

## Patient Autonomy and End-of-Life Care: Cross-Cultural Considerations

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### About the author:

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## **Patient Autonomy and End-of-Life Care: Cross-Cultural Considerations**

### **Introduction**

The purpose of this paper is to describe the influence of culture and religion on end-of-life decision making and advance care planning. Over the last few decades there has been increasing amounts of attention and controversy on end-of-life planning. Highly publicized North American cases such as Karen Quinlan and Nancy Cruzan have brought the topic of patient's rights to refuse unwanted treatment into the limelight. This public debate of end-of-life treatment paved the way for federal legislation. One such piece of legislation is the enactment of the Patient Self-Determination Act of 1990. It requires health care facilities to provide information about advance directives to patients at the time of admission (Guido, 2010, p. 181). Recently there has been a growing interest in cultural and religious influences on end-of-life planning. Members of the multidisciplinary team need to be aware of the practices in different religions and cultures regarding end-of-life care. The United States is becoming increasingly more culturally diverse, including increased diversity between members of the health care team. As of 2001, literature on end-of-life care had only begun to investigate the related cultural differences on the matter (Kagawa-Singer & Blackhall, 2001).

End-of-life decision making is an important topic for me because I plan on pursuing a career in critical care nursing. Nurses in critical care units frequently encounter patients from a variety of cultures and religions who are in their end stages of life. During my critical care rotation, I observed an ethical dilemma relating to end-of-life care. An adult patient in my unit was admitted following a motor vehicle accident. The patient was unconscious upon admission and was in need of a blood transfusion. The parents of the patient would not allow a blood transfusion to be done due to their religious beliefs. At the time I was shocked to hear that a

parent would choose to withhold life-saving treatments, even after hearing that it may result in the patient's death. I also wondered if the patient held the same belief system as the parents however, there was no advance directive. This incident validated the importance of advance directives and encouraged me to explore the decision-making processes people from different cultures have in advance care planning.

### **Review of the Literature**

In the United States, patient autonomy is the primary focus of ethical decision making in health care regarding end-of-life planning (Johnstone, & Kanitsaki, 2009). This holds true in the Australian, Canadian, and United Kingdom health care systems where autonomy is seen as empowering and has been the moral bases of end-of-life decision making. Johnstone & Kanitsaki, (2009) note that individuals from Greek, Chinese, and Ethiopians cultures do not regard autonomy as empowering. Groups such as these view autonomy as isolating and burdensome to patients who are sick and too uniformed about their condition to make reasonable choices.

In some cultures patient autonomy may not be a valued ethical element in end-of-life planning but seen primarily as a duty of the family. They believe it is the family who has the responsibility to protect the dying patient from the burden of making difficult choices about medical care (Kagawa-Singer & Blackhall, 2001). In the qualitative study by Kwak and Salmon (2007) there was a general agreement between the Korean-American participants that the cultural expectation is for the family to make the final end-of-life decision. Medical professionals who insist on patient autonomy for end-of-life decision making, without taking into consideration the patients cultural perspectives, could be seen as paternalistic and hostile (Johnstone & Kanitsaki, 2009).

In the cases where consent cannot be obtained, the end-of-life decision is usually left in the hands of the patient's proxy or the health care team. This poses a problem with patient autonomy. In an example where the patient and the patient's family are Jehovah's Witnesses, a life-saving blood transfusion may be refused for the patient due to religious beliefs. The health care professional may feel that denying this patient a blood transfusion goes against their ethical principal of non-maleficence and beneficence, yet respecting the family's decision deals with autonomy (Cartwright, 2000).

Veracity is another valued ethical element that is part of the American Nurses Association (ANA) professional code of ethics (Guido, 2010, p. 15). Certain cultures have different view points on what should be disclosed to the patient for end-of-life planning. In the Chinese culture the family has the primary responsibility to care for the patient, especially in times of severe illness. In their culture, not disclosing information to the patient about their illness and prognosis can be viewed as a way of protecting them (Kirsch, 2009). In the study by Blackhall, Murphy, Frank, Michel, and Azen (1995), a sample of 200 Korean-American subjects were surveyed asking whether they favored the physician disclosing information regarding a terminal prognosis. The results of the study showed that 65% of the participants said that they believe the patient should not be told their terminal prognosis.

Kagawa-Singer and Blackhall (2001) described that often a patient will request to not directly receive information from a healthcare provider about the terminal nature of their illness. They further described that this does not mean that this information can be provided through other communication means such as nonverbally, or indirectly. This is a common practice in some Far East Asian cultures and the Japanese term for this is "inshi denshin" which literally translates to "knowing without being told". Some clinicians have developed strategies to handle

situations where the patient does not want to be informed and it is referred to as “informed refusal” (Kagawa-Singer & Blackhall, 2001). Informed refusal is similar to a durable power of attorney, for health care purposes. Informed refusal is when the patient designates someone to receive all medical information and make health care related decisions on their behalf. Medical professionals need to make sure they do not stereotype various cultures, such as assuming a Chinese woman would not want to be told her diagnosis because she is Chinese. That is why it is important for the medical professional to take culture seriously and attempt to understand cultural differences by assessing a patient’s health care values and beliefs (Kagawa-Singer & Blackhall, 2001).

Lack of advance directives and communication is the bases for much of the distress that occurs during end-of-life planning (Kirsch, 2009). In cases where patient autonomy is the priority of the family, utilization of a durable power of attorney for health care decisions may allow the patient to use their autonomy to appoint a surrogate to decide health care based decisions. There are many barriers to patients participating in advance care planning. Research reviewed by Johnstone and Kanitsaki (2009) suggests:

Patients of minority cultural and language backgrounds are fearful that if they complete advance care plans and advance directives in a mainstream health care context, they may be left to die in instances where further medical intervention could improve their health outcomes. (p. 408)

Johnstone and Kanitsaki (2009) concluded that empirical studies exploring cross-cultural differences in end-of-life decision making consistently show that advance directives and advance care plans are less frequently completed in people of minority cultural backgrounds compared with the majoritarian population. In the qualitative study done by Kwak and Salmon (2007), a

majority of the elderly Korean-Americans and caregivers that were interviewed had no knowledge of or had misconceptions about end-of-life care. The main misconception was the inability to reverse decisions made in their advance directives (Kwak & Salmon, 2007). Kwak and Salmon (2007) found that “Many of the caregivers also expressed that it was ultimately the family’s decision, but all caregivers wished that their parents would complete an advance directive to guide them in making decisions” (p. 1869).

### **Conclusion**

Nurses along with other health care professionals have a fundamental responsibility to assist patients and family with the end-of-life decision making process. Being culturally competent is more than having a basic understanding of different cultural norms. It is more the interaction with the patients and their families to better understand their needs and values that is needed. It has been shown that culture plays an important role in a person’s perception of health and the health care decisions they make (Kagawa-Singer & Blackhall, 2001). One of the things I learned from researching for this project is that culture can play a significant role in the choices patients make in regards to healthcare. It also reiterates the importance of cultural competence in health care by being able to effectively assess the influence that a patient’s culture has on their end-of-life decision making process. Obtaining and then using this information would help ensure the presence of adequate communication resources for non Caucasian population.

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