
Cultural Barriers to Compassionate Care — Patients' and Health Professionals' Perspectives

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Cultural barriers to compassionate care are presented from two perspectives in healthcare: the patient and the health professional. Content areas include autonomy clashes between the patient and health professional, end-of-life values and preferences, cultural responses to pain and pain management, and the problem of stereotypical and uncaring behaviors toward people different from ourselves. Suggestions to address content areas caused by conflicting value systems include (1) a review of the literature on diversity, and (2) discovering one's sensitivity through exposure to various ethnic and cultural groups.

Culture is the "totality of socially transmitted behavior patterns, arts, beliefs, values, customs, lifeways, and all other products of human work and thought characteristics of a population that guides its worldview and decision making" (Purnell and Paulanka 1998, p. 481).

Behavior patterns may be explicit or implicit, are primarily learned and transmitted within the family, and are shared by the majority of the culture. Provider-patient miscommunication occurs when providers dissemble the patient's cultural tapestry and analyze it according to the template of their own culture (Kagawa-Singer 1994). Culture is not evident as a set of rigid beliefs that can be biopsied or extracted from individuals, but is only meaningful when analyzed and interpreted in particular local sites and within particular political and historical contexts (Hern et al. 1998).

The culturally molded outer appearance and behavior of an individual may change with the adoption of another cultural pattern (Surbone and

Zwitter 1997). Still, it is the roots, not branches or leaves, that determine patients' responses. When facing serious disease or death, they often return to the cultural values and practices bestowed during childhood.

Culture, ethnicity, and race are not interchangeable terms (Lipson 1996). Specifically, culture denotes a learned set of perceptions and expectations, while race refers to human biological variation, and ethnicity to a common ancestry — a sense of historical continuity, common language, religion, and identification with a distinctive group. Lipson emphasizes that culture refers to a broader set of values and beliefs than does ethnicity.

Meanings of health, well-being, illness, disability, access to healthcare, and death are shaped by culture (Foster 1996). Culture also influences the choice of a decision maker for the patient who is morbidly ill (Orr, Marshall, and Osborne 1995). For example, a Korean elderly woman whose husband is hospitalized with multiple injuries will hesitate to make medical decisions for her

husband. Instead, by custom, this duty falls to the eldest son, even if he is in another country and has to be reached by telephone. The son may then give provisional authority to his mother to make treatment decisions for his father, and stipulate that she consult her pastor or other designated Korean male, for all decisions she makes on behalf of her husband.

Autonomy vs. Truth-Telling Obligations

The novel emphasis that different cultures place on autonomy shapes the level of communication between patients and health professionals. For a large segment of North American and European populations, autonomy and self-determination may be more illusion than reality. Both physician and patient are bound in a network of beliefs, customs, experiences, prejudices, rules, and responsibilities that limit choices (Surbone and Zwitter 1997). Autonomy is an ethics principle that plays out differently in cultures. The patient's perception of autonomy often collides with the health professional's legal responsibility for truth-telling before informed consent is obtained for medical and surgical intervention.

To illustrate, a Chinese patient avoids discussions of death as a matter of culture, while an Arabic patient adheres to well-entrenched patriarchal members who oversee all areas of living and dying. Because optimism is a vital part of the healing process for Navajo Native Americans, it is highly likely that Navajo patients will react negatively to the doctor's bad news about their health. Telling Navajo patients that they have a terminal illness implies that the deliverer of the news wishes the patient dead (Purnell and Paulanka 1998). Based on the best information that the patient chooses to hear, and under lifelong cultural customs, each patient—the Chinese, the Arab, and the Navajo—exerts autonomy by willing that appropriate family or tribal members should make decisions for them regarding medical treatment.

Patients have the right, on the basis of adequate information, to reach decisions that may seem irrational if judged by the usual standards of medical delivery in America (Giesen 1993, as cited

in Butow, Tattersall, and Goldstein 1997). Cultural clashes, instigated by misunderstanding of each other's motives, often lead to ethical conflicts between patient and family and the healthcare team. Genuine respect for human dignity requires deeper understanding of the patient's values, culture, family, and community (Gostin 1995).

The danger of placing patients into culturally specific categories is the assumption that each individual can be treated alike. Parens (1998) reviewed transcripts of interviews with Chinese-speaking, Spanish-speaking, and English-speaking San Franciscans. He came to two realizations: (1) advance directives presuppose that patients want to hear the truth about their condition and

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make treatment decisions for themselves; and (2) not all of the Anglos were acting like Anglos and not all of the "others" were acting like "others." The latter finding supports the assertion that all cultures are composed of individuals and that intracultural variation can be as great as, or sometimes greater than, intercultural variation (Klessig 1992).

In fact, insensitive and misinformed generalizations based on stereotypes (also known as "ethnic profiling") can be coercive—for example, when the Western-oriented concept of patient autonomy is forced on other cultures. The 1992 American Hospital Association's Patient Bill of Rights, which calls for the patient to be informed of diagnosis, treatment options, and prognosis, is contradicted when family members, responding to their culture, keep a bad prognosis from the patient, with or without the patient's consent. The Western convention of truth telling is counter to cultures where such information is first given

to family members or designated decision makers who then decide how much truth the patient will be told.

To meet the legal requirements of informed consent for care, Parens (1998) and Mouton, Johnson, and Cole (1995) strongly advise health professionals to offer patients the choice either to accept or refuse being told the truth rather than assume that all persons in a specific ethnic or

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cultural class are alike. Autonomy remains intact if it is the patient's decision to relinquish decision-making rights to the family. Another method is to "titrate" the amount of information given to patients by allowing each one to ask his or her own questions.

End-of-Life Values and Preferences

The importance of communication between the patient and family and the health professionals is evident when caring for African American elders. For example, withholding intravenous hydration to avoid prolonging the dying process may be misinterpreted by African American elders, as well as other cultures' elders, and their families if the meanings of medical choices are not clarified in advance (Mouton, Johnson, and Cole 1995).

Culture itself is sometimes treated as a barrier to providing scientific medical care to diverse patients (Hern et al. 1998). Such factors as fear, personal histories of mistreatment, and distrust of the medical system greatly influence when and how America's minority groups enter the healthcare system. Many African Americans enter the healthcare system late — even when money is not a factor. Elderly African Americans who lived a large portion of their lives under segregation in America have lingering memories of unethical research. They fear that doctors will not offer them

the same level of treatment that a white patient might receive for the same physical ailment, or that they will receive experimental care (Burrus 1995). They fear that race, age, or lack of insurance may trigger that disparity.

Some African American patients may have a personal desire to avoid the healthcare system based on the long-standing cultural preference of African Americans for using home remedies rather than seeking care from a doctor (Reese et al. 1999). One major impact of delayed entrance into the medical system is the lower survival rate among black patients with early-stage, non-small-cell lung cancer. This type of cancer has a substantial cure rate if treated by surgical resection; however, blacks are less likely to receive surgical treatment than whites (Bach et al. 1999). Bach et al. studied 10,984 patients who were 65 years or older: 8 percent were black and 92 percent non-Hispanic white. The study covered close to 14 percent of the U.S. population.

Bach et al. did not determine why black patients have a lower rate of resection than their white counterparts, but concluded that the difference in treatment has a substantial effect on survival. Many African Americans have long feared that black patients are offered optimal treatment less frequently than white patients. However, the most important disparity between the two groups, according to Bach et al., is that black patients were substantially more likely to reside in a zip code area with a low median income — which is not a cultural or racial factor.

Another patient-generated barrier to end-of-life care for African Americans is their relationship with time. Many African Americans are more oriented to the present than to the past or future (Purnell and Paulanka 1998). Therefore, they do not plan for death by preparing legal wills, living wills, funeral plans, powers of attorney, or plans for their dependents' survival. Even when the medical team deems further curative treatment futile or harmful to the patient, the family may reject vehemently any suggestion of a "do-not-resuscitate" order. Instead, patients choose life-sustaining treatment and prayers for a miracle

(Reese et al. 1999; Burrs 1995; Lowe, Barg, and to Bernstein 1995; Caralis et al. 1993). The family reacts from the cultural value that one's church and family should provide care in terminal illness in place of strangers, thus rejecting the hospice philosophy of palliative care in the home. In addition, black patients and their families fear that if advance directives are signed, they will be allowed to die so that their organs can be harvested (Purnell and Paulanka 1998). Thus, the fear of receiving less than adequate care becomes a quest for aggressive care.

Pain Responses and Pain Management

The influence of ethnicity and culture on pain responses and the undermanagement of pain at end-of-life is well-documented in the literature (Cleeland, Gonin, Hatfield et al. 1994; McDonald 1994; Cleeland, Gonin, Baez et al. 1997; Bernabei et al. 1998; Bach et al. 1999). Patients' response to pain is culturally determined and is expressed in one of two reactions — either vocally or stoically. Patients and family members who react vocally exemplify the cliché that "The wheel that squeaks the loudest is the one that gets the grease" (Morris and Morris 1988, p. 547). Those who respond stoically submit impassively to pain without complaint, gritting their teeth and bearing it (Purnell and Paulanka 1998).

Examples of ethnic groups identified by health professionals as consistently vocal in making the presence of pain known and understood tend to be from the following ancestries: Jewish, Italian, Cuban, Egyptian, Arabic, and Greek. Excluding Jewish patients, individuals in these groups tend to be expressive with their family but restrained in the presence of health professionals. It can be unnerving to the doctor and nurse when family members at visiting hours forcefully accuse them of having withheld pain medication that the patient "obviously" needs (Purnell and Paulanka 1998).

For Americans of Cuban origin, verbal complaints and moaning, crying, and groaning publicly are culturally appropriate behaviors in response to pain. They moan because they believe that moaning will help relieve the pain. Before

administering an analgesic to these patients, nurses should assess whether or not the expression of pain has in fact eliminated the need for medicine (Villarruel and Montellano 1992; Purnell and Paulanka 1998). An effective pocket tool for the doctor or nurse to use with the patient when assessing pain intensity is a pain assessment "ruler" or the numeric pain intensity scale — printed in the patient's language.

Ethnic groups that view pain as a way of life tend to be impassive, rarely expressing the intensity of their pain, and creating a self-imposed barrier to adequate pain management. This group includes Filipino-Americans, Navajo Indians,

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African Americans, and Vietnamese Americans. Filipino-Americans view pain as part of living an honorable life. Pain is an opportunity to reach a fuller spiritual life or to atone for past transgressions. Therefore, they may appear stoic and tolerant of a high degree of pain. The health professional ought to encourage pain-relief for patients who do not complain despite physiological indicators of pain. Vietnamese-Americans also view pain endurance as an indicator of strong character. Deep cultural restraints against showing weakness are barriers to the use of pain medication (Nguyen 1985; Purnell and Paulanka 1998).

Older patients and minority patients who are at risk for substandard or less aggressive treatment are also those at greatest risk for poor pain management. In the Cleeland, Gonin, and Hatfield et al. study (1994), pain inventory tools were used to measure either the patient's level of pain or the physician's response to a patient's pain. Of the 1,308 outpatients diagnosed with

recurrent or metastatic cancer, 67 percent (871) reported having pain or were taking pain medication daily and 62 percent of patients rated their pain as substantial. The percentage of patients with the worse pain were being treated at community clinical oncology programs that treated

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predominantly minority patients, mostly blacks and Hispanics. Hispanic patients were half as likely to receive analgesic drugs for long-bone fractures as were patients who were not minorities and who were treated in the same emergency setting. Black patients were likely to receive less adequate treatment, and women and patients who were at least 70 years old also had scores indicative of inadequate analgesic medication.

Health professionals' reserved approach to pain management in different ethnic and cultural groups is responsible for the large percentage of patients dying with inadequate analgesic orders (Cleeland, Gonin, and Hatfield et al.1994). This study also indicates that accurate appraisal of the severity of pain may be more difficult for patients who are not of the same gender, race or ethnic background as the treating physician. This finding is logically extended to nurses on the healthcare team who must determine how much analgesia is administered when the order is written on a sliding scale, such as "Morphine Sulfate 12 to 15 mg. IM, Q 3 to 4 hrs for severe pain."

A retrospective survey of 180 medical records from three hospitals explores whether nurses provided different amounts of narcotic analgesics to male and female patients, and different amounts to white and ethnic minority patients (McDonald 1994). The findings indicate that male patients received significantly larger initial doses of narcot-

ics than female patients did, and white patients received significantly more total postoperative narcotic analgesics than ethnic minority patients. McDonald explains that male patients may express more pain during the initial postoperative period than female patients. The large difference between the total narcotic analgesic dose received by Asian-, African-, and Hispanic Americans compared to whites is more problematic. Minority patients may have been either less likely to express their pain or more reluctant to receive narcotic analgesics; or, perhaps their complaints were given less credibility by insensitive health professionals.

Cleeland, Gonin, Baez, et al. (1997) studied minority outpatients with recurrent or metastatic cancer who were treated at university cancer centers, community hospitals and practices, and centers that primarily treat minority patients. One limitation of this study is that it did not consider the family and patient's reluctance to report pain or take analgesics or their ability to pay for pain treatment. The following factors can influence prescriptions for pain management:

- concern about potential drug abuse in minority patients,
- fewer resources with which to pay for analgesics,
- greater difficulty in accessing care and in filling analgesic prescriptions, and
- greater difficulty in assessing pain in minority patients.

Although this study deals with narcotic doses during the postoperative period, it appears — habits being what they are — that doctors and nurses are more likely to respond to end-of-life patients in the same way. However, as Cleeland, Gonin, Baez, et al. observe, awareness of the increased risk for poor pain management in minority patients may, in itself, lead to improved pain assessment and care for these groups.

Health professionals also lack knowledge about the race-related variances in the way the body

handles medications. For example, Egyptian Americans tend to metabolize beta-blockers poorly (Kudzma 1999; Purnell and Paulanka 1998); and the analgesic Codeine is more likely to be effective in Chinese, Japanese, Malaysian, and Thai patients than in those of European descent (Purnell and Paulanka 1998). Propranolol, a drug that regulates heartbeat and blood pressure, is more effective for Chinese and black men than white men. Diazepam is a commonly used antianxiety agent that is metabolized poorly in Chinese and Japanese patients who require lower doses to be effective. Although health professionals have paid little attention to drug polymorphism caused by cultural and racial differences, with the fast pace of demographic changes now underway, these factors can no longer be ignored (Kudzma 1999).

Stereotyping and Uncaring Behaviors

Another barrier to care for culturally diverse patients is stereotyping, racism, and mistreatment. Cancer patients have expressed how their anger and frustration advanced to despair, helplessness, and hopelessness after experiencing uncaring

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acts while hospitalized (Halldorsdottir 1999). However, only a few patients have complained about uncaring behavior to people in authority, perhaps because most of them fear retaliation for complaining (Halldorsdottir 1999; Ferrell 1999). Health professionals should be advocates to clear the way for patient complaints.

Racism is defined as the execution of a deterministic theory that is supported by the structure of a country and reinforced through daily practice (Shala 1998). A deterministic theory with an assumed genetic or biological background is used

as a basis for assumptions about individuals or groups who are seen as different from other individuals or groups (Corley and Goren 1998). For example, nurses have been caught stereotyping suicidal patients, AIDS patients, sex offenders, and racial/ethnic groups.

The dark side of provider behaviors include controlling and manipulating patients; hostile, angry, or interpersonally distancing responses to patients; minimizing or avoiding patient contact; and failing to provide care to patient needs (Corley and Goren, 1998). Stereotyping, labeling and stigmatizing by nurses and other caregivers persist despite professional education, including ethical and legal content. The danger lies in the potential for marginalizing the patient and decreasing the quality of care. Marginalization is defined as the process through which persons are peripheralized on the basis of their identification markers, such as age, gender, ethnic background, social and economic status, associations, experiences, and environments (Hall, Stevens, and Meleis 1994).

Whether a nurse likes a patient can affect the quality of care provided. In Rodabough and Rodabough's 1981 study of dying patients, nurses gave better care to dying patients they liked than to patients who were difficult and hostile. Patients who were homeless also experienced stigmatizing behavior from the staff (Minick et al. 1998; Murray 1996). Nurses gave patients labeled "difficult" significantly less supportive care, made greater use of restraints, and failed to meet individual needs (Carveth 1995). They also failed to advocate for patients, criticized patients, and demonstrated disapproval when they showed anger or hostility, and provided leadership in negative labeling (Johnson and Webb 1995). Deegan (1990), speaking from her experience as a disabled patient, described the dehumanizing and depersonalizing care she received as "spirit breaking," a symptom of the rupture in human relatedness between caregiver and patient.

The point here is not to impugn nurses but to question whether any providers can deliver

quality care to individuals they do not respect since one's biases influence how one relates to and delivers care to persons from another culture (Erlen 1998). While we may agree that respect for cultures is a value that should characterize our delivery of care, other values and beliefs may interfere with what we actually do. The result is that care may differ for patients from other cultures (Erlen 1998; Shala 1998). Thus, response to the patient's diversity becomes a barrier to care.

One course that medical and nursing programs could emulate was piloted for physician assistant students at the University of Southern California. The course heightened cultural awareness before graduation, providing depth of knowledge about underserved groups as well as personal awareness of prejudicial feelings. There were healthy discussions on racism, bias, prejudice, fear, and insensitivity to others in cross-cultural communication. The model was "Differences Plus Discomforts Equals Discoveries," meaning that the differences that cause discomfort are opportunities for discoveries (Stumpf and Bass 1992).

Conclusion

A variety of barriers to compassionate care intertwine and include cultural influences from Western medical perspectives regarding autonomy, fear that one's end-of-life values will not be respected, fear of mistreatment (including being allowed to die), inadequate pain management, and caregiver behaviors that lack respect for diversity and so-called difficult patients. The ethnic composition of America is changing rapidly, indicating that cultural competency is a crucial value for health professionals working with various cultures in America's healthcare delivery system. The rich diversity of cultures is a reality and an opportunity to develop personal and professional competencies.

The recognition of cultural diversity is not meant to complicate the delivery of healthcare but to simplify it. At times of life-threatening and moribund illnesses, many individuals will

adhere to customs and habits that are familiar and comforting. Communication occurs when the health professional and patient reach the "sweet spot" of mutual understanding, the meeting place where cooperation is nurtured within the fertile ground of mutual trust and respect. This is the loving and lovely place where beneficence for the patient flourishes and compassionate, culturally competent care is a reality.

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