

To the Bitter End: Disparities in End-of-Life Care

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ABSTRACT. Although technological advancements have provided the means to sustain life and provide care regardless of whether the treatment is appropriate and compassionate given the condition of the patient, bioethical, legal, and moral concerns related to disparities in care still arise in the United States. These concerns call into question the necessity to continue life-sustaining or palliative care treatments when patients and/or families are faced with end-of-life decisions. This study will focus on various historical, clinical cultural, and ethical issues that have placed this dilemma into a controversial public spectrum, by using case studies retrieved from referenced literature, which illustrate disparities in care at the end of life.

KEYWORDS. Bioethics, medical futility, health disparities, end-of-life care, palliative care

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INTRODUCTION

A brief historical review is all one needs to see the development of modern dilemmas in the United States brought on by the rapid advancement of modern technology: the medical means to sustain life and provide care regardless of whether the treatment is appropriate and compassionate, given the condition of the patient. In 1976, the New Jersey Supreme Court granted the parents of Karen Ann Quinlan, a single, 21-year old woman, the right to decide her fate after she slipped into a coma (Angell, 1994). However, it was not until 1990 that the U.S. Supreme Court decided that every individual has the right to control his or her own medical treatment, including the right to die with dignity, under the Patient Self Determination Act (Supreme Court of the U.S., 1990). As is almost always the case in a highly and rapidly advancing techno-industrial society, those technologies advance faster than what laws can be put into place to protect an individual's rights, especially those rights one has in determining his or her own life course, based on culture and/or beliefs.

Even with the precedents set by both of these cases, as recently as 2005, the legal tug-of-war for the end-of-life decision for Theresa (Terri) Schiavo, a 41-year-old woman from Florida who had lived in a persistent vegetative state for over 15 years, developed a storm of controversy that eventually led to the Office of the President (Quill, 2005). The patient's family became embroiled in challenging affirmed legislation already in place and opened up other legal, moral, ethical, and religious issues worthy of consideration (Annas, 2005). Most problematic of all, though, in this case, was the passing of the "Compromise Act" signed into law by both the U.S. House of Representatives and the U.S. Senate, and signed by the President of the United States, specifically addressing the rights of Ms. Schiavo's parents to file suits in Florida to keep her living, although her legal next of kin, her husband, had already made decisions on her behalf to allow her to live and die with dignity (Annas, 2005).

Medical futility is a term used by physicians and medical ethicists to denote the inappropriate application of medical interventions to patients who have no potential for benefit. Schneiderman, Jecker, and Jonsen (1990) proposed the concept of medical futility, measured qualitatively as not ending dependence on intensive medical care, and quantitatively as having less than a one in 100 chances of benefiting the patient. They refuted criticisms related to assertion of power by physicians over patients in determining futility (Schneiderman et al., 1990). Tan defined medical futility as a treatment or medical intervention that cannot bring

reasonable improvement to a patient's quality of life. Treatment must offer a benefit, whether or not it achieves a physiologic result, in order to be deemed not futile (Tan, 1995). Treatment that does not change the current state or that maintains a state of permanent unconsciousness or dependence upon intensive medical care may also be deemed futile. Treatments can be classified as not futile, futile, futile from the patient's perspective, or futile from the clinician's perspective (McConnell, 1997).

End of Life (EOL) decisions regarding the withdrawal or withholding of life support and futile care have become commonplace within hospital intensive care and critical care units (ICU/CCU's). The concept of futile care is controversial and difficult to define, in contrast to the alternative of palliative care. Efforts to prolong life, once considered an outcome of healing, may be viewed by some as harmful acts of prolonging suffering (Romesberg, 2003). The social and economic costs of futile care for the dying are enormous. Futile care can present challenges to patients and clinicians because of the monetary cost of such care, its negative effect on clinical caregivers, and the emotional burden it creates for the patient and family (Coppa, 1996; McConnell, 1997; Harvey, 2000; National Consensus Project for Quality Palliative Care, 2004). The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing life-threatening illness through the prevention assessment and treatment of pain and other physical, psychosocial, and spiritual problems (WHO, 2007).

Health disparities are defined as differences in health outcomes occurring by gender, race, ethnicity, social class (income and/or educational level), disability, geographic location, or sexual orientation (U.S. Department of Health and Human Services, 2000). The Institute of Medicine (IOM) report "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" and in the U.S. Department of Health and Human Services "Healthy People 2010" directive, the goals for reducing health disparities, especially for racial and ethnic disparities, are of the highest priority (U.S. DHHS, 2000; Institute of Medicine, 2002). It also indicated healthcare workers need to learn the underlying causes of health disparities and to prepare themselves to care for patients from diverse populations. Some of the most recent research has shown that disparities still exist and that more research needs to be conducted before any real and positive changes can begin to take place that will reduce those disparities (van Ryn and Fu, 2003; Connor, Tecca, LundPerson, and Teno, 2004). When culture, racial/ethnic identity, religion, gender, and even age are factored into the decision to implement palliative care, the disparities of

EOL treatment appear to be discriminatory in practice, especially in the last 3 years of a person's life (van Ryn and Fu, 2003; Lorenz et al., 2004; Shugarman et al., 2004; Asch et al., 2006).

The aim of the present study was to identify disparities in care at the end of life and to assess the ethical application of standards of care for diverse patient populations in the United States.

METHODOLOGY

The methodology of this literature review follows the basic principles of a systematic search, conducted in discrete stages, although it is not a comprehensive review, which was not feasible due to resource constraints. The review of literature included comparison of national standards of EOL care that were developed by consensus among healthcare organizations, professions, patients, and families. The stages in the search included: defining the search strategy, identifying representative case studies, assessing the relevance and validity of the studies retrieved, and data extraction and synthesis.

Search Strategy

The aim of the search was to retrieve published literature, which complied with the inclusion criteria given below. The terms used in the search strategy were "palliative care" or "end of life" or "health disparities" or "ethics" or "medical futility" or "standards" and "United States." To identify papers, six electronic databases for the years 1997–2007 were searched—MEDLINE (Ovid), MEDLINE (Pub Med), Psyc-INFO, Psychology and Behavioral Sciences Collection, Health Source Nursing/Academic, and Academic Search Complete. Reference lists from retrieved data papers were also examined.

Case Studies

To compare diverse perspectives on EOL care disparities, a total of three real cases extracted from the literature were selected, each case with its own healthcare issue related to decisions for palliative care (Beresford, 1999; Carrillo, Green, and Betancourt, 1999). These cases represent three different racial or ethnic groups and two different gender groups. The next phase of the methodology was to analyze and compare the socio-demographic aspects and healthcare issues of each of the three cases with

existing literature regarding healthcare disparities based on culture, race, ethnicity, gender, and age. The basis of comparison of ethical issues in each case was to evaluate the literature on the barriers to quality in EOL care for each group. This analysis compared diverse EOL care perceptions, outcomes, and accepted practices, in the context of availability of training to healthcare professionals, state initiatives regarding disparities in care, and other legal, ethical, moral, and bioethical issues that are related to EOL care (Brody and Engelhardt, 1987; Doescher, Saver, and Fiscella, 2000; Callahan, 2000; Hall, 2002; Yabroff, Mandelblatt, and Ingham, 2004). Lastly, related areas of research, including international programs and initiatives in EOL care, and recommended improvements in the existing national EOL care disparities were analyzed for potential for changing the outcomes of the cases (Levine, 1989; Blackhall, Murphy, Frank, Michel, and Azen, 1995; Blackhall et al., 1999; Fiscella and Franks, 1999; IOM, 2003; Kutner, Main, Westfall, and Pace, 2005). This analysis serves as a basis for comparison of ethical issues in the selected cases.

Inclusion, Exclusion, and Assessment

The search strategy was limited to articles published within the last 20 years in the English language. Letters and editorials as well as original articles, reviews, and monographs were all included, including primary and secondary data. Unpublished literature was not included. As it was anticipated that the retrieved literature would reflect a range of research methods, it was felt that utilizing conventional design weighting criteria would be inappropriate. Citations and abstracts identified by the search were assessed in order to identify relevant articles. Full text copies of such articles were then reviewed. The literature search was conducted by TQ and validated by other members of the research team.

RESULTS

Standards for End-of-Life Care

Several efforts have been made by organizational coalitions and professional associations to develop a consensus among providers and patients on standards for EOL care. The following sets of national standards demonstrated efforts to ensure appropriate and compassionate EOL care.

Last Acts

Last acts are a coalition of more than 900 organizations representing healthcare providers and consumers nationwide. In their 2002 publication *Means to a Better End: A Report on Dying in America Today*, there are five principles of palliative care that are laid out for clinician, consumers, and families to use as a guide for what is minimally acceptable care. Those principles are: palliative care respects the goals, likes, and choices of the dying person; palliative care looks after the medical, emotional, social, and spiritual needs of the dying person; palliative care supports the needs of the family members; palliative care helps gain access to needed healthcare providers and appropriate care settings; and palliative care builds ways to provide excellent care at the end of life (Last Acts, 2002).

National Consensus Project (NCP)

The NCP is a collaboration of five major palliative care organizations throughout the United States (NCP, 2004). Its mission is to develop a clinical guideline for all healthcare professionals, agencies, and organizations to use to provide quality EOL care based on recommendations from the IOM, the Hastings Center, National Hospice and Palliative Care Organization, American Association of Colleges of Nursing, and the National Hospice Workgroup. The NCP relies on reports from each of these agencies calling for better delivery of palliative care and improvements in the way clinicians and other professionals are educated about delivering EOL services. The NCP established eight domains of quality palliative care which are structure and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious, and existential aspects of care; cultural aspects of care; care of the imminently dying patient; and ethical and legal aspects of care (NCP, 2004). Also developed by NCP are core elements which are necessary for quality EOL care. Those elements are: patient population; patient- and family-centered care; timing of palliative care; comprehensive care; interdisciplinary team; attention to relief of suffering; communication skills; skills in the care of the dying and bereaved; continuity of care across settings; equitable access, and quality improvement (NCP, 2004).

Institute of Medicine

A 2003 report from the IOM called *Describing Death in America: What We Need to Know* went further in addressing the categories of data, or

domains, relevant to the quality of life and care of those people facing EOL treatment (IOM, 2003). Those domains are: the management of symptoms; spiritual and personal growth; a familiar setting surrounded by loved ones; understandable information to guide decision-making and planning; confidence that one will not be a financial, emotional, or physical burden to family members and the right of self-determination and control of treatment choices (IOM, 2003).

National Hospice and Palliative Care Organization (NHPCO)

According to the IOM report *Describing Death in America: What We Need to Know*, NHPCO also established some recommended outcomes to be targeted within three domains. Those domains are: self-determined life closure; safe and comfortable dying; and effective grieving. These domains were developed to ensure caregivers provided EOL care appropriate to treat and prevent coping problems, assist the patient and family through normal grieving, and prevent unnecessary premature death. Furthermore, NHPCO also developed a National Data Set (NDS) with other hospice organizations to better understand the demographics of the consumers of hospice care (Connor et al., 2004). The NDS consists of two parts: Part I consists of data collected on program, patient, and financial statistics. Part II contains the above domains broken down further into elements of self-determined life closure, safe dying, comfortable dying, effective grieving, and family evaluation of hospice care (Connor et al., 2004).

Since the above sets of standards demonstrate efforts to ensure appropriate and compassionate end-of-life care, they served as bases for comparison of ethical issues in the following cases.

Cases in End-of-Life Care

Case 1

Paula Ramirez, a 65-year-old married woman with three adult children has been suffering from Amyotrophic Lateral Sclerosis (ALS) for several years. Since leaving her native country, El Salvador, for the United States as a young woman, her neurological condition has deteriorated so that she can no longer control any voluntary muscles. Confined to a bed in a nursing home in a small midwestern American city and breathing with the aid of a respirator, she can communicate through the electronic monitor that responds to eyelid blinks and can write words and brief sentences in this way. Mrs. Ramirez understands that her condition cannot be treated and that

it will inevitably lead to her death. But she has been an active participant in her healthcare and has been determined to continue functioning as long as possible. Her physician, Dr. Samuels, believes that she is not receiving adequate nutrition and that the time has come to insert a naso-gastric feeding tube. When he proposes this procedure to her, she quickly blinks, "No more!" He asks, "Do you understand that you will die slowly of starvation if we do not insert this feeding tube?" "Yes," she blinks, "No more." When Mrs. Ramirez's family, which has been close and supportive throughout her illness, learns of her opposition, they have divided opinions. Her husband believes that her wishes should be respected, but two of their three children are convinced that her life should be prolonged. The nursing staff believes that she should not be made to suffer any longer. There is no question that Mrs. Ramirez is legally competent, that is, that she understands the procedure being proposed and the consequences of refusal.

Case 2

Lawrence Byrd, a 59-year-old non-Hispanic black man, has metastatic colon cancer. He had surgery for Duke's stage D adenocarcinoma of the colon and adjuvant chemotherapy with 5-fluorouracil and leucovorin. Four months ago, he developed liver metastases and did not respond to two cycles of chemotherapy. At his last visit, the patient declined to discuss hospice when his physician raised this option. He has a living will indicating his desire for aggressive treatment if artificial means are required to sustain his life. The physician suspects that the patient's insistence on aggressive care may stem from his failure to understand the limits of available interventions. Communication between Mr. Byrd, a non-Hispanic black, and his physician, a non-Hispanic white, has been difficult. In an effort to improve their relationship, the physician suggests using first names. Mr. Byrd does not use the doctor's first name, although the physician calls him "Lawrence." The doctor says, "Lawrence, I am worried about what happens when we reach the point where these interventions you are asking for, would be costly and serve only to prolong your suffering." Mr. Byrd angrily demands that he should receive "every medical test and procedure you've got—regardless of the cost." The physician asks for advice from a non-Hispanic black colleague, who suggests that the physician's well-meaning behavior might have seemed disrespectful. Calling an older non-Hispanic black man by his first name is impolite. Non-Hispanic blacks who have suffered discrimination may fear neglect if

they do not insist on maximal care. Many patients seek aggressive treatment because they value the sanctity of life, not because they misunderstand the limits of technology. Mr. Byrd may have perceived discussions of costs and the ineffectiveness of treatment as a devaluation of his life. At the next visit, the physician asks Mr. Byrd whether he has experienced disrespect or racism: "Mr. Byrd, it is important for me to know if you have ever felt unfairly treated by me or anyone else involved in your care." Mr. Byrd relates incidents when his requests for pain medication went unanswered. The physician responds apologetically, "I am truly sorry if I have failed to communicate clearly in the past; I never intended to be disrespectful." The physician addressed the issue of pain directly, "Mr. Byrd, I would like to talk with you about your pain medication. Are we failing to treat your pain adequately?" Mr. Byrd reports that pain interferes with his sleep. The doctor continues, "Your well-being is important to me. Let's figure out how we can get the pain under better control." The doctor asks the patient to quantify his pain on a 10-point scale and to indicate what point would represent desired relief. With this information, the doctor increases the dose of analgesics and switches to sustained-release preparations.

Case 3

Fengming Wang, a 90-year-old Korean American and retired since 1955, was admitted to a community hospital with bronchial pneumonia, advanced pulmonary edema, urinary tract infection, and anemia. Mr. Wang responded to treatment initially, but then his condition worsened. Mrs. Wang asked the attending physician to do "everything possible" for her husband and assured him that they were able to pay for the costs of treatment not covered by Medicare. On the morning of his fourteenth day in the hospital, Mr. Wang's physician visited him and assessed his condition. Although he was not improving, Mr. Wang was alert and asked, "Am I all right, Doctor?" Fifteen minutes later a nurse entered the room and found that Mr. Wang was not breathing and that all vital signs were absent. She summoned the doctor, who immediately decided not to attempt to resuscitate Mr. Wang. The cause of death was recorded as ventricular fibrillation. According to hospital officials, it was the institution's policy to make an all-out effort to revive all unresponsive patients. Like other hospitals, this one had a "code"—usually a series of numbers or a color—for summoning staff members with portable defibrillators and other resuscitation equipment to the bedside of a patient in cardiac arrest. "Code blue"—as it is called in all hospitals—is known only to insiders and can

thus be called without alarming other patients and visitors. But physicians may also issue "no code" orders. That is, in certain circumstances they may direct staff not to resuscitate a patient should cardiac arrest occur. Patients, however, are usually not told about coding. "It would make already anxious patients and relatives even more fearful," one official explained. "They don't need to know about it. They will be coded anyway. People should assume whatever care is needed is going to be given." Mr. Wang's physician and hospital officials maintained that Mr. Wang was coded, but both conceded that "code blue" was not called. Mr. Wang's physician argued, "Doing 'everything' for a patient in my mind does not include Cardio-Pulmonary Resuscitation (CPR). In Mr. Wang's case it might mean doing nothing." According to the physician, "Mr. Wang was not sent to the intensive care unit for two reasons. There was a shortage of beds in the unit and Mr. Wang didn't seem like he belonged there because he was not acutely ill. When it comes to resuscitating, it's reasonable for a man in his fifties or sixties, but criminal to try to resuscitate in [Mr. Wang's] age group to prolong life a week at the most, given his condition. I don't see any sense in calling code blue with a 90-year-old man who has no future to look forward to. That's doing him a disservice and increasing his hospital costs." Mrs. Wang disagrees. Upon being informed that no emergency measures were taken in her husband's case, Mrs. Wang said that that was against her wishes. "Doing everything," she says, "is the difference between life and death. The doctor was playing God when he decided he should not try to save my husband. You're not playing God when you've tried everything and exhausted all methods. All I wanted was for them to try. My husband knew how to love and be loved. That was his quality of life. That suited him and it suited me."

DISCUSSION

These three cases represent diversity of patients in the United States with respect to race/ethnicity, cultural traditions, religious/spiritual beliefs, and health issues. The standard of the dominant Judeo-Christian, Caucasian belief system is currently one in which euthanasia is not accepted, except in one state, Oregon, and only then if very stringent criteria are met beforehand. There does, though, appear to be an exception based on patient autonomy, wherein one can, if one is deemed mentally fit, request no further life-sustaining care; the other alternative is to continue any and all life-sustaining care until the body ceases living. Regardless of when life

will cease for a person, whether or not one is terminal, life is comparable to a line drawn on water (Harvey, 2000).

Case 1

The case of Mrs. Ramirez presented a very unique set of circumstances, but many issues surrounding her situation are very typical in the processes that Hispanic families would encounter concerning the care and eminence of a close family member. Although being in a nursing facility is not a usual practice in her culture, the fact that her family has been close and supportive is a common practice (Koenig and Gates-Williams, 1995; Sullivan, 2001). "Family First" is the concept by which Hispanics plan and live daily; interdependence among family members can preclude healthcare planning with only one member. The family matriarch is usually the one responsible for everyone else's healthcare needs, with the men in her family the most reluctant to see a doctor for routine visits (National Resource Center on Diversity, 2002a). Since Mrs. Ramirez has been in a nursing facility and since her children are all grown adults, the next woman in line, typically the eldest daughter, takes on the responsibility of the family's health. Physicians and public institutions are usually looked at with some level of deference and it is expected that health providers will communicate in a manner that reflects an understanding, or at the very least an appreciation, of the Hispanic culture (Sullivan, 2001). Since Mrs. Ramirez can only communicate with eye blinks, this places a big strain on her ability to communicate and thus places her at the mercy of others to communicate for her. This case also raises the issue of pain and suffering: many view it as a test of their faith. One of the biggest parts of the equation of dealing with pain and EOL care, for Latinas especially is the concept of *el espíritu*, or the spirit (NRCD, 2002a). Although many Hispanics would never allow one of their parents to be placed in a nursing home, Mrs. Ramirez's placement in one may be due to acculturation or assimilation of her family since being in the U.S., or it very well may be out of her extreme physical and neurological needs that could not be met at home for someone suffering end stages of ALS (Sullivan, 2001). Nevertheless, Mrs. Ramirez is still only one Hispanic patient of the 3% who use any hospice services in the United States (Connor et al., 2004). The concepts of autonomy and paternalism may be different in the Hispanic culture, in particular among Mexican-Americans as well as other Latinos, compared with the non-Hispanic white or black culture. Religious beliefs, specifically fatalism, traditionally play an intrinsic role in decision-making processes

for Mexican-Americans. Of outmost importance is the strong faith in—and reliance on—God. Mexicans often have the attitude “if something happens it’s ok because God gave it to me” or “Life support isn’t any good. If God wants you, he’ll take you” (Sullivan, 2001). In this context, critically ill patients and their families should be expected not to have advance directives and either to request extraordinary or high-technology treatments to sustain life or, as in the case of Mrs. Ramirez, to deem further life-sustaining treatment as futile.

Language and cultural understanding are, nevertheless, essential pillars of providing compassionate quality care to ethnically diverse clients because without these pillars, invisible barriers continue to hinder access to much needed information and support (NRCD, 2002a). Although various governing agencies for palliative care have what appear to be sufficient standards of care that address cultural, psychosocial, and religious issues, to name but a few, there is evidence that those needs are still not being met satisfactorily at both individual and family levels (Connor et al., 2004; NCP, 2004; Lorenz et al., 2004). But which side of the patient-provider relationship is most responsible for the continuation of these disparities appears to be confusing, since arguments and justifications can be legitimized almost equally when taken into their objective context (Blackhall et al., 1995, 1999; Taxis, 2006). The only argument that cannot ever be legitimized is outright discrimination, which does appear to be the single barrier most faced by patients and their families by the providers at all levels (Fiscella and Franks, 1999; Asch et al., 2006).

Case 2

In the case of Mr. Byrd, non-Hispanic blacks are a very diverse population and their variations are based on regional, urban, and rural differences, age, education, and socio-economic status (NRCD, 2002b). Mr. Byrd felt disrespected, or ignored by the doctor, albeit completely unintentional. However, Mr. Byrd is of a growing aging population of minority American elders. It is estimated that by 2030 in the U.S., there will be as many as 7.3 million non-Hispanic black elders (NRCD, 2002b). Mr. Byrd did have a very legitimate concern regarding his care and demanding everything, that could be done regardless of cost. Some may see his actions as having a devout respect for the sanctity of life which is not uncommon in this community. But those actions could be a direct result of years of discrimination and racism, especially at the hands of science as reported by several studies (Taxis, 2006). When his doctor attempted to be less formal,

an act that was perceived as disrespectful to Mr. Byrd, it also opened up the possibility that the physician's style and trust were ill intended. In this case, the physician felt further care would be futile especially when considering the cost of that care. Mr. Byrd was able to convince this physician that his healthcare is not futile based solely on cost.

Although there are written standards for hospice and other palliative care facilities/agencies, which specifically address meeting the cultural, spiritual, and psychosocial needs of patients and families, even incorporating the families own choices of providers, healers, shamans, clergy, and many others, there still appears to be an overt rejection of the services offered by different racial, ethnic, and cultural groups (Beresford, 1999; Crawley, Marshall, Lo, and Koenig, 2002; NCP, 2004). Many non-Hispanic blacks still suffer, albeit physically, emotionally, or psychologically, from decades of past, and even current discrimination from healthcare providers and mistrust, due to the Tuskegee Syphilis Study or other overt, or covert, acts either here in the U.S. or in other countries (Gamble, 1997; Wermuth, 2003; Shi and Stevens, 2005; Taxis, 2006). Hispanics, too, have faced discrimination, but in the U.S. have also faced language barriers and legal action, such as laws and ordinances, specifically addressing those language barriers and their ability to be in, and access care in the U.S (Sullivan, 2001; Wermuth, 2003; Shi and Stevens, 2005; Grace, 2005). Asian Americans have also experienced many of the same discrimination issues of exclusion from care, language barriers, and legal actions disenfranchising them from accessing healthcare suitable to meet their needs (Harvey, 2000; Hall, 2002; Shi and Stevens, 2005; Ahn et al., 2006). When groups of people who are actively being discriminated against continue to allow this behavior and allow laws to be passed condoning this behavior without speaking out against it, then there is a level of responsibility that is shared, both collectively and individually, by those who are allowing this discrimination to happen to them by not standing up and demanding better, more equitable treatment. When this is happening to someone, though, at one of the most stressful and important times in a persons's life, taking a stand for one's rights for equal treatment may seem a momentous and overwhelming task.

Case 3

In the case of Mr. Wang, there appear to be two issues at hand, his race/ethnicity (Korean-Asian American), which is also a direct influence of his cultural beliefs, and his very advanced age of 90 years, which, again,

is directly influenced by his cultural beliefs. Most Korean Americans of Mr. Wang's age are first generation immigrants, mostly due to the Immigration Act of 1965, and their Confucian teachings emphasize a respect for authority and acquiescence to a patriarchal hierarchy (Takaki, 1989; NRCDC, 2002c). However, his wife, Mrs. Wang, was very clear about her expectations of the medical staff doing everything possible to keep him alive. After all, he is the elder patriarch of the family. Although many Asian Americans utilize traditional Asian medicine practitioners, this was not the case for Mr. Wang according to the case summary (Ahn et al., 2006). There are indications that Mr. Wang was very aware of his circumstances when he asked the doctor directly if he was all right. But he also appeared to acquiesce to the doctor's "authority" and not push the issue of his treatment and medical needs, which led to his demise 15 minutes later. Clearly, the issue of ageism is reflected in this case, in that the doctor felt any efforts to try to save Mr. Wang's 90-year-old life, by calling a code blue, performing CPR, and/or admitting him to the ICU, would be a disservice to him and financially place a hardship on his family even though Mrs. Wang stated from the beginning that they have the money and preferred to keep him alive (Aube and Pfitzenmeyer, 2003). She then accused the doctor of "playing God" for deciding not to try to save Mr. Wang, another cultural violation based on her beliefs (Doescher et al., 2000). From an ethical perspective, this doctor's actions, or rather inactions, are a blatant violation of the most basic and primary principles of non-maleficence and beneficence (American Medical Association, 2001). In Mr. Wang's case, his own assertiveness for his healthcare may have brought about a different outcome, but since his wife was advocating for him, it can easily be assumed that he may have felt everything was being taken care of and that there was no need for him to speak up (Carrillo et al., 1999). Ironically, what started as a not futile care case, because of blatant age discrimination, quickly changed to a futile from the physician's perspective only case and subsequently cost Mr. Wang his life.

These discrimination issues faced by various cultural and social groups, compounded by their own attitudes and perceptions, may make those who are from these particular cultures leery of accessing EOL care, regardless of the standards and protocols set forth by the healthcare and/or palliative care industry's governing bodies (Blackhall et al., 1995, 1999; DHHS, 2000). The attempts made by the healthcare and palliative care industries to be inclusive of various racial and ethnic groups in studies, providing the Patients Bill of Rights, treatment standards, and protocols of care, may

have actually appeared to many disparate groups as an industry trying too hard to show it does care while still harboring a practice of categorizing people based on traditionally discriminated features (Doescher et al., 2000; van Ryn and Fu, 2003; Lorenz et al., 2004). There are, though, many suggestions from diverse populations and advocacy organizations on remedying this matter, especially in regard to EOL care (Beresford, 1999; Doescher et al., 2000; Yabroff et al., 2004; Carlet, 2004; Volker, 2005).

DISCUSSION

Based on the above cases, it is apparent that language and cultural understanding are essential pillars for providing compassionate quality care to ethnically and racially diverse patients. In their absence, such barriers would likely continue to hinder access to much needed information and support for patients and families (NCP, 2004).

Since interventions deemed as futile offer no benefit to patients, physicians are not obligated to offer futile interventions based upon the ethical principle of beneficence. The ethical principle of justice requires physicians to be good stewards of healthcare resources, which also supports not providing futile treatments. Doty and Walker reported that over 10% of all healthcare expenditures are expended during the last year of life, with a significant portion spent on hospital care that is futile or of marginal utility (Doty and Walker, 2000). The concept of moral hazard may exist from an economic point of view, as most such patients are not directly responsible for their medical expenses due to insurance, Medicaid, Medicare, or indigent status (Shugarman et al., 2004).

The role of patients in care decisions varies, as those with limited knowledge and access may be most concerned about accessing care. However, more informed patients and their families can become highly involved in making decisions about care due to increased patient autonomy, greater availability to medical information, more treatment options, rising costs, and increased prevalence of chronic illness (Aube and Pfitzenmeyer, 2003). There is potential for improving the delivery of palliative care, so that it will be more available to patients and sensitive to psychosocial needs. The perspectives of patients and families are most important—those patients and families who have been marginalized and discriminated against are the only ones who can teach the world how to make appropriate improvements.

RECOMMENDATIONS

Processes that can help to avoid, or decrease the level of, medically futile care include: development and implementation of treatment protocols; moving to a team approach in the care-giving process; patient and family education, including understanding the function and use of an advance directive and end-of-life care facilities (i.e., hospice) as an alternative treatment for terminal patients; use of ethical consultation for the hospital ethics committee; and education on the ethics of EOL for healthcare providers. Ethics committees involve groups of individuals from diverse professional backgrounds who support healthcare institutions with three major functions: providing ethics consultation, developing and/or revising select policies pertaining to clinical ethics (e.g., advance directives, withholding and withdrawing life-sustaining treatments, informed consent, organ procurement), and facilitating education about topical issues in clinical ethics (Pearlman, 1998). Patients and families would benefit from additional education regarding healthcare decisions, especially those concerned with end-of-life care. Hospitals might consider outreach education, which is culturally sensitive based on the patient demographics, that addresses issues such as advance directives and hospice care rather than waiting to address them during the time of crisis when patients and families may be less able to make rational and informed decisions. Doing so would give consumers more time to think, ask questions and make informed decisions.

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