

Virtual Mentor

American Medical Association Journal of Ethics
December 2001, Volume 3, Number 12: 438-443.

VIEWPOINT

Recommendations for Culturally Competent End-of-Life Care

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There is general agreement among researchers and caregivers that rapport is an essential ingredient in, and the virtual foundation of, an effective patient-caregiver relationship. Differences in race, ethnicity, and cultural background of caregivers and their patients can be one of the most challenging aspects of end-of-life care. Yet, while the effects of caregiver race and ethnicity have been studied and are regarded as the most important characteristics in the patient-caregiver relationship, they have seldom been looked at in combination with end-of-life care giving^{1,2}.

The role of racial and ethnic differences in the patient-caregiver (or therapist) relationship has been particularly well studied in both the mental health^{3,4} and physical health^{5,6} of people of color. Racism is *itself* often the cause of mental and physical health problems and, along with stereotyping and discrimination, is believed to influence the under utilization of health services by people of color and the high attrition rates of those who do enter into care.

There is a general consensus among behavioral scholars that the culturally congruent patient-caregiver relationship (i.e., one in which patient and caregiver share the same racial or ethnic background) is ideal⁷. In such relationships the quality of the rapport and the communication process (e.g., openness, empathy, disclosure, and trust) are improved, and the feeling that caregiver and patient can relate "on common ground" is maximized⁸.

Conversely, in culturally incongruent patient-caregiver relationships there is a greater probability that the caregiver will lack essential understanding of the patient's culture or background, a fact that increases potential for cultural misunderstandings and decreases the probability that the caregiver will be able to relate to the patient's dilemma. Such basic cultural misunderstanding can erode the all too fragile patient-caregiver relationship. For example, a study of caregivers' interpretation of nonverbal communication and facial affect revealed that culturally congruent caregivers were significantly better in interpreting facial affect and nonverbal signals than culturally incongruent caregivers⁹. The communication disadvantage is most evident in cross-racial pairings where the patient and caregiver do not speak the same language. Basic language differences, which include street slang in many urban subcultures, can hamper communication and rapport. In many cases, the cultural differences can also be the basis for mistrust, lack of empathy, muted speech in culturally alienated and disenfranchised patients, inhibitions of

disclosure, and defensiveness, as well as a lack of patient compliance in end-of-life care. While cultural mistrust is likely in any culturally incongruent patient caregiver relationships, the most common aspect of cultural mistrust is the mistrust of Euro-Americans by ethnic minorities or people of color¹⁰. These factors can serve to undermine a meaningful quality and level of rapport that is essential to an effective patient-caregiver relationship in end-of-life care.

On the other hand, cultural congruence between patient and caregiver minimizes misunderstandings about attitudes, beliefs, and values regarding end-of-life issues, such as individual versus collective decision making, distinctive cultural meanings of death and dying, and the importance of collective psychosocial support in end-of-life care in some cultures, as well as the cultural regard for funeral rites and culturally sensitive approaches to aftercare.

Another literature supports the position that matters of race, ethnicity, and cultural congruence are less important than more individual, interpersonal caregiver traits such as genuineness, warmth, acceptance, and empathy, which are crucial to establishing a bond and meaningful rapport with patients at the end of their lives. Most important, on this view, is the caregivers' willingness to become acquainted with aspects of their patients' culture, social class, and spirituality as they affect attitudes, beliefs, values, and traditions about death and dying. By so doing, caregivers build confidence, credibility, cultural trust, competence, and professional effectiveness and skills^{11, 12}. The ultimate goal in culturally sensitive care giving is to "move beyond the initial issue of . . . racial (and sociocultural) difference[s] to focus on the patient's problem"¹³.

Consideration of other caregiver cultural characteristics, such as gender, religion, and social class, as well as intercultural aspects of diversity, such as sexual orientation, age, disabilities, and regional differences, are also arguably legitimate "cultures" worthy of consideration, but there has been little if any empirical study of the impact of these considerations on the patient-caregiver relationship. One can infer, however, from the aforementioned extensive investigative study of race, ethnicity, and culture that these other dimensions of multiculturalism significantly affect patient-caregiver rapport and relationship.

While culturally congruent patient-caregiver relationships may be ideal and sought-after in care giving situations, matching the patient and caregiver on all relevant variables is difficult if not impossible in our increasingly multicultural society. There is consensus across most care-giving vocations that, in the face of these multicultural realities, caregivers must become culturally competent in caring for diverse patient populations in spite of the absence of cultural parity between them^{14,15}. Across a vast array of professional organizations, standards for cultural diversity education have been formulated as guidelines for professional training and conduct in cross-cultural care giving.

From this work^{15, 16} come 7 recommendations for culturally competent caregiver in end-of-life care.

1. *Culturally competent caregivers should not rely upon stereotypes or on any "magic recipe" when approaching patients*¹⁴. Stereotypes are often misleading. Culturally competent caregivers put aside assumptions and predispositions and make individual assessments of each patient and situation. Stereotypic generalizations are often used as guides in the absence of specific information but should never take the place of a careful inquiry into each patient's situation. Few are exactly alike.

2. *Culturally competent caregivers are aware of and sensitive to their own multicultural heritage and identity, and they value and respect multicultural differences in others*. Cultural sensitivity starts with the self. Caregivers ought to be introspectively aware of their own personal attitudes, beliefs, and values about end of life. Awareness of how cultural systems may have affected their own disposition on many end-of-life matters may enable caregivers to appreciate and be sensitive to differences in their patients' views regarding end-of-life concerns. Similarly, culturally competent caregivers make no assumptions about the meaning of the cross-cultural experience for the patient, while fully understanding the meaning of the cross-cultural experience for themselves¹⁷.

3. *Culturally competent caregivers are aware of their own values and biases regarding end-of-life care and how those may affect their relationships with patients who do not share those values and biases*. While most professionals actively strive to minimize biases, prejudices, and stereotyping, it is helpful to confront one's own biases and be aware of their potential influence on relationships with patients. Culturally sensitive caregivers are vigilant in keeping their assumptions and values regarding end-of-life matters from biasing their perceptions and regard for patients who may approach end-of-life care differently. Consultations, supervision, and intercultural continuing education efforts for professional development can help to minimize biases and maximize cultural competence in end-of-life care.

4. *Culturally competent caregivers are comfortable with multicultural differences in approaches to end-of-life care*. They neither ignore multicultural differences nor pretend or behave as though legitimate cultural differences do not exist. A significant body of research on cross-cultural differences in death and dying has established that such differences are real and challenge caregivers to remain open minded and not impose "shoulds" or judgments on the various approaches to end-of-life care concerns that exist among an increasingly diverse patient population. Culturally competent caregivers realize the importance of cultural knowledge as a means of enhancing their own credibility and skill in the end-of-life care giving relationships¹⁸.

5. *Culturally competent caregivers are willing to facilitate referrals of patients to caregivers who share critical multicultural background variables.* Significant limitations in the patient-caregiver relationship may minimize caregivers' effectiveness. In some end-of-life situations, certain pairings of patients with caregivers work better than others. This realization allows caregivers to acknowledge their limitations and make referrals to others who may be better able to assist the patient's end-of-life care outcomes. While cultural congruence may be the ideal, in many cases the quality of the patient-caregiver relationship can be meaningfully enhanced by the interpersonal style, credibility, and empathy of the caregiver.

6. *Culturally competent caregivers are sensitive to and aware of the institutional barriers that prevent minorities from using institutionalized end-of-life care.* A host of factors (e.g., lack of health insurance, cultural mistrust, and other socioeconomic constraints) limit and serve as barriers to institutionalized end-of-life services for many minority patients and thus may limit the patient's end-of-life care choices. Some adjustments and accommodations can be made to enhance the patient's end-of-life choices. Those factors that cannot be changed must at least be understood so that there is less of a tendency to error in "blaming the victim."

7. *Culturally competent caregivers appreciate the independent role of individual multicultural dimensions (e.g., race, gender, culture), while appreciating the often combined and interaction of multicultural dimensions (e.g., religion, social class, age, sexual orientation) and their influence on end-of-life issues and care*¹⁴. Racial, cultural, and ethnic stereotypes are seldom reliable guides alone, but can improve understanding when viewed in combination with considerations of spirituality/religion and social class¹⁹. Many multicultural dimensions are significant in patient-caregiver end-of-life relationships.

In summary, the importance of the having someone of the same racial and ethnic background is believed to be more important to the ethnic minority patient than to the caregiver. Cultural congruence is believed to enhance the patient-caregiver relationship. While a racial and cultural match between the patient and caregiver is the ideal, other caregiver characteristics are perceived as being as important and worthy of consideration (regardless of the race) in achieving cultural competence in end-of-life care giving. Culturally competent caregivers bring enhanced credibility and particular skill to meeting the end-of-life care needs of an increasingly diverse patient population.

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