Cultural Mistrust and Use of Hospice Care: Challenges and Remedies

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ABSTRACT

Cultural mistrust is a prominent barrier to the involvement of African Americans in hospice care. While disavowing the theory that cultural mistrust has its origin in any single factor or event, it is argued that there needs only to exist the cultural construct of community for cultural mistrust to perpetuate itself among any ethnic group. The attitudes toward hospice care are advanced as illustrative of the relationship between African Americans and the health care system, and many other institutions of American society. From a perspective that accepts the existence of the phenomenon of cultural mistrust, suggestions for structuring training for cultural competence are discussed. These suggestions are relevant for workers in institutions that serve the African American community in critical health care areas in general, and administrators and staff of hospices in particular.

INTRODUCTION

WITHIN RECENT TIMES federal legislation has provided checks and balances for the health care industry in the matter of advance directives. These legislations are enacted in all 50 states of the union in an effort to inspire confidence in the health care system, and provide good-faith evidence of respect for patients' final wishes, thus opening the way for greater use of end-of-life provisions within the system. These legislations mandate health care institutions to: (1) provide written information to patients about their rights to refuse treatment; (2) ask about advance directives and document responses; (3) provide education to staff on these issues; (4) ensure compliance with existing state laws regarding advance directives; and (5) maintain written institutional policies about these legislations.[1,2] Despite these good-faith efforts at encouraging confidence in the health care system, ethnic and racial minorities represent only 5% to 7% of the hospice patient population,[3] and African Americans in particular, are seriously underrepresented in this institution.[4]

As some literature on this issue would point out, African Americans face peculiar barriers on the consideration of end-of-life/palliative care in general, and hospice care in particular. Within the African American community health care decisions are usually a family affair. Therefore, many African Americans first consult their family circle in making decisions about where to seek help, and show a general reluctance to go outside of their family circle for help with medical care-giving.[5] As a corollary of this culture pattern they often hesitate to welcome strangers from hospice into their homes.[6] In addition, lack of knowledge about hospice services constitutes another barrier to hospice use for African Americans.[7–8]

The use of the emergency department rather than private physicians for health care can indi-

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rectly create another barrier for a sizable part of the black community. Medicare regulations require that a physician certify terminality for entry into hospice programs. But, many African Americans do not have a regular physician and are consequently without such certification and therefore unable to utilize hospice care.[9] Most striking, however, is the lack of agreement with hospice philosophy among African Americans. Among other things, hospice philosophy stresses acceptance of death and palliative, rather than curative care. African Americans see longevity as an intrinsic good,[10] are often reluctant to discuss advance directives,[11] and often prefer curative care as a means of avoiding the reality of certain death.[12] This perspective perhaps contributes to the reason that African Americans are the most reluctant of minority groups to agree to negotiate the end-of-life decisions concerning the withdrawing of life-prolonging therapy,[1,13,14] tissue and organ donation,[15–18] and palliative care in the hospice setting.

The discussion of barriers would do well to include the caution that, "what may look like a barrier from the vantage point of a health care giver may be a protective strategy or a source of comfort and security when viewed from a different angle."[19] It must be remembered that for African Americans, death has often been associated with various forms of social injustice. Some of these are high mortality from a host of diseases, which reflects societal disparities that affect African Americans disproportionately, and homicide and mayhem at the hands of individuals and institutions that are supposed to protect rather than harm individuals. Might it not then be reasonable to "go down fighting" if one's death is part of a perceived pattern of social injustice? Going down fighting in this sense may be reflected in reluctance to face death and the associated preparations, and/or resistance to hospice, an institution that deals in the business of death.

It is with full recognition and respect for the fact that the African American community is not a monolith, that in addition to the barriers mentioned above, I explore the theme of cultural mistrust as a powerful factor in the decision making processes of African Americans as they negotiate the issue of utilization of hospice care. In this paper, cultural mistrust, which will receive detailed attention later, is taken to mean the fear that African Americans, because of their ethnicity, will receive experimental or inferior care at the hands of whites.[3] While some of the issues that are mentioned, are by no means common to African Americans, this racial group receives the focus of this discussion. This paper further discusses challenges, which the phenomenon of cultural mistrust presents for the health care system, and ways in which health care administrators and lower lever health care workers can deal with their own cultural inadequacies, and deliver quality care despite attitudes of cultural mistrust that may be present in their patients.

CULTURAL MISTRUST AND HOSPICE CARE

Potential hospice patients are typically but not exclusively older persons. This cohort is often familiar with the Tuskegee study, and feel that African Americans are still likely to be treated as guinea pigs by the health care system. In addition, they hold the belief that their race is devalued in the eyes of American society, and see this as the cause of episodes of neglectful and inhumane treatment in public health care facilities that provide care for poor people. These sentiments constitute a formidable barrier to the use of hospice care, and encourage this older generation to choose to care for themselves at home.[3]

Cultural mistrust within the context of the health care system in general, and hospice care in particular, is believed to be peculiar to African Americans.[20] Furthermore, the perspective of mistrust seems to flourish most within a setting where the cultural/racial background of health care workers is not the same as the patients'.[21] While the notion that a facility with minority volunteers would be able to attract minority patients is untested, as Haber[22] argues, it is true that hospice facilities, for perhaps different reasons, have been unable to attract minority volunteers and workers. This situation gives more fuel to the cultural mistrust with which a patient may have entered the facility.[3] The health care system is further caught in what may be described as the proverbial "rock and a hard place," when it comes to cultural mistrust. Haber describes this dilemma thus:

Cultural insensitivity and mistrust are engendered by a health care system that tends to be complex, busy, impersonal, and often brusque . . . hospice care which is not im-

personal or brusque, may be viewed by minority families as intrusive, especially if they believe that unfamiliar caregivers will try to take over and change things.[22]

Even in cases where hospice workers may enter the home, their presence may not be welcomed into the intimacy of the racial/ethnic family, and viewed with mistrust, especially when they are seen as mainstream health care workers with ties to the mainstream health care system.[6] The dilemma for hospice is that hospice, being what it is in terms of its philosophy, and the makeup of its workforce, is a foreboding place for African Americans. Of the 5% to 7% minority population of hospice in America,[3] it is reasonable to assume that perhaps less than half of this group is African American. The meaning of this for the health care industry is that hospice care is not presently a feature of African American life. This situation could hardly be acceptable to the industry from a moral or financial perspective.

IDENTIFYING CULTURAL MISTRUST

The term "cultural mistrust" is an apt one for the lived experience of African Americans. If culture is indeed a design (or blueprint) for living,[23] then the combined term indicates that African Americans' attitudes, decisions, and actions are directed by a persistent mistrust for the wider society. Cultural mistrust refers to African Americans' mistrust of white Americans and traditional American systems (e.g., education, health care, criminal justice, etc.).[24] The prevailing opinion among researchers who investigate minority health utilization is that cultural mistrust is a phenomenon specific to blacks.[20] Cultural mistrust is evidenced for example, in biases brought to the counseling process,[21] and acts as a barrier to rehabilitation.[25]

Cultural mistrust has been illustrated to have far-reaching and decidedly negative consequences for patients when it is present in medical care settings. Among white and black cardiac patients, black patients were more likely to perceive racism in the medical system.[26] Furthermore, black patients were more likely to report mistrust, and when mistrust was present, it led to less satisfaction with medical care. Therefore, to the extent that satisfaction with care influences recovery—and there is mounting evidence that it

does—African Americans are at a recovery disadvantage in medical settings, because of cultural mistrust. In mental health settings, cultural mistrust, when present in black mental health patients, is believed to be responsible for a disproportionate number of schizophrenia diagnoses of African Americans by white clinicians. These diagnoses are believed to be the result of African American patients' perceptions of white clinicians as part of a distrusted, white dominated, power structure within the wider society in general, and within medicine in particular.[21,27]

There is evidence that cultural mistrust or distrust of whites in general, or of white controlled institutions, may affect knowledge of acquired immune deficiency syndrome (AIDS) and willingness to try what the medical establishment sees as effective AIDS treatment drugs.[28,29] Other evidence suggests that many African Americans may distrust and perhaps resent any institution or its representative, which is established by the dominant Caucasian culture, and has power over their lives.[30]

Some researchers ascribe cultural mistrust to a specific event in the experience of African Americans as a group. One such incident, is the Tuskegee Syphilis Study of 1932 to 1972, which is believed to have influenced mistrust even among African Americans who do not know about it. This notion is discredited by Gamble, who argues:

The Tuskegee Syphilis Study is frequently described as the singular reason behind African American distrust of the institutions of medicine and public health. . .The narrowness of such a representation places emphasis on a single historical event to explain deeply entrenched and complex attitudes within the Black community . . . Black Americans' fears about exploitation by the medical profession date back to the antebellum period and the use of slaves and free Black people as subjects for dissection and medical experimentation.[31]

History combines with contemporary social experiences to further cement the perspective of mistrust in the psyche of the African American community. In a nation that boasts a creed of racial, sexual, and religious freedom, race still matters. Because it matters, people tend to identify with and feel loyal to their in-group, and of-

ten treat those in the out-group less favorably.[32,33] Race matters to African Americans because they are frequently reminded that they are members of the out-group. It matters for African Americans as they go in search of a job and wonders if they are discriminated against when they do not get the job they think they should get. They wonder if they are racially profiled when they are stopped by a police officer for a traffic infringement. They question whether or not they are fairly treated by the justice system that seems to disproportionately imprison so many blacks. They wonder if they will be given equal treatment by a health care system that treated blacks as guinea pigs not so long ago. African Americans question if the financial system that denied them a home loan would have dealt the same way with a white person in a similar financial position. This reality, justified or not, is ever present with African Americans. Therefore, any attempt to delve into the perspectives of African Americans is an exercise that must confront the phenomenon called race. "Race is the most explosive issue in American life precisely because it forces us to confront the tragic facts of poverty and paranoia, despair and distrust."[34]

The questioning mind might rightly inquire: "What about those African Americans who have not been exposed to historical or contemporary experiences of racial injustices?" The sociological perspective called symbolic interactionism provides an answer through the views of W.I. Thomas, an answer that helps to lay a foundation for examining the perspectives of African Americans including end-of-life issues. Thomas stated: "Situations that are defined as real, are real in their consequences."[35] It is indeed not the "truth" of an experience or situation that produces action, but the way it is defined or perceived by the actor. I propose that the collective attitude of the African American community toward a social system that they define as discriminatory, promoting doubt rather than inspiring confidence, is powerful enough to dictate their attitude toward end-of-life issues. William Wallard states it this way: "The attitudes of others are in fact the most important limitations upon the behavior of any one person, and they are also the most important inducements to any particular action."[36] From this perspective, an African American person does not have to know about the Tuskegee Syphilis Study to be skeptical about the health care system. He or she does not have to be vic-timized by the justice system to be uncertain about the treatment he or she would receive at the hands of any institution vaguely connected to what is perceived as "the government," or controlled by white society, generally referred to as "the man." An African American only has be part of the social construct called "community," to be socialized into the perspective of that community. He or she has only to be an African American raised by an African American community to view the health care system through the lens of cultural mistrust. Cultural mistrust is the lived reality of a large sector of the African American community.

THE NEED FOR AN ATTITUDINAL CHANGE IN HEALTH CARE

This unfortunate phenomenon presents a barrier to African American participation in hospice care. Hospice care is perceived by the health care community as a valued opportunity, and is described as "a quality-oriented alternative to the health care system—so that, at least at the end of life—an individual could have appropriate care."[37] To the extent therefore that African Americans do not participate in hospice care, they are being excluded from an important health care opportunity.

Moving beyond the presence of this phenomenon requires that important questions be considered. How can this phenomenon be confronted? What can the health care community do to raise awareness about this problem, and move toward involving more African Americans in hospice care?

Participants in an action research study reported that, "fears of the health care system are compounded by the lack of diversity among healthcare staff."[3] This lack of diversity is a fact about which the health care community must show some concern. It is the opinion of some researchers and observers of the health care system that there is a lack of will on the part of leaders within the health care industry to make a positive effort to hire competent minority staff at all levels. A palliative care director expresses this concern this way: "Ideally, we think anybody of any race can help someone if you relate to each other as a competent health professional and as a human being. However, I think it is naïve not to acknowledge that the health care provider

population should be representative of the people who comprise the communities they serve."[38] This literature strongly opines that the ethnic and racial diversity of the health care providers really does make a difference in terms of the acceptability of these programs to minority communities.

While the wider health care community works toward remedying this racial discordance in the worker force, the challenge to the African American community is to deal with the situation by seeking to make the best use of the health care system despite this apparent shortcoming. It is not always possible for African American and other minority users of the health care system to always see a practitioner of their own ethnic orientation whenever they use the system. This situation offers a greater responsibility for the health care system to operate within the context of this knowledge and make the system more "user-friendly" to their African American clients. In order for this to take place administrators of individual institutions within the system must acknowledge this problem, and attempt to effectively adopt the goal of making their institutions more user-friendly. The sincerity of this effort would be reflected in the measurability of this goal. "Effective goal-setting requires measurable objectives and a plan of action for achieving the goal and evaluating progress along the way."[22]

In order for an institution to embark on a path of cultural sensitivity, the leaders within the institution must first acknowledge that their clients are of a different cultural background to their own, whenever this is the case. Racial isolation, housing segregation, economic marginalization, and the persisting presence of race in the American psyche, consort to prevent African American assimilation, and further preserve the separateness of culture that exists in the African American community. African Americans therefore constitute a specific cultural group with specific attitudes, orientations, and perceptions of the larger society within which they exist. The presence of cultural mistrust is a stark reminder of this fact. The challenge that confronts the U.S. health care system—specifically that section of the system that provides services to African Americans at the end-of-life stage of care—is twofold. First, the system as a whole, institutions that make up the system, and practitioners who serve within these institutions must act to reduce the consequences of cultural mistrust that already exist within the African American community. Second, these facets of the system must work to achieve cultural competence. (While these goals may be viewed as a singular concept, they are separated in order to facilitate specific attention to cultural mistrust.) This goal should be pursued not just for the African American community, but for all people who are of a different cultural orientation; not just because it will help in the delivery of health care at the end-of-life stage, but because it is a goal that is worthy in and of itself. It is a goal that needs to be achieved by a system that needs to show itself as "kinder and gentler."

CONFRONTING AND REMEDYING CULTURAL MISTRUST

Cultural mistrust is an unfortunate dynamic of the relationship between African Americans and the health care system in America. The consequence is that many choose not to accept hospice care and in the process deny themselves health care that, without doubt, enhances the quality of end-of-life existence. Recognizing that the lack of hospice use among African Americans is a result of their own choice, the issue of whether the disparities caused by this choice constitute a social injustice and is therefore the responsibility of society to remedy is one that may be subjected to theoretical arguments beyond the scope of this paper. However, it is the opinion of this author that when the formation of preferences or choices is a product of a legacy of intentional discrimination that results in disparities, culpability for these disparities lies at the door of the society that nourished the historical conditions that led to these preferences.[39] Administrators of health care institutions are therefore in a unique position to plan competently to confront and remedy cultural mistrust. From an administrative perspective they can implement some measures prominently featured in the literature addressing this issue. Although there is obviously a great deal of overlap of measures, examples relevant to health care institutions in general are:

- Encourage at the board level the perspective that it is the responsibility of the institution to reach out to a community whose mistrust of the system works against their best interest.
- Participate in advocacy campaigns to move the industry toward a recognition of this problem

and a willingness to ameliorate it through educating a new breed of health professional who are more sensitive to cultural mistrust and its consequences.[22]

- Adopt a posture of reaching out to the community through an active and genuine participation in a diversity of community activities.

Following are examples of measures relevant to hospice in particular are. These measures are easier to implement at the level of single hospices through the activities of a community liaison person or outreach worker.

- Hire competent African American staff, and recruit minority volunteers.[22,40]
- Ensure that key family members and friends are involved in the decisions pertaining to the care and end-of-life issues of the patient.[41]
- Respect cultural differences regarding medical treatment preferences.
- Conduct public education campaigns, perhaps via television, community festivals or local community organizations, newsletters, and church presentations.
- Involve African American pastors in capacities that permit them to be bridges of trust between health care institutions and the communities they serve—examples of these capacities are community representatives, public relations persons, and members of boards of hospices and other health care facilities.[3,22]
- Avoid making promises that the institution is incapable of fulfilling. Burrs[7] states it succinctly: "Promise only what you can deliver and deliver everything you promise." This caution is given with a cognizance of the history of inequality and injustice, which have been the lot of African Americans in the most recent past. And the fact that the trust, which may now be developing, is tenuous and at best precariously balanced.

ACHIEVING CULTURAL COMPETENCE

The second part of the goal, that of working toward cultural competence, is one for which literature provides a great deal of guidance. Cultural competence can be identified through a simple operational definition. A culturally competent system of health care "acknowledges and incorporates—at all levels—the importance of culture, the assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally unique needs."[42] One important precondition for working towards the goal of cultural competence is of course, acknowledging and respecting existing cultural differences.

The challenge is especially important for health care workers whose jobs bring them into personal contact with persons of minority groups who hold perspectives of cultural mistrust. These health care workers must become aware that because the United States is one of the most ethnically diverse nations in the world, there is need for cultural competence, and a consideration and understanding of the role of race and ethnicity in end-of-life issues. "Providing health care that meets the needs of ethnic groups requires the health care professional to consider culture [race], social, religious, and linguistic differences."[43]

A curriculum for training health care workers in cultural competence should therefore include certain important components. These components may be conceptualized as either knowledge content areas, or goals toward which workers should strive. Such training can and should target both administrative and lower level workers who come into close contact with health care consumers of different cultural backgrounds. An example of some of these components are:

- Understanding one's own cultural and social location. As part of the effort to reduce ethnocentrism, health care workers should be brought fact to face with the fact that they are themselves part of a cultural/racial group, with their distinct culture patterns. "The multicultural perspective requires an understanding of the significance of social location in shaping human experience, including valuing one's own cultural heritage . . . acknowledging the importance of one's own culture helps one recognize its importance to others."[44] Without seeing one's own position, it is impossible to really grasp the position of others.[45]
- Gaining knowledge of other cultures. Gutierrez et al.[44] argues that knowledge includes awareness of the history, traditions, and values of other groups. A cultural competence curriculum aimed at African Americans as a target group, should include a reasonable view of the historical experience of blacks that helped to shape their cultural mistrust. (The film media has done a reasonable job in docu-

menting some of these historical experiences. Film is therefore a good medium to use for such activities.) All cultures have cultural context,[46] therefore an opportunity to become aware of this context will greatly enrich a cultural competence curriculum.

• Recognizing cultural competence as a dynamic experience rather than a state of accomplished expertise. The challenge of becoming culturally competent involves mastering skills in many areas of a foreign culture. This is the work of a lifetime of dedication. Cultural competence involves learning to speak other languages; immersing oneself in other cultures; and understanding the history, food, and lifestyles of another country and its people. Cultural competence is "an ongoing process in which we continuously strive to achieve the ability to work effectively within a community's cultural context."[47]

I invoke a developmental perspective to further analyze cultural competence as a personal quality. The culturally competent person should not be viewed only as a person who has achieved a specific level of cultural expertise. If awareness of one's own cultural location, coupled with a genuine desire to achieve cultural competence is a worthy goal in and of itself, then the parallel of a biological type of development is fitting. The seedling, the sapling, and the adult tree are all viewed as healthy organisms at each stage of development. Similarly, a person should be viewed as "healthy in a culturally competent sense," if he or she has internalized and adopted the goal/process of cultural competence, and is in the process of developing the skills and perspectives needed to interact with persons of other cultures in a culturally competent manner.

Within the context of cultural competence, learning to speak another culture's language involves more than just the grammatical structure of that language. It also involves the nuances of the language, and the nonverbal communication that enriches any culture. African American culture is no exception. There are even words and terms that no "outsider" is welcome to use to an African American, while African Americans use them freely among themselves. Such is the nature of language. Cultural competence involves a thorough knowledge of these nuances; a knowledge that takes dedication and time to acquire.

The goals for the non-African American—of achieving cultural sensitivity, for the African American of overcoming cultural mistrust, and for the health care industry of making the system more acceptable for African American clients are achievable. Some institutions are shining examples of working toward these goals, and present models that deserve emulation by institutions that are sincerely trying to reach out to minority groups, especially African Americans. The Harlem Palliative Care Network which serves an African American and Hispanic community has done the following in reaching out to their community:

1. Selected a broad-based advisory board that includes high-level stakeholders and community leaders from the target community.
2. Instituted an education program among community organizations, especially churches, in the target area.
3. Made a special effort to hire staff reflective of the racial makeup of the target community.
4. Incorporated clergy from the local churches in non-board positions either as contact persons, volunteers, or links between the organization and the community.
5. Invested a greater level of person hours in meeting patients' nonclinical family needs in terms of contacting estranged relatives and pastors of clients.
6. Provided bereavement support after the patient's death in the form of cards, symbolic packages containing perhaps a memento, and follow-up literature.

This institution reported that they were able to involve minority persons in their program to the level of their capacity because they were able to foster in their staff the perspective that "people will respond to a sincere effort to meet human needs when we in involve them in planning their own care, and deliver those services we say we are going to deliver."[38]

Hospice of the Valley, in Santa Clara County, California, has been successful in increasing their minority clientele by using a few simple innovations to their program. They engaged a minority volunteer to survey the minority population in their community, and the information gathered was compiled into a handbook designed as a guide for hospice workers. This initiative enabled hospice staff to "open their personal windows" and become more comfortable in dealing with foreign cultures. A hospice nurse commented: "Ethnic clarity no longer is a primary issue-the experience of dying is the primary issue. Just like

when everyone is in an earthquake together, everyone looks the same."[48] Despite the fact that larger barriers to cross-cultural care giving remained, such progress toward cultural competence is a testimony to the progress that results when a sincere effort is made to reach out to minority groups by hospice staff.

CONCLUSION

The phenomenon known as cultural mistrust can be viewed in three ways. It can be seen first as a racial inadequacy, which has no place in a progressive society, and therefore must be ignored. Second, it can be seen as an unfortunate racial characteristic, which should be accepted without question or challenge. Or, third, it can be seen as an unfortunate phenomenon, which must be acknowledged, but can be remedied by a sincere and structured program of intervention on the part of the wider society, and an effort to move beyond unfounded perceptions, on the part of minority groups. This paper is written from the third perspective.

Cultural mistrust is a response that is unfortunate but real. It is a response to perceived devalued status and the actions, which might proceed from it at the hands of the wider society. It dictates the decisions of many African Americans in end-of-life issues especially and specifically in reducing their use of hospice facilities.[3] "For many racial and ethnic minorities, preferences for treatment are often difficult to separate from mistrust of health professions that stems from racial discrimination and the history of segregated and inferior care for minorities."[49] African Americans are caught in this web of mistrust, which is a formidable barrier to their use of hospice care. Such barriers are viewed by many contemporary researchers as among the root causes of healthcare disparities.

If indeed disparities within the health care system are unacceptable in the U.S. society,[49] and cultural mistrust restricts the use of health care by minorities and contributes to disparities, then the presence of cultural mistrust presents challenges, which must be confronted by the U.S. society in general, and the health care industry and hospice institutions in particular. These challenges include recognizing the presence of cultural mistrust, having a desire and will to intervene in the way it creates health care disparities, and genuinely making efforts to ensure that the health care industry, hospice as an institution within this industry, and individual hospice staff at all levels, become involved in the effort to banish this phenomenon from the landscape of healthcare delivery. One promising method is by instituting a well-structured program of training in cultural awareness and cultural competence throughout the ranks of the health care system. When such an effort touches a wide cross-section of the healthcare industry it may filter over into the wider society. The effort at working towards a "kinder and gentler" health care system may yet pay dividends in reducing cultural mistrust and push the society one step closer to eliminating health disparities between minority groups and the rest of the society.

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