members (¶. 1).

Murphy, S. T., Palmer, J. M., Azen, S., Frank, G., Michel, V., & Blackhall, L. J. (1996). Ethnicity and advance care directives. *Journal of Law, Medicine & Ethics.*, *24*(2), 108-117.

Sample	Description	Results	Comments
Follow up study from Blackhall et al. (1995). 200 subjects (100 male & 100 female) for each ethnic group minus 24 for unmet criteria (189 WAs, 196 AAs, 195 MAs, and 196 KAs; aged 65 years and older. 388 male & 168 female.	Purpose: to explore the relationship between ethnicity and attitudes toward advanced care directives among different American races. Design: one-on-one private interview. Demographic factors: functional status (the Duke Activity Status Index & the Katz Index of Activities of Daily Living), acculturation (the Marin Short Acculturation Scale - measures language use, use of English language media [television and radio], and ethnic social relations), access to health care, and the subject's experience with illness were evaluated in relation to withholding and withdrawing care. Several methods were used for analysis.	AAs are fairly positive about ACP in general but have negative feelings about formal ADs (p.115). 55 % of the WAs had knowledge of living wills compared with only 15% of AAs (p<.01), which suggest that when access is held constant, various ethnic groups may be differentially motivated to seek out information actively. This highlights an often overlooked fact, namely, that the acquisition of knowledge is not a passive process but one that requires engaging the intended audience (p. 115). Holding income and education constant, ethnicity still emerges as an independent factor predictive of AD possession, which suggests that income or education alone cannot simply explain the differences observed among the four ethnic groups.	Authors concluded the necessity to listen to the diverse voices of the communities and adapt the practices to fit their needs better (p. 116). They also stated that possible reasons of low completion rate of ADs for AA are distrust of the medical profession or of legal documents and a belief that life or death decisions are best felt in the hands of God.

Nolan, M., & Bruder, M. (1997). Patients' attitudes toward advance directives and end-of-life treatment decisions. *Nursing Outlook, 45*(5), 204-208.

Sample	Description	Results	Comments
34 out of 48 hospital cancer patients within 24 hours after admission	Purpose: to describe patients' attitudes towards AD & the relationship of these attitudes to the decision about whether to issue an AD Design: AD attitude Survey (17-item, 4-point Likert scale) based on previous qualitative study of AD (Rein et al. '96) such as severity of the illness, the opportunity for Tx choices, the effect of AD on Tx & the impact of AD on the family. Data analysis: frequencies, t-tests, χ_2 analysis, ANOVA	No significant relationships were found between the total score and age, educational level, ethnicity, or marital status. Over half of the subject knew how to issue a living will (59%) or health care power of attorney (63%). When they can't make a decision for their Tx, most (93%) thought their family should be given choices and 41% thought physician should decide. More participants (85%) thought AD ensures Tx they want than it would prevent Tx they don't want (67%). Many thought that their family wanted them to have AD (82%), and that AD would prevent family conflict (74 %), guilt over Tx among family (78 %), and costly expenses for family (74 %). Most (96%) thought they should issue ADs when they were healthy, but only 2 (6%) brought ADs with them to hospital.	An example of the difference between decisional autonomy (information seeking) and executional autonomy (desire to make decisions).

Orona, C. J., Koenig, B. A., & Davis, A. J. (1994). Cultural aspects of nondisclosure. *Cambridge Quarterly of Healthcare Ethics, 3*(3), 338-346.

Sample	Description	Results	Comments
Two Chinese, three Latino, and two Euro-American patients receiving treatment for advanced stage of cancer, their families and outpatient clinic staff.	Purpose: to address the issues of the decision-making process among culturally diverse patients. Design: ethnographic methods including participant-observation and in-depth semistructured interviews.	Five themes are: The Family as Care Giver; Disclosure vs. Non-disclosure: Different Expectations; Language as a Strategy in Nondisclosure; Reasons for Nondisclosure (protecting distress, polite - speaking of death is rude, disrespectful, and a portent of bad luck, & keeping hope); and The Contradictory "as if" World, especially at home, all act as if the situation is not serious. Towards the end of life, the patient disengages, meaning she "implicitly decides to not decide any care decision like an autonomous act" (p. 344).	Authors found from Chinese and Latino groups that nondisclosure as filial duty was described "by making the remaining time comfortable and free of distress," which is tied to a cultural value; it becomes the implicit norm; and it involves keeping hope (p. 341). Confucianist tradition teaches "[o]ur obligation is to care for our parent" from respect (p. 343). Latinos describe the need to protect their elderly as "our way," as part of their cultural identity (p. 341). They support veracity and not to put a time frame on the "probable time left." Thus, the participants' view of patients' life appeared to focus on day-by-day rather than on the longer period of the rest of life as mainstream Americans generally express.

Perkins, H. S., Geppert, C. M., Gonzales, A., Cortez, J. D., & Hazuda, H. P. (2002). Cross-cultural similarities and differences in attitudes about advance care planning. *Journal of General Internal Medicine, 17*(1), 48-57.

Sample	Description	Results	Comments
Purposive sampling of 26 MAs, 18 WAs, and 14 AAs in hospitals.	Purpose: to characterize the cultural attitudes influencing a patient's decision whether to perform ACP. Design: Structured, open-ended interviews with blinded content analysis to generate hypothesis.	Shared views, potentially reflecting elements of an American core culture are: "the patient deserves a say in treatment," and "ADs improve the chances a patient's wishes will be followed." Different themes which are likely to reflect specific ethnic cultures: most MAs believed "the health system controls treatment," trusted the system "to serve patients well," believed ADs "help staff know or implement a patient's wishes," and wanted "to die when treatment is futile." Few WAs believed "the system controls treatment," but most trusted the system "to serve patients well," had particular wishes about life support, other care, and acceptable outcomes, and believed ADs "help staff know or implement a patient's wishes." Most AAs believed "the health system controls treatment," few trusted the system "to serve patients well," and most believed they should "wait until very sick to express treatment wishes."	Authors concluded that while grounded in values that may compose part of American core culture, ACP might need tailoring to a patient's specific ethnic view. All appeared to honor the patient's individual autonomy, which is the same result of Blackhall et al. (1999). The rest of the findings are also consistent with other studies.

The SUPPORT Principal Investigators. (1995). A controlled trail to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of American Medical Association 274*(20), 1591-1598

Sample	Description	Results	Comments
4,301 patients at 5 teaching hospitals for phase I & 4,804 patients randomized by 27 physician groups (intervention group=2,652 & control group=2,152)	Purpose: to improve end-of-life decision making & reduce the frequency of a mechanically supported, painful & prolonged process of dying. Phase I: a 2-year prospective observational study to understand/confirm barriers to optimal management and shortfalls in patient-physician communication Phase II: a 2-year controlled clinical trial, (a) provide physician with accurate predictive information on future functional ability & survival probability for each day up to 6 months; (b) elicit and document patient & surrogate preferences for EOL care; (c) provide for skilled nurses involvement for 4-6 times.	Phase I: 47% of physicians reported accurate patients' preferences; 49% of DNR requests weren't written; among the dead (N=1150) 79% died with a DNR order but 46% of these orders were written within 2 days of death; median number of days spent in ICU was 8, 38% spent more than 10days, 46% were on ventilator within 3 days of death; 22% reported moderate to severe pain at least half the time while family claimed patients were in such pain level 50% of the time during their last 3 days of life. Phase II: no improvement in patient-physician communication (40% vs. 37% in control) nor in 5 outcomes such as physician's understanding of patient's preferences, incidence and timing of documentation of DNR order, level of reported pain, time spent in an ICU with a ventilator or comatose status, and hospital resource use.	The authors concluded that intervention failed to improve care or patient outcomes and suggested enhancing opportunity for more patient-physician communication. The way interventions were provided was a more routinized approach rather than personalized one.

Vaughn, G., Kiyasu, E., & McCormick, W. C. (2002). Advance directive preferences among subpopulations of Asian nursing home residents in the pacific northwest. *Journal of the American Geriatrics Society, 48*(5), 554-557.

Sample	Description	Results	Comments
A total of 423 residents (199 discharged between 1995 and 1998 and 244 current residents) of Asian descent (aged >55) from two ethnic nursing homes. Median age=83 +/- 9; Chinese 43%, Japanese 40%, & other Asian (Korean, Filipino, Southeast Asian) 17%.	Purpose: to study ADs (code status) among subgroups of Asian nursing home residents. Design: cross-sectional chart review to ascertain code status, age, gender, ethnicity, comorbidity (using the Charlson Index), and religion. Bivariate analysis & multivariable logistic regression were used.	The majority of the patients in any subgroup (72% overall) were 'no code'. Ethnicity, increased age, and comorbidity were correlated with no code status. Japanese residents were more likely to be no code (OR 4.1 [95% CI, 3.1- 5.4]) controlling for age, comorbidity, gender, and religion. Chinese were more likely to be full code (OR 3.3 [95% CI, 2.6-4.2]).	Unfortunately length of time in the US wasn't assessed. It is not clear who issued ADs. Study has all the problems of a retrospective chart review regarding validity and reliability of data.

Voltz, R., Akabayashi, A., Reese, C., Ohi, G., & Sass, H. (1998). End-of-life decisions and advance directives in palliative care: A cross-cultural survey of patients and health-care professionals. *Journal of Pain & Symptom Management, 16*(3), 153-162.

Sample	Description	Results	Comments
159 patients in palliative care institutions. 90 Americans: Mean age = 68.0, 61% Female, 51% cancer; 34 Germans: Mean age = 62.6, 65% Female, 97% cancer; 34 Japanese: Mean age = 58.6, 65% Female, 79% cancer. 93 health-care professionals. 26 Americans (8MD, 18RN), 29 Germans (14MD, 15RN), & 38 Japanese (14MD, 24RN).	Purpose: to explore possible differences in the scope of end-of-life decisions and attitudes toward ADs in palliative care. Design: explorative survey by a self-administered, open-ended questionnaire. Descriptive statistics was used.	The prevalence of a formal written AD was 79 % in the U.S., 18 % in Germany, and 9 % in Japan. An additional answer for entrusting all decisions to the family was necessary for Japanese when a question asked "what important decision do you expect in the near future?" In Japan, there was a high prevalence of entrusting all decisions to the family (known as omakase). More than 80 % of the participants in the U.S. and Germany had negative feeling such as sadness, loneliness, fear, loss of control, frustration, concern, and anger toward ADs, in contrasting to 45 % in Japan. Professionals in all three countries favored ADs, but there were no specific instruments for obtaining ADs in Germany and Japan. Some German and Japanese had given an informal AD (i.e., verbally express).	As a pilot study for content validity, survey results were used to derive a checklist for content and procedural aspects in end-of-life decision-making.

Appendix B

Explanatory Studies of Factors Affecting Family's Experiences with End-of-Life Decision Making

Baker, R., Wu, A. W., Teno, J. M., Kreling, B., Damiano, A. M., Rubin, H. R., et al. (2000). Family satisfaction with end-of-life care in seriously ill hospitalized adults. *Journal of the American Geriatrics Society, 48*(5 Suppl), S61-69.

Sample	Description	Results	Comments
Family members and other surrogate respondents for 767 seriously ill hospitalized adults who died at five teaching hospitals in the United States. A part of SUPPORT study.	Purpose: to examine factors associated with family satisfaction with end-of-life care. Design: a prospective cohort study with patients randomized to either usual care or an intervention that included clinical nurse specialists to assist in symptom control and facilitation of communication and decision-making. Eight questionnaire items regarding satisfaction with the patient's medical care expressed as two scores, one measuring satisfaction with patient comfort and the other measuring satisfaction with communication and decision-making.	Of the respondents, 16% reported dissatisfaction with patient comfort and 30% reported dissatisfaction with communication and decision-making. Factors found to be significantly associated with satisfaction with communication and decision-making were hospital site, whether death occurred during the index hospitalization (adjusted odds ratio (AOR) 2.2, 95% CI, 1.3-3.9), and for patients who died following discharge, whether the patient received the SUPPORT intervention (AOR 2.0, 1.2-3.2). For satisfaction with comfort, male surrogates reported less satisfaction (0.6, 0.4-1.0), surrogates who reported patients' preferences were followed moderately to not at all had less satisfaction (0.2, 0.1-0.4), and surrogates who reported the patient's illness had greater effect on family finances had less satisfaction (0.4, 0.2-0.8). Conclusions: Satisfaction scores suggest the need for improvement in end-of-life care, especially in communication and decision making. Further research is needed to understand how factors affect satisfaction with end-of-life care. An intervention like that used in SUPPORT may help family members.	Two other factors were recognized as important although the results were not statistically significant. A Match with Patients' Preferences at the end of life tended to increase family satisfaction level while the Use of Life-Sustaining Treatment tended to decrease family satisfaction level. A lack of in depth information about the experience of families involved in end-of-life decisions for a family member is a drawback of the study.

Tilden, V. P., Tolle, S. W., Nelson, C. A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research, 50*(2), 105-115.

Sample	Description	Results	Comments
Data were collected from hospital decedent charts, 74 family members of decedents, and clinicians who cared for decedents.	Purpose: to assess levels of family stress associated with decisions to withdraw life-sustaining treatments, to assess factors that affected stress, and to compare families and clinicians on their reasoning about the decision. Design: Data from families were collected in individual interviews, shortly after decedent death and 6 months later, using psychometric measures and semi-structured interview questions. Clinicians were interviewed once shortly following patient death.	Family stress associated with the withdraw decision was high immediately following the death of the decedent and, while it decreased over time, remained high a half a year later. Several factors affected stress; most notably, stress was highest in the absence of patient ADs. In reaching the decision, both families and clinicians prioritized what the patient would want, although families, more strongly than clinicians, endorsed doing everything medically possible to prolong the patient's life. Findings add compelling evidence for the power of ADs, whether written or verbal, to reduce the stress associated with family decision-making.	Three factors that affected the level of stress experienced by families were absence of ADs, being an ethnic minority, and a longer commute distance from the hospital. A lack of in depth information about the experience of families involved in end-of-life decisions for a family member was a drawback of study.

Appendix C

Descriptive Studies of Factors Affecting Family's Experiences with End-of-Life Decision Making

Jacob, D. A. (1998). Family members' experiences with decision making for incompetent patients in the ICU: A qualitative study. *American Journal of Critical Care, 7*(1), 30-36.

Sample	Description	Findings	Comments
17 family members who were involved in decisions on behalf of their 15 loved ones in the ICU	To describe and explain the experiences of family members in order to promote understanding of such experiences and to suggest areas for effective, supportive intervention. Grounded Theory	Three major themes were identified. **Arriving at a Judgment** - consideration of the patient's condition (availability, family's perception of the amount of information needed, and certainty attached to information, judgment, and decision) and the patient's preference about treatment (an objective way to know such as ADs (5/15 had), and subjective sense as "just knowing"). A concern to choose against prolongation of life that required others agreement, effects on the family, and doing what was the best for the patient were other considerations. **Moving in Concert** - relationships with health care providers. Connecting (taking time and being available and supportive, care shown, information sharing, and attention to the mutuality of treatment goals) **versus Disharmony** - being misunderstood or ignored, lack of caring shown, without attention to the mutuality of treatment goals. **Looking Back and Going on** - positively about their involvement in decision making although the emotional burden of responsibility was a common theme.	Limited to White Americans and seriously ill patients in the ICU. Life-sustaining treatment decision affected directly on the death of family members. Strong relation with health care providers because of ICU settings.

Jeffers, B. R. (1998). Research for practice. The surrogate's experience during treatment decision-making. *MEDSURG Nursing, 7*(6), 357-363.

Sample	Description	Findings	Comments
11 older adults who had served as surrogate decision-maker for hospitalized incapacitated family member. Interviews done after 14 months to 15 years post death.	To explore the experiences, thoughts, and feelings of surrogates making decisions for older adults and to identify nursing practices perceived as helpful to surrogates. Phenomenology	Three paradigm cases were **Caregiving** that represented a surrogate's sharing her home with the ill family member, **Protecting** that symbolized a surrogate's action of protecting incapacitated family member from aggressive treatment, and **Trusting** that expressed a surrogate's feeling towards health care provider in treatment decision. Four main themes were **Contextualizing the Decision, Actualizing Agency, Reviewing and Resolving and Transcending** **Contextualizing the Decision** - surrogates' perception of the terminal nature of present illness within the context of the past, present, and future health and quality of life of their family member. **Informing and Gathering Information** were major codes that surrogate decision maker tried to make sense of the present illness within the context of the patient's health trajectory. **Actualizing Agency** reflected the experiences and feelings of the surrogates; responsibility and burden were expressed. Two separate but related codes identified were being **alone/presenting**. **Reviewing and Resolving** included expression of feelings of regret or guilt regarding treatment decisions. The presence of ADs (4/11) and prior treatment discussions (3/11) did not ease the decision making or mitigate negative feelings associated with decisions. **Transcending** denoted surrogates' strength from having faith, the support of others and using their experience as a way of reaching out to others.	Limitation. No ethnic diversity and decision making was for ill family member who was hospitalized and incapacitated.

Meeker, M. A. (2004). Family surrogate decision making at the end of life: Seeing them through with care and respect. *Qualitative Health Research, 14*(2), 204-225.

Sample	Description	Findings (Processes)	Comments
20 family surrogates (16 individual interview plus 4 in a focus group) Decision making during the terminal phase of 18 family member's cancer illness. Urban & suburban in Western NY 9/5 hospital & 9/9 home /hospice Interviewed 3 months to 8 years post death of family member.	To describe family surrogates' experiences with, perceptions of, and strategies used in EOL decision-making; and to explain the process used to make EOL decisions, Grounded theory	It was ongoing, basic social process and interwoven with the other activities of their lives. Family surrogates continuously synthesized the core values of caring for their family member and respecting their family member's autonomy and self-determination. **During Learning the Diagnosis** - family continuously sought information while being shocked and both family and a patient lived fully until the diagnosis confirmed. **Standing With and Acting for** - characterized the orientation and activities of the surrogates. **Standing With** - Active Presence to be supportive and vigilance for the patient and Respect for the Person to know and learn about the patient's wishes, to understand and empathize for the patient, and to discern the meaning. **Brokering Information and Working with Family** - gating (transitional) categories which located between Standing With and Acting For. They facilitated or impeded decision making. **Brokering Information** - surrogates' activities in seeking and receiving information from health care providers and in conveying or providing information to others. **Working with Family** - surrogates' experiences and interactions with other family members **Acting For** - Advocating and Protecting. Advocating includes surrogates' effort to ensure access to and continuity of care and honoring of the patient's choice while they felt they were hitting the wall about the patient's care. Surrogates described Protecting patients from health care providers by Treading Lightly or Taking patients' wishes over those of other family members or health care providers. **Taking Leave** - activities near the time of the patient's death and subsequent to it. **Knowing/Preparing** for pending death and **Honoring** the life were its subcategories. Outcomes expressed surrogates' experience such as **Persisting Concerns, Satisfaction, and Learning**.	Limitations include a lack of ethnic diversity and a focus on the surrogates of terminally ill patients with cancer. Honoring Choice included the use of ADs but it was not clearly described.

Swigart, V., Lidz, C., Butterworth, V., & Arnold, R. (1996). Ethical issues. Letting go: Family willingness to forgo life support. *Heart & Lung: Journal of Acute & Critical Care, 25*(6), 483-494.

Sample	Description	Findings	Comments
30 family members of 16 critically ill patients (14 White Americans and 2 African Americans) in the critical care setting. 10 died & 6 survived	To describe the process of family decision making about life support Interviews were done while a real decision-making process was undertaking. Grounded Theory	Found that "letting go" of the patients for their families involved three interrelated and complex processes comprised of cognitive and emotional work: **Seeking and understanding information about the critical illness of the patient,** family member's started accepting a death is imminent. **Reviewing the life story of the patient and seeking the meaning of the patient's life**, family members reviewed the patient's life such as contributions, values, and problems and searched their own sense of morality about making a decision. **Struggling with family roles and relationships** family members searched for the "right thing to do" to fulfill the responsible and caring roles. With interpersonal and intrapsychic work in all process, most families reframed the issues related to the critical illness and reached that foregoing life support for the patients would not destroy family relationships.	Limitation: limited ethnic diversity. Strength is that interviews occurred during the decision making. Information about ADs is not available.

Appendix D

Poster Advertisement about Study

Would You Share Your Story To Help Improve End-of-Life Care for Japanese-American Family Members?

My name is Yoshiko Yamashita Colclough, a Japanese RN licensed in both the U.S. and Japan. I am living in Bozeman, Montana, teaching nursing at Montana State University. I am also a doctoral student at Oregon Health & Science University in Portland, OR. I am studying how Japanese-Americans have made decisions about end-of-life care for a family member who has died within the past five years.

I would like to hear your story.

What was your experience like? What could others learn from it? It is hoped that the study will help improve communication between families and health care providers such as nurses, including addressing the needs of different cultural groups during this difficult time. The study involves a one-time interview for up to one and half hours.

If you are a Japanese American who has lost a family member within the last 5 years, PLEASE contact me at **yoshikoc@montana.edu** or (406) 994-6048. I would like to talk with you to explain more about the study. Your privacy is guaranteed.

Appendix E

Recruitment Letter to Possible Participants and Organizations

IRB Approved # 8409

Name:
Address:

Date:

Dear

I am writing this letter to ask you respectfully to consider sharing your story about your late family member's death with me. Your name was given to me by (Key Informants, friend, etc).

I would like to introduce myself and to explain my study briefly. My name is Yoshiko Yamashita Colclough; a Japanese RN licensed in both U.S. and Japan. I am living in Bozeman, Montana, teaching nursing at Montana State University. I am also a doctoral student in nursing at Oregon Health & Science University in Portland, OR. I am studying how Japanese Americans have made end-of-life care decisions for a family member who has passed away within the last five years. The purpose of my project is to understand the experience of Japanese Americans who have made end-of-life care decision for a family member, including the process used within the family to make such decisions. It is hoped that the study will help improve communication between health care providers and families, including taking into account the needs of different cultural groups.

If you are willing to participate in this study, I will come to your home or a place of your choice to interview you. The interview will take from one to one and half-hours. You will be informed of the study purpose, procedures, potential risks and benefits, and confidentiality, and that participation is voluntary. You will have the right to withdraw from the study at any time. Because of the sensitive nature of the topic, maintaining privacy is guaranteed; no names will be used in the interviews or any research reports including my dissertation.

I will contact you by telephone soon to see if you are willing to participate. You can ask any questions at that time, but your participation in the project is completely voluntary.

If you have any questions about this project or wish to contact me, please feel free to do so by email at yoshikoc@montana.edu or by telephone at 406-994-6048.

Thank you very much for your time and consideration.

Sincerely,

Yoshiko Colclough, MS., RN

IRB Approved # 8409

Name:
Organization:
Address:

Date:

Dear

I am writing this letter to respectively ask you to allow me to recruit possible participants for my doctoral dissertation research project through a poster advertisement, and if possible, through referral of possible participants.

I would like to introduce myself and to explain my study briefly. My name is Yoshiko Yamashita Colclough, a Japanese RN licensed in both U.S. and Japan. I am living in Bozeman, Montana, teaching nursing at Montana State University. I am also a doctoral student in nursing at Oregon Health & Science University in Portland, OR. I am studying how Japanese Americans have made end-of-life care decisions for a family member who has died within the last five years. The purpose of my project is to understand the experience of Japanese Americans who had made end-of-life care decision for a recently deceased family member, including the process used within the family to make such decisions. It is hoped that the study will help improve communication between health care providers and families, including taking into account the needs of different cultural groups.

To gather data for my study, I will conduct a one-time interview for up to one and half-hours with Japanese Americans over age 40 who agree to participate in the study. Potential participants will be informed of the study purpose, procedures, potential risks and benefits, confidentiality, contact information, and that participation is voluntary and they have the right to withdraw from the study at any time. Because of the sensitive nature of the topic, privacy will be maintained and no names will be used.

I hope you will be able to help me. If you have any questions about this project, please feel free to contact me at yoshikoc@montana.edu or 406-994-6048.

Thank you very much for your time and thoughtful consideration.

Sincerely,

Yoshiko Colclough, MS., RN

Appendix F

Master List of Potential Participants

Master List

Names	Telephone numbers	Addresses	Eligibility	Codes

Appendix G

Screening Sheet for Potential Participants

Screening Sheet

Inclusion Criteria

(1) U.S. citizenship	Yes	No
(2) English speaking	Yes	No
(3) Self-identified Japanese Americans with both parents of Japanese descent	Yes	No
(4) Being over 40 years old	Yes	No
(5) Having a deceased family member 60 years old or older who passed away more than three months previously but less than five years ago	Yes	No

Treatments

(6) Having experienced decisions making about withholding and/or withdrawing end-of-life care treatments for the deceased family member	Types of Treatment	Withheld	Withdrew	Continued
	Antibiotics			
	Artificially administered fluids			
	Artificially administered nutrition			
	Cardiopulmonary resuscitation			
	Chemotherapy			
	Renal dialysis			
	Hospitalization			
	Intubation			
	Surgery			
	Transfer to the intensive care unit			
	Ventilation			
Other Treatments	Oxygen therapy			
	Hospice care			
	Blood transfusion			

Appendix H

Research Consent Form

IRB# 8409

Protocol Approval Date: July 21, 2004

OREGON HEALTH & SCIENCE UNIVERSITY
Research Consent Form

TITLE: An Exploration of End-of-Life Decision Making Within Japanese-American Families

PRINCIPAL INVESTIGATOR:	Beverly Hoeffer, DNSc, RN	(503) 494-3894
CO-INVESTIGATORS:	Yoshiko Colclough, MS, RN	(406) 994-6048
	Kathleen Chafey, PhD, RN	(406) 994-4493
	Sheila Kodadek, PhD, RN	(503) 494-3826
	Heather Young, PhD, RN	(541) 552-6706

PURPOSE:

You have been invited to be in this research study because you are a Japanese American who recently lost your family member. The purpose of this study is to better understand Japanese-American family members' involvement in making decisions to withhold and/or withdraw life-support treatment for their family member. If you agree to participate and do not withdraw later, you will be in this study for up to twelve month. As many as 25 people will be enrolled into this study, which will be conducted through Oregon Health & Science University.

PROCEDURES:

You will be interviewed only one time by a nurse researcher either in your home or at another location that is agreeable to you. You may be invited for a second interview because the researcher has additional questions about information from the first interview or because the researcher wants feedback form you about whether or not findings from the study make sense to you. The nurse researcher is a Japanese RN, licensed in both Japan and the U.S. You will be asked questions concerning how you made decisions about end-of-life treatment for your deceased family member.

An interview in which you will be asked about your experiences will take about one hour, up to one and a half hours. You will be asked for your permission to tape record the interview. You will be identified on the tape only by number to protect your privacy. After the interview, the tape will be transcribed (typed up).

RISKS AND DISCOMFORTS:

It is possible that you could become tired from taking part in the interview. Some of the questions may seem very personal, upset you, or cause you to recall some unpleasant experiences you have had in the past. You may refuse to answer any of the questions that you do not wish to answer. If the questions make you very upset, we will help you to find a counselor.

BENEFITS:

You may or may not personally benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients and families in the future.

ALTERNATIVES:

You may choose not to be in this study. You may also drop out of the study at any time if you wish.

CONFIDENTIALITY:

We will not use your name or your identity for publication or publicity purposes. Information collected in this study will include information you provide in the interview related to how you made decisions concerning end-of-life treatment for your deceased family member. Information will also be collected from questions we ask you about age, gender, and religious affiliation of both you and your deceased family member, your generation, relationship to the deceased, the date, cause, and place of death of the deceased, and the types and the length of the deceased illness. This information will be collected to help us analyze the research results from this study.

The persons who are authorized to use and disclose this information are: All investigators listed on page one of the Research consent and Authorization From, others at OHSU who are participating in the conduct of this research protocol and the OHSU Institutional Review Board.

The persons who are authorized to receive this information are: the Office for Human Research Protections (OHRP).

You may continue to use and disclose protected health information that we collect form you in this study until this study is completed.

While this study is still in progress, you may not be given access to medical information about you that is related to the study. After the study is completed and the results have been analyzed, you will be permitted access to any medical information collected about you in the study.

You have the right to revoke this authorization and can withdraw your permission for us to sue your information for this research by sending a written request to the Principal Investigator listed on page one of the Consent and Authorization Form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date she receives you request. However, the Principal Investigator is allowed to use and disclose information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with OHSU.

Only persons listed in this consent form will have access to information from the recorded tape. Recorded tape will be identifiable only by number to protect your privacy. All information will be kept in a locked file cabinet or on the computer in password protected files. All the material used for interviewing will be kept in a locked file cabinet. Upon completion of the study, recorded tapes, the screening sheets, and the master list will be destroyed.

COSTS

There are no costs to you for taking part in this study.

LIABILITY:

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

Yoshiko Yamashita Colclough at (406) 994-9048 has offered to answer any questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

Your consent to participate in this study is voluntary. You may refuse to sign this consent form. If you refuse to sign this consent form, your health care and relationship with OHSU will not be affected, however, you will not be able to enter this research study.

Although it is unlikely that this will happen, you will be told if we learn anything in doing this study that might make you want to change your mind about continuing to be in the study.

It is possible that you could be removed from the study before the study ends if you were to become ill and unable to participate or if you did not want to answer any of the interview questions. If you choose to withdraw from the study, you will not be asked to answer any more questions. You will have an option of allowing your data in the recorded tape to be sued or request that it be destroyed and not used. If you simply dropped out and didn't respond to queries, the data could be used and managed the way all other data are managed.

You will be given a copy of this consent form.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

Subject's signature Date

Subject's printed name

Yoshiko Y Colclough, MS., RN.

Investigator's signature Date Investigator's printed name

Appendix I

Interview Guide: Sample Questions

Interview Guide: Sample Questions

Focus Area	Sample Questions	Probe Questions
Initial Question	Could you share with me your experience - what was it like to be with your (father, mother, wife, husband, etc.) as he/she was passing away?	
1. Experience and process around Decision Making	What were the most difficult decisions you had to make when your (father, mother, wife, husband) was passing away? What made those decisions difficult?	What was your responsibility around decision making? What guided your decisions about end-of-life care? What was the most (the least) helpful thing that anyone said or did during decision making? How did the fact that he/she knew (or didn't know) he/she was dying affect the decision making? Do you think your (family member) passed away as he/she liked?
2. Advance directives	Did the deceased have an advance directive (living will)?	If yes: Who was involved in completing the advance directive? Who was involved in implementing it? What was that like for you? For other members of your family? If no: Was an advance directive ever discussed? What guided your decisions about end-of-life care instead, and what was that like for you? For other members of your family?
3. Perspectives about the Decision Made	How do you feel about the decision(s) that was (were) made now? Could you tell me how you made sense of the decision made?	What, if anything, would you do differently? Why? How do you see the decision made for your family member? The death of your family member?
4. Comments to Health Care Providers/ Reflection	What would you tell nurses if you had the chance that would help them help others? What advice would you give to families who are faced with end-of-life care decisions or go through a similar experience to yours? What should I have asked you about the experience?	

Appendix J

Demographic Data Collection Form

Code Number _______

Demographic Data

1. Participant's Code Number: ____________________
2. Interview Number ____________________
3. Date of Interview: ____________________
4. Place of Interview: ____________________
5. Participant: Age ____________________

    Gender: M F

    Self-Identified: Issei Nisei Sansei

    Religious Affiliation: ____________________

    Relationship to the Deceased: Spouse Child Siblings
    Other (Specify) _____________

6. Deceased: Age ____________________

    Gender: M F

    Religious Affiliation: ____________________

    Date of death: ____________________

    Cause of death: ____________________

    Place of death: ____________________

    Types of Illness ____

    Length of the Illness: ____________________

Appendix K

Participant Observation and Reflection

Code Number _______

Participant Observation

Reflection

1. What did I learn about end-of-life decision making for the deceased family member?

2. What did I get?

3. What did I wonder about?

4. What questions do I have?