Abstract: Attention to culturally specific rituals germane to end-of-life rituals are important for the nurse who is delivering culturally competent care. The Patient Self-Determination Act implemented in the United States in 1991 brought with it some specific assumptions of values related to end-of-life care involving patient autonomy, informed decision making, truth telling and control over the dying process (USC, 1990). The assumptions and values assumed in this act are not necessarily shared by persons in the United States who are from a minority culture, particularly one other than White of European descent. This manuscript considers the values of the Patient Self-Determination Act passed in the United States and specific cultural beliefs which may pose a conflict for the care giver in the delivery of culturally competent care. "The Giger and Davidhizar (2004) Transcultural Assessment Model" is used as a way to assess patient and the family in an effort to plan culturally appropriate care that recognizes the uniqueness of each individual at the end of life.

Key Words: Advanced Directives, Culture, Cultural Competency, End-of-Life, Ethnicity, Patient Self-Determination Act

MULTI-CULTURAL AND MULTI-ETHNIC CONSIDERATIONS AND ADVANCED DIRECTIVES: DEVELOPING CULTURAL COMPETENCY

As the United States becomes increasingly culturally diverse, it is imperative that health care providers address end-of-life healthcare concerns, as well as pay particular attention to culturally specific rituals germane to end-of-life for all individuals for whom care is rendered. In 2000, 70.9% of the population in the United States were White of European descent, 12.3% were African American, 12.5% were Hispanic American, 4.1% were Asian American, and 0.9% were American Indian (U.S. Department of Commerce, Bureau of the Census, Summary File 3, 2002). It is projected that by the year 2020, only 53% of the U.S. population will be White of European descent. It is further projected that by the year 2021, the number of Asian Americans and Hispanic Americans will triple, while the number of African Americans will double (U.S. Department of Commerce, Bureau of the Census, Summary File 3, 2002). As the demographic composition of the United States changes, it is essential that culturally competent care be rendered by all healthcare professionals. Seemingly, end-of-life care concerns, including advanced directives, would not be exempt from this premise. Thus, It is essential that health care providers appreciate differences in values, attitudes, beliefs, and customs held by different cultural and ethnic groups related to the dying process.

This article: 1) describes the Patient Self-Determination Act; 2) provides an in-depth look at cultural views on advanced directives; and finally, 3) provides a practical application of the Giger & Davidhizar Transcultural Nursing Assessment Model to assess the culturally and ethnicity diverse dying patient and the family in an effort to plan culturally appropriate care that recognizes the uniqueness of each client at the end-of-life. Providing end-of-life care that is culturally appropriate requires changes in attitudes health care professionals toward death and dying (Callahan, 1995).
THE PATIENT SELF-DETERMINATION ACT
In 1991, the United States legislature implemented the Patient Self-Determination Act (PSDA) (Annas, 1991). This legislation came in the wake of the Cruzan and Quinlan cases (1990) and the desire to reengineer the manner in which end-of-life care and decisions were made (Annas, 1991). These highly publicized court cases brought to the forefront, the high costs of care in the final months of life and concern with who could make end-of-life decisions when a person was incapacitated (Wheeler, 1990). Initially, advanced directives were viewed as a solution to decreasing the use of costly life-sustaining technology which did not sustain life at a quality level. Individuals, regardless of race, ethnicity, culture and cultural heritage, feared that life-extending technology might potentially increase suffering without ultimately resulting in sustained and prolonged life and thus many of these individuals desired the ability to be self-determining (Callahan, 1988). Additionally, many of these individuals, believed that advanced directives could have a positive effect on the escalating cost of healthcare (Emanuel, 1996, Institute of Medicine, 1997).

It is also important to note that the PSDA came in the wake of the consumer rights movement in the 1970s, which culminated in the American Hospital Association’s Patient’s Bill of Rights. The consumer rights movement prompted the consideration of a shift in decision-making control from physicians to patients. What this essentially meant was that physicians would no longer solely be entrusted with all decisions relative to end-of-life care. As the movement to regain control over personal decision-making at end-of-life continued to grow, patients who were approaching death and even well individuals continued to seek avenues to gain personal control over care decisions.

A major goal of the designers of the PSDA was to clarify and protect individual’s health care decisions through the increased use of a formal advance directive (Diamond, 1991; Kagawa-Singer, 1998; Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998). An advanced directive was designed as a document to be completed by a competent adult to provide specific direction for medical care should the individual become incompetent (Diamond, 1991; Kagawa-Singer, 1998; Ersek et al., 1998).

The goal of the PSDA is to encourage adults to exercise control over medical treatment decisions, and outlines requirements that healthcare agencies are expected to meet for advanced directives. Healthcare agencies must provide patients with written information about advanced directives, must ask about advanced directives which may be present, must educate staff and the community about advanced directives, must ensure compliance with state law, must provide patients with written assurance that their healthcare is not contingent upon having an advanced directive, and must have institutional policies regarding advanced directives (Ersek et al., 1998). It is necessary for the health care agency to be cognizant of state laws related to advanced directives which, while differing from state to state, include regulations related to living wills (documents that allow predetermined acceptance or rejection of life-saving therapies) and durable power of attorney for health care (authorization for another person to act as one’s agency for healthcare decisions if the individual is incapacitated) (Diamond, 1991; Kagawa-Singer, 1998; Ersek et al., 1998).

An advanced directive is based on four interconnected values (see Table 1), which include patient autonomy over end-of-life decisions, informed decision-making, truth telling, and control over the dying process. In the United States and other Western countries, where self-determination or autonomy is regarded as a basic right and informed consent an element of responsible health care, the idea of health care providers withholding from patients the information needed to make informed end-of-life treatment decisions is viewed by many as inexcusable and untenable (Diamond, 1991; Kagawa-Singer, 1998; Ersek et al., 1998). While the individual may consult others, the premise of the PSDA is that the ultimate decision should be a personal one and this notion is embraced by many White American more so than some African-Americans, Mexican-Americans, American Indians, and Asian Americans. (Orona, Koenig, & Davis, 1994).

Despite all that has been done to bring this new (PSDA) initiative forward, the implementation of PSDA has been often fraught with unsolvable problems creating many new challenges for healthcare professionals. It goes without saying that some racial and ethnic groups have been slow to embrace the PSDA initiative (Diamond, 1991; Kagawa-Singer, 1998; Ersek et al., 1998). It is true that while most people state that they would like to die at home, only 23% currently do (Mitty, 2001). For some individuals, failure to execute an advanced directive is lack of foresight, for others it is based on a differing set of beliefs and relative to the dying process (Caralis, Davis, Wright, & Marcial, 1993).

While ethnic minorities have different values and ideas about health care and the dying process, they are not alone in this ideology. Even among some sub-cultural groups who represent White Americans, there are

Table 1. Values of Patient Self-Determination Act

| 1. Patient autonomy-people have the inherent right to make treatment decisions and should be active participants in their own care. |
| 2. Informed decision making-people have access to all the information relevant to the particular decision. |
| 3. Truth telling-information provided will be provided openly by health professionals |
| 4. Control over the dying process-people should and can have control over their own life and death. |
persons who do not wish to make decisions about end-of-life care. For example, some elderly, regardless of race, ethnicity, or culture, prefer a passive voice deferring to the medical profession or family (Mitty, 2001). In addition, some of the poor may perceive that advanced directives are nothing more than a legal device of the health care system to deny care to the needy (Mitty, 2001). Some close-knit families believe that advanced directives are in direct conflict with family’s rights and obligations to be the primary decision-maker on matters pertaining to end-of-life (Gostin, 1993).

In a 1998 study by Kaufman, four cultural forces that influence end-of-life care in an intensive care unit were identified that included: 1) biomedical knowledge as a dominant conceptual framework for understanding old age and death; 2) the power of the technological imperative to determine events; 3) the incompatibility of lay and medical knowledge; and 4) the general ambivalence about end-of-life goals. Thus, not only may patients and health care professionals differ in end-of-life goals, but individuals themselves may be ambivalent and change their minds regarding end of life goals.

CULTURAL BELIEFS AND ADVANCE DIRECTIVES

Culture is a “patterned behavioral response that develops over time as a result of imprinting the mind through social and religious structures and intellectual and artistic manifestations” (Giger & Davidhizar, 2004). Culture is shaped by values, beliefs, norms and practices that are shared by members of a cultural group and guide thinking, doing, and being. Culture becomes a patterned expression of who we are and is passed down from one generation to the next. Cultural values are unique expressions of a particular culture that become acceptable as they are practiced over time. Person in the general U.S. society and those who work in the U.S. healthcare system may have opposing views based on cultural values related to life and death.

Traditionally, the United States healthcare system is based on three values: 1) life is sacred and should be preserved at all costs; 2) autonomous decision-making should be maintained at all times; and 3) above all, no individuals should suffer needlessly (Kagawa-Singer, 1998). It is interesting to note that these Western Judeo-Christian values are often not shared by some persons in the United States and in such cases the incongruities between those receiving care and those providing care may result in overwhelming distress (Kagawa-Singer, 1998).

In the United States and other Western countries where self-determination or autonomy is commonly regarded as a basic right and informed consent an element of responsible health care, the idea of withholding from patients the information needed to make informed end-of-life treatment decisions is viewed by many as inexcusable and untenable (Mitty, 2001). Nevertheless, because so many individuals in the United States do not adhere to this belief system, it is essential for healthcare professionals to not make the assumption that common beliefs and values are held but to assess each individual patient for their personal belief system. It is necessary to proceed cautiously and in a sensitive manner if communication about end-of-life information is to be delivered in a culturally appropriate care.

In today’s health care arena, a patient’s cultural background is considered a fundamental dimension which must be considered in providing care (Ersek et al., 1998). Findings from some studies indicate that there are cultural variations in attitudes toward truth-telling, life-prolonging technology, and decision-making styles at the end of life exist between and among persons from diverse cultural backgrounds (Blackhall, Murphy, Frank, Michel & Azen, 1995; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Caralis et al., 1993). The nursing literature includes differences among patients from different cultures in relation to the four aspects of the Patient Self-Determination Act including autonomy, informed decision making, truth telling, and control over end-of-life processes (Mitty, 2001). It is important to remember that while studies may show differences noted within a cultural group each patient must be considered as an individual and not be stereotyped in relation to a culture.

Autonomy

In the United States healthcare system and among many mainstream Americans, the value of autonomous decision making is strongly held. In a study of four ethnic groups, Blackhall, Murphy, Frank, Michel and Azen (1995) noted that Korean and Mexican individuals believe in a family-center model of decision-making rather than a patient-centered model of decision-making. Some Korean individuals may seek to avoid the unnecessary suffering they believe that will ensue if their loved one is told of the diagnosis or prognosis. For many people in the general U.S. society, autonomy is reaffirming and empowering. Yet for many Korean individuals, autonomy is not empowering; rather, it is isolating and burdensome and causes loss of hope (Blackhall, Murphy, Frank, Michel, & Azen, 1995). Others cultures where the group decision-making is of paramount importance and where consensus of the family group is highly valued include some Japanese and some Hispanic individuals (Blackhall et al., 1995; Kagawa-Singer, 1996).

Some Hispanics act on the concept of jerarquismo (respect for hierarchy) which considered in combination with personalismo (trust borne of mutual respect), anticipates the tendency of some Hispanic patients and their families to defer to a physician’s opinion or decisions in regard to end-of-life care issues (Mitty, 2001). On the other hand, some Hispanics believe that “apoderado para casa de asistencia media” which translates as reaffirmation in English as a “health care proxy,” roughly meaning in its literal translation, “that another has power over you or will act for you as a
result of this power.” For some Hispanics, the concept of Familismo, (welfare of the family) suggests that some Hispanics hold a cultural view that is predicated on the fact that a personal illness will cause a burden on family members (Mitty, 2001).

Findings from a study by Morrison, Zayas, Mulvihill, Baskin, and Meier (1998) on African-American, White and Hispanic elders in New York city in a senior center suggest that most were uncomfortable with the prospect of planning in advance for end-of-life care. These seniors equated less aggressive treatment with abandonment and many perceived that advance directives were harmful. A surprising finding was that among these elders, while many viewed family decision-making as important, many of these elders did not want to name family members as proxies for their end-of-life care issues.

The interaction of Buddhism, Confucianism, and Christianity support filial piety for Asians and Pacific Islanders. This belief is premised on the fact that as an act of control over elders, family members must assume decision-making roles in serious health situations. Stauffer (2004) notes that when a health care team member anticipates that a Vietnamese patient may die, the head of the family, usually the parents or the eldest child, should be informed first. For some Vietnamese patients, a decision about advanced directives will usually be a family rather than an individual decision (Stauffer, 2004).

For many Americans Indians, autonomy is not an individual concept but rather decision-making lays in the community. For some American Indians, an advance directive is considered a death warrant and a violation of their fundamental tribal views (Carrese & Rhoades, 1995). Carrese and Rhoades (1995) noted that where some American Indians are concerned, the concept of advance directives is perceived to be detrimental not only to the individual but to the family and community as well.

Informed Decision Making

Blackhall, Murphy, Frank, Michel, and Azen (1995) found that Korean and Mexican Americans were more likely to believe that the patient should be informed in the decision-making process in medical decisions at the end-of-life. These researchers noted that the family centered decision making process was valued and consequently utilized by persons in these cultural groups.

In the typical Filipino culture, the family will want to be the first informed of a family member’s terminal illness diagnosis. Often times, the family will want to discuss the terminal illness with healthcare professionals and the family usually wants to disclose this information to the patient themselves. A decision regarding an advanced directive is more likely to be a family decision rather than an independent decision by the patient (Vance, 2004).

Jewish law dictates that patients should be informed that death is near which allows the person to put worldly affairs in order. However, because of two controversial passages in the Torah, some Rabbis believe that while it is important to inform a dying patient about serious illness, it is not necessary to say that death is near. To tell a patient that death is near is thought to eliminate hope and thus some Jewish people fear this information will hasten death (Schwartz, 2004).

Truth-Telling in End-of-Life

In some cultures, it is considered inappropriate for the health care professional to tell the patient the truth about the seriousness of their health status in order for their caretaker to prepare advanced directive for their care. Telling the patient about their health status is considered harmful to the patient and an infringement on the proper role of the family (Gostin, 1995). Rather, the serious health information should be provided to designated family members who will determine to be provided with this information. In general, full disclosure and truth telling are more likely to be found in European American cultures than in non-European cultures (Ersek et al., 1998).

A study of 800 individuals from four ethnic groups which included Whites, African Americans, Korean Americans, and Mexican Americans, Blackwell, Murphy, Frank, and Azen (1995) found that Mexican Americans and Korean Americans were significantly less likely than Whites and African-Americans to believe that a patient should be told a diagnosis of metastatic cancer. Major findings in this study where that Korean Americans (47%) and Mexican Americans (65%) were significantly less likely than Whites (82%) and African-Americans (88%) to believe that a patient should be told of a diagnosis of metastatic cancer. Another finding from this study suggests that Korean American (28%) and Mexican Americans (41%) held an overriding belief that individuals should not be allowed to make decisions about life supporting measures in stark opposition to Whites (65%) and African Americans (60%) who believed that they should (Blackwell, Murphy, Frank, & Azen, 1995). DeSpelder and Strickland (1999) also noted that within the Mexican culture, it is believed the dying should be protected from knowing their prognosis as death is viewed as an adversary.

Some African-Americans distrust the health care system. Awareness of the Tuskegee experiments causes some to feel that an advance directive may legalize neglect. For some African-Americans, illness is seen as a test of faith and therefore aggressive treatment and care are indicated. While decision-making among African-Americans with regard to end-of-life care varies with individual history, religiosity and socioeconomic status, a significant number of African-Americans regard an advanced directive as a way to legalize neglect, to deny treatment and to commit genocide (DeSpelder & Strickland, 1999).

Some Navajo Indians believe that thoughts and language shape and influence reality. Therefore, it is im-
portant to think and speak positively and to avoid speaking negatively. In contrast, the belief that talking about bad things can actually bring them on is also held by some people in Greece, China, Italy, Korea, Mexico, and the Horn of Africa nations (Carrese & Rhoades, 1995).

CONTROL OVER LIFE’S PROCESSES

The typical American society is a death-defying culture. “Do not go gently into the night” (Blake, 1988) is supported by the image of fighting illness, fighting cancer, and fighting death as an enemy (Kalish & Reynolds, 1981). In contrast to this image of antagonism is the concept developed by some societies of transition where cultural practices support the dying process and the patient and family enter into the process together (Spiro, Curnen, & Wandel, 1996).

One aspect of the dying process that differs with cultures is the attitude toward pain (Davidhizar, Dowd, & Newman-Giger, 2003). The desire for pain avoidance is not a universally shared belief. How a patient experiences or expresses pain is filtered through a cultural perspective as well as the cultural perspectives of the caregiver. Pain may be seen as life-affirming in some cultures, that is, the body is fighting back against the dying process in an attempt to recover (Post, Blustein, Gordon, & Duber, 1996). In other cultures, pain is regarded as a punishment, and evil spirit, a cleanser or a body builder (Post, Blustein, Godeon, & Duber, 1996). For cultures that believe that pain may be existential depriving the patient of the chance to work through their suffering and thus achieve peacefulness and comfort is considered harmful (Mitty, 2001).

There are a number of reasons why persons with a Hispanic culture will hesitate to do advance planning. For some Hispanics, life is viewed as a gift from God, a temporary loan. While life should be maintained, death is a natural part of the life cycle (Mitty, 2001). The common Hispanic phenomena of present time orientation (presentismo) may also contribute to lack of advance planning for persons of this cultural orientation.

Blackhall, Murphy, Frank, Michel and Azen (1995) found that some African-American patients are only half as likely as their White counterparts to opt for treatment such as pain medication that improves the quality of life at the expense of the length of life, even if it means that physiological pain might be constantly present. In contrast, Whites are more likely to refuse intubations and continuation of life-sustaining treatments, in the case of dementia, than their Hispanic or African-American counterparts. In other words, longevity, for some African-Americans, actually trumps the quality of life. For some African-Americans, illness is seen as a test of one’s faith; one should not, therefore, put barriers, like treatment refusal or withdrawal in the way of God’s will (Blackhall, Murphy, Frank, Michel, & Azen, 1995). The belief that living is difficult, nonetheless mature responsible people will carry on despite life’s inevitable adversities, contradicts the typical value in the American healthcare system that no one should suffer.

When life-sustaining treatments are considered, Caralis, Davis, Wright, and Marcial (1993) noted that non-Hispanic Whites were more likely to agree to withhold life-sustaining treatments than Hispanic and African Americans. Klessig (1992) also found that persons of European descent were less likely to utilize life support even in hopeless and terminal situations than African-Americans, Chinese Americans, Filipino Americans, Korean Americans, and Mexican Americans.

USING THE GIGER-DAVIDHIZAR TRANSCULTURAL ASSESSMENT MODEL TO ASSESS BELIEFS AND VALUES RELATED TO ADVANCE DIRECTIVES

In today’s multicultural health care area nurses must carefully assess each patient for values and beliefs regarding the end-of-life. When the patient and nurse do not speak the same language this may be especially difficult. It is important to avoid approaching patients with pre-conceived ideas about their cultures, but to take knowledge and re-validate it with individual patient beliefs. According to Scanlon (1989) among the many assessment questions a nurse can ask and the most valuable are “What is your greatest concern?” and “How can I be of help?” so that care can begin with what the patient feels is the greatest priority.

The Giger-Davidhizar Transcultural Model (2004) has been used for 13 years by health care professionals in a variety of disciplines and provides an assessment framework which can organize information on which to base patient care. The model requires that data be collected on six phenomena including 1) communication, 2) time, 3) space, 4) social organization, 5) environmental control, and 6) biological variations (Giger & Davidhizar, 2004). This model can provide a framework for collecting information related to end-of-life concerns and advance directives. Once assessment data have been collected the nurse can plan culturally appropriate and sensitive care which is based on knowledge, mutual respect, and negotiation between professional caregivers and patients (Chrisman, 1991). It is only when the nurse has completed a comprehensive assessment for culturally related factors that culturally appropriate care can be planned and delivered (Giger & Davidhizar, 2004). A complete listing of questions to provide a comprehensive cultural assessment can be found in Transcultural Nursing: Assessment and Intervention (2004). For the purposes of assessment related to end-of-life care and advanced care, Table 2 provides samples of questions which can assist the health care professional collect relevant information.

ASSESSING VALUES OF THE HEALTH CARE PROFESSIONAL RELATED TO ADVANCE DIRECTIVES

It is important to remember that each patient and care provider bring individual beliefs and values to the
patient-care provider interaction. As the United States becomes increasingly diverse, it is more and more common for patients and caregivers to come from different cultural backgrounds and to have their own belief system based on their culture of origin (Kagawa-Singer & Blackhall, 2001). In addition to cultural differences, age differences, and educational differences between family, patient, and care providers, culture can influence beliefs and values. Kagawa-Singer and Blackhall (2001, p. 2993) note, “You got to go where he lives” in order to provide culturally appropriate care. Kagawa-Singer and Blackhall (2001) note that failure to take the culture of the patient seriously means the value system of the professional is inappropriately elevated and can have the result of being “culturally destructive.” Rather there must be communication between the health care professional and patient and negotiation between worldviews and cultures in order to reach mutually acceptable goals.

While the North American culture of medicine presently advocates explicit disclosure related to prognosis, this practice has only become commonly accepted in the last 40 years. For older physicians who received their training before this was part of the educational system, for physicians from other countries where this orientation was not present, or for older patients, this concept may not have been valued or accepted. There may also be incongruity between values placed on patient autonomy versus family decision-making since this differs between individuals and cultures. It is critical that health care providers assess personal values and beliefs as well as that of the patient and family so that collaboration can occur and individualized and culturally appropriate care be provided (Candid, 2002). If healthcare providers are not comfortable with the desires of the patient, it may be important that a referral to care providers who are more accepting of the patient’s beliefs and values be made.

The recent work of the End of Life Nursing Education Consortium (ELNEC) has developed a module on cultural considerations in end-of-life care. This curriculum module communicates three key concepts: 1) culturally sensitive care encompasses recognition of multiple factors including but not limited to ethnicity, gender, sexual orientation, and social class, 2) cultural factors significantly influence communication with patients and families at the end-of-life, and 3) culturally appropriate care is best provided through an interdisciplinary approach (Matzo, Herman, Mazanec, Barber, Virani, & McLaughlin, 2002). The material from ELNEC is readily available for educators to use in developing culturally competent nursing skills in end of life care.

**SUMMARY**

In order to assist patients at the end-of-life in the decisions that affect them it is essential that healthcare professionals have cultural understanding and sensitivity. It is essential to appreciate differing world views and to negotiate with patients for mutually acceptable goals. An appreciation and respect of cultural differ-

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**Table 2. Assessment Factors Related to End-of-life Decision Making**

| Communication | Who is the decision maker in the family (the individual, family, mother vs. father, male vs. female?)
| | Can health care providers and family members be trusted?
| | Are questions asked freely or only after trust is developed?
| | Are concerns offered freely or only in response to questions?
| | Does the individual have a stoic or expressive manner?
| Space | Is family closeness valued?
| Time | Is the individual past, present, or future-oriented?
| Environmental Control | Who holds the control over the future?
| | Do personal actions influence the future?
| | Is there belief in internal control? (i.e., does the power to affect change lie within?)
| | Is there belief in external locus-of-control (i.e., does luck, fact, and chance have a great deal to do with how things turn out?)
| Social Organization | Is there belief in a supreme being?
| | What is the function of the family system?
| | What is the function of the religious system or church?
| | What is individual’s assigned role in the family (e.g. mother, father, child, sibling)?
| Biological Variations | What is the health status of the individual?
| | Is pain expressed freely or only when asked?
| | Does the person believe pain should be tolerated?
ences can lead to increased trust, better clinical outcomes, and higher satisfaction of patients and family members.

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