Hospice Access and Use by African Americans: Addressing Cultural and Institutional Barriers through Participatory Action Research

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This article describes a participatory action research project addressing the problem of African American access to and use of hospice. Qualitative interviews conducted with six African American pastors resulted in the identification of major themes used for development of a scale to measure barriers to hospice. A subsequent quantitative study documenting these barriers was conducted with 127 African Americans and European Americans. Results of both studies, which were used to further social action efforts in the community, indicated the cultural barriers of differences in values regarding medical care and differences in spiritual beliefs between African Americans and European Americans. Results also indicated institutional barriers, including lack of knowledge of services, economic factors, lack of trust by African Americans in the health care system, and lack of diversity among health care staff. Implications for social work practice and policy are discussed.

Key words: *action research; diversity; hospice; spirituality; strengths perspective*

Hospice developed in the United States in the 1970s as a grassroots movement to promote more humane care for dying people. Hospice philosophy stresses patient self-determination, acceptance of death, and palliative rather than curative care. In addition, it advocates for dying in the home surrounded by loved ones, rather than in an institution surrounded by technology. Social workers provide hospice care in collaboration with an interdisciplinary team of professionals, who attend to biopsychosocial and spiritual needs of patients and families. Nationwide, ethnic and racial minorities represent only 5 percent to 7 percent of the hospice patient population.

A need for hospice care in the African American community is justified by the higher cancer mortality rate (Lowe, Barg, & Bernstein,

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1995) and the prevalence of the AIDS virus among African Americans (Infeld, Crum, & Koshuta, 1990). This article describes a project that was conducted within the context of a participatory action research project, aimed at increasing African American access to and use of hospice. This article provides research results that address gaps in the literature and discuss implications for social work practice and policy.

Literature Review

The hospice literature reflects a number of barriers to hospice access and use for African Americans. The literature in this area contains mainly nonempirically based discussion papers, as well as surveys of hospice staff and records, rather than studies carried out directly with African Americans. Before discussing these barriers, however, two issues must be considered. First, we may not assume that the African American population is homogeneous, because there is wide variability among African Americans in terms of income, education, employment, geographic region, and country of origin (Dowd, Poole, Davidhizar, & Giger, 1998; Lowe et al., 1995). Within this diversity, however, a cultural unity may be detected that traditionally has characterized many African American families (Nobles, 1974), and during the great stress of terminal illness, patients who normally do not adhere to ethnic culture may resort to traditional modes of behavior (Harwood, 1981). It may be argued, thus, that it is useful for social workers to be informed about traditional African American cultural characteristics while avoiding stereotypes and unquestioning assumptions about clients.

Second, within the European American population, hospice is not well recognized or understood (Burrs, 1995). The general population is unfamiliar with hospice (Mor, Hendershot, & Cryan, 1989), and physician barriers to hospice referral abound, including inadequate physician training (Miller, Miller, & Single, 1997), availability of a program, and Medicare requirements, including a six-month prognosis and a requirement for 24-hour family caregiver in the home (Miller et al., 1997). Because referral to hospice is primarily by the physician (Gordon, 1995; Infeld et al., 1990), most terminally ill patients do not have their care provided through hospice programs. In 1995 only 37 percent of all people who died of cancer-related causes in United States and 31 percent of all who died of AIDS-related causes were cared for by hospices (National Hospice Organization, 1995).

Despite these barriers to hospice care for the population as a whole, hospice access and use are skewed toward European Americans. Medicare regulations describe patients and families from mainstream America and create barriers for disadvantaged groups. For example, European Americans are more likely to have the required full-time caregiver in the home (Gordon, 1995). Medicare regulations also require certification of terminality by a physician, and African Americans use emergency room care over a regular physician, regardless of other demographic factors such as income or insurance coverage (Heckler, 1985; Neighbors & Jackson, 1987). Additional information is needed about whether current managed-care approaches will change this pattern.

Another barrier to access is that many African Americans lack knowledge about hospice services (Burrs, 1995; Harper, 1995). In addition, lack of trust by many African Americans in the health care system as a whole (Lundgren & Chen, 1986; Neubauer & Hamilton, 1990) is a barrier to hospice use. African Americans often fear that they will receive experimental or inferior care (Burrs, 1995), do not want to be treated like "guinea pigs" (Harris, Gorelick, Samuels, & Bempong, 1996), and relate past experiences with being treated disrespectfully by health care professionals (Griffin & Bratton, 1995). African Americans often show a general reluctance to go outside of their family and circle of friends for help with medical crises (Harper, 1990; Lundgren & Chen, 1986) and often hesitate to welcome strangers from hospice into their homes (Gordon & Rooney, 1984). Lack of diversity among health care staff is cited as part of this problem (Burrs, 1995; Gordon & Rooney, 1984).

Another barrier to use has to do with values about medical care and extent of agreement with hospice philosophy. African American attitudes often are inconsistent with the hospice philosophy of palliative rather than curative care (Klessig, 1992; Neubauer & Hamilton, 1990; Ita, 1995–96, now Reese). African Americans often see longevity as an intrinsic good (Klessig) and have expectations of living a long life (Kalish & Reynolds, 1976). Most prefer curative care (Ita) and all life-sustaining measures until death (Klessig), and many have not established a "do not resuscitate" order (Ita). In addition, most African Americans prefer not to die in the home, in opposition to hospice philosophy (Burrs, 1995; Gordon, 1995; Ita).

We found no literature on the influence of state regulations on access and use of hospice care. Medicaid covers only 7 percent of hospice patients, whereas Medicare covers 65 percent (National Hospice Organization, 1995). State policy on hospice coverage under Medicaid may be an important underlying factor in the small proportion of Medicaid patients in hospice and an important barrier to African American access and use.

Value differences between African Americans and European Americans may be based to an extent on mistrust of health care professionals' motives for suggesting palliative rather than curative care, but may be based to a large extent on differences in religious beliefs. Despite the well-documented importance of the church in African American society (Frazier & Lincoln, 1974; Griffin & Bratton, 1995; Pipes, 1981; Raboteau, 1978), African American religious beliefs have largely been neglected in empirical studies of barriers to hospice care.

Traditional African American Religious Beliefs

Explanations of the importance of religion to African Americans may be found in their history. African slaves were stripped of their social heritage by being captured, shipped, and sold without any regard for family or tribal affiliations. Any attempt to preserve or use their native languages or religious traditions was discouraged or prohibited (Frazier & Lincoln, 1974). Christianity was forced on the slaves and used to justify slavery. But the new Christian religious beliefs, practices, and traditions formed a new basis of social cohesion, creating solidarity and a sense of union among these strangers from a variety of African nationalities. Despite prohibition of any assembly of slaves without the presence of European Americans, the "invisible institution" of the African American church took root through secret meetings in secluded places (Raboteau, 1978). The church became the most important social institution in African American culture and has remained a source of social stability through the disruptive effects of emancipation and migration to northern urban areas. The pastor, as the leader of this institution, has played a significant leadership role in African American culture (Frazier & Lincoln).

It may be helpful here to summarize some common beliefs pertaining to death and dying. Traditionally, African Americans believe in the omnipotence of God (Burrs, 1995; Cooper-Lewter & Mitchell, 1992). Illness and death are God's will and are not necessarily affected by treatment (Creel, 1991; Dowd et al., 1998; Pipes, 1981). At the same time, God is benevolent and has miraculous powers—God is able to cause recovery or turn into good ends whatever may occur (Burrs; Cooper-Lewter & Mitchell; Creel). Another traditional belief is the belief in a better life after death, without sickness, disease, poverty, or hunger, a life in which victims of injustices will be compensated (Cooper-Lewter & Mitchell; Creel; Frazier & Lincoln, 1974). Thus, traditionally there is little apprehension at the prospect of dying; rather a sense of joy may be detected (Cooper-Lewter & Mitchell; Creel). When a death is expected, the dying person is surrounded by the community, which offers comfort and support (Creel; Dowd et al.). According to Burrs, the tradition of honoring and respecting the great spirit of African ancestors leads to discomfort with death in the home.

It should be noted that traditional African American beliefs have changed over time (Frazier & Lincoln, 1974). Beliefs of the upper- and middle-classes have broken away from the traditional African American belief system, as have beliefs of many northern urban African Americans. Despite these changes, the church continues to function as an important element in African American society, providing a refuge for the masses of African American people (Frazier & Lincoln, 1974). Most African Americans consider themselves religious, seek health care advice from their pastors (Griffin & Bratton, 1995), and use religion as a coping strategy (Mailick, Holden, & Walther, 1994). When researchers asked African Americans what their immediate response would be to a diagnosis of cancer, they replied, "I would prepare to meet my maker" (Dignan, Michielutte, Sharp, Young, & Daniels, 1991, p. 75). Pipes (1981) stated that the African American pastor is traditionally the leader of the African American community, and it is to him or her that the great majority of African Americans still look for guidance. A 1997 Gallup Social Audit (Gallup Organization, 1997) reported that 71 percent of African Americans attended mostly or all-African American congregations, that 73 percent of African Americans were Protestants (48 percent Baptist), and that 9 percent were Catholic; only 8 percent had no religious affiliation.

European Americans often have failed to honor and respect traditional African American beliefs. Frazier and Lincoln (1974) characterized mainstream America's attitude as one of condescending amusement. During the Civil War some observers were appalled at what they interpreted as resignation among the slaves. The patience in sickness was so general and remarkable, it seemed like apathy (Creel, 1991). European American researchers have regarded the African American belief system as "fatalistic" and "pessimistic" (Rana, Knasel, & Haddy, 1992) and potentially interfering with preventive health practices (Dignan et al., 1991). As noted earlier, hospice researchers have found some conflicts between traditional African American beliefs and hospice philosophy. A purpose of this project was to gain understanding of such conflicts and to develop some solutions for culturally sensitive practice.

Action Research Model

This project is an example of the use of research as a tool for social action. Participatory action research is increasingly in use in the social work field (Hick, 1997; Wagner, 1991) and is consistent with a strengths perspective and social work values regarding integrating social action efforts into practice. Models of participatory action research vary, but hallmarks are the transfer of power to the research participants (Sarri & Sarri, 1992), engaging the participation of the community in research activities (Hick, 1997), producing knowledge that is useful to service providers and clients (Penuel & Freeman, 1997), and using the knowledge for social change (Malekoff, 1994) or change in service approaches (Martinez-Brawley & Delevan, 1993; Rapp, Shera, & Kisthardt, 1993).

Our model consisted of seven strategies: (1) literature review, (2) integration with social work education, (3) collaboration with respondents, (4) collaboration with practitioners, (5) ongoing social action efforts, (6) qualitative study, and (7) quantitative study. We integrated our project with social work education through the use of independent studies, graduate research assistantships, class projects, lectures, and discussions. We engaged in ongoing collaboration with respondents and practitioners, setting several meetings between the ministerial association and local health care providers to discuss the problem and to present results of the study. Definition of the problem, as well as the quantitative measure, was based on the input of the target population, which was gathered during these meetings as well as through the qualitative interviews. The project ultimately benefited the target population by forging a new connection between the African American community and local health care providers, by developing an understanding of existing barriers, and by collaboratively developing a plan for solutions to the barriers.

Qualitative Study

The purpose of the qualitative portion of the study was to explore unexpected reasons for the lack of participation of African Americans in hospice. Qualitative study uses an inductive method of inquiry in which theory and working hypotheses are developed after the data are collected. Qualitative methods allow for in-depth input from respondents that is not restricted by the closed-ended questions used in quantitative methods. Thus, we see qualitative methodology as an important component of participatory action research.

Because of the importance of the church in African American communities and the importance of the pastor as a community leader, we selected African American pastors for the qualitative sample. Six Christian pastors were recruited from four Baptist, one Christian Methodist Episcopal, and one Catholic congregation in a midwestern city of 100,000 population. Their beliefs largely represented the traditional African American belief system, with the Catholic pastor being somewhat more nontraditional. The pastors were recruited through the local African American ministerial association and were asked an open-ended question, "Why do you think there are very few African American patients in hospice?" Interviews lasted for approximately one hour and were tape recorded. Transcripts of the interviews were then typed from the tape recordings.

Glaser and Strauss (1967) outlined criteria for rigor of qualitative analysis, which include "comparing and contrasting" responses to develop major themes and presenting results to the respondents to verify credibility. To further establish trustworthiness and credibility of findings, Lincoln and Guba (1985) suggested using "triangulation," in which the researcher consults additional sources of data to assess consistency with the conclusions from the original source of data. Trustworthiness and credibility are the focus in qualitative research, rather than validity and reliability, which apply to quantitative research. Transferability of results to similar contexts is the goal, rather than generalizability. Because an attempt was not made to generalize to the population through inferential statistics, the large sample typical of survey research was not necessary.

In this study the qualitative analysis was conducted manually by the senior researcher, based on the method described earlier. The transcripts from the tape-recorded interviews were analyzed for major themes. The resulting categories were collapsed further into two overriding classifications: (1) cultural barriers to hospice care and (2) institutional barriers to hospice care. A second researcher conducted an independent analysis to check on the reliability of the coding, with similar results. After the data were analyzed, a second interview was conducted with each respondent to focus on themes that emerged during the analysis. Open-ended questions were still used, but they were focused on asking the respondents for feedback on the credibility and trustworthiness of the researchers' findings. In all cases, the participants agreed with the researchers' conclusions. The themes were used to develop a quantitative measure, which was used in the subsequent quantitative phase of the study. The quantitative findings were used as triangulation to examine the credibility of the qualitative findings.

Results of the qualitative study indicated the existence of cultural barriers and institutional barriers to hospice access and use for African Americans. Cultural barriers included differences in values regarding medical care and differences in spiritual beliefs between African Americans and European Americans. Institutional barriers included lack of knowledge of services, economic factors, lack of trust by many African Americans in the health care system, and lack of ethnic diversity among health care staff. Results also included many recommendations for dismantling these barriers, which are summarized in the Discussion.

Cultural Barriers

Differences in Values Regarding Medical Care. Participants reported African American values regarding medical care that differ from hospice philosophy, stating that many African Americans do not agree with the hospice philosophy of palliative care in the home. Participants described a preference for life-sustaining treatment (chemotherapy, resuscitation, life support, artificial nutrition, and hydration) as opposed to palliative care. African Americans often prefer not to plan for death (that is, legal wills, living wills, funeral plans, DNR orders, powers of attorney, plans for dependents, and so forth). Participants stated that there is a cultural belief system opposed to accepting terminality, planning for it, or discussing it with others. They described a long cultural tradition of using home remedies rather than going to a doctor. Finally, participants reported a cultural value that one's own people—church and family—should provide care in terminal illness, rather than strangers.

Differences in Spiritual Beliefs. Participants stated that many African Americans would rather pray for a miracle than accept terminality. They also explained that acceptance of terminality in this culture, while everyone around the patient is praying for a miracle, would be seen as a lack of faith. Finally, they reported a belief that God determines whether you live or die, not medical treatment or the lack of it.

Institutional Barriers

Lack of Knowledge of Services. Most of the African American pastor participants themselves were not familiar with hospice. One of the participants emphasized that if the pastors, on whom people rely for advice if a family member is dying, are unaware of hospice, it is highly unlikely that the African American community in general would be aware of hospice care.

Economic Factors. The respondents indicated that many African Americans do not have health insurance and do not believe they can afford hospice care.

Lack of Trust by African Americans in the Health Care System. Respondents thought that African Americans, especially elderly African Americans, have a lack of trust in the health care system. They reported that the African American community is aware of the infamous Tuskegee study in which African American men with syphilis were observed through the course of their illness without being offered treatment. One respondent indicated a reluctance to seek medical treatment, lest he or she "end up being a guinea pig in one of their experiments." Other respondents indicated awareness of neglectful and inhumane treatment in public health care facilities that provide care for poor people. As mentioned earlier, there was a sense that many African Americans would rather care for themselves at home with home remedies or pray for a miracle than seek health care from the health care system.

Lack of Diversity among Health Care Staff. Participants reported that fears of the health care system are compounded by the lack of diversity among health care staff. There was strong concern expressed by the pastors about the lack or complete absence of African American staff working for local health care providers. There was a concern that African American patients have a "friendly face" to comfort them and share an understanding of cultural differences and fears.

Consistent with the inductive method of inquiry, we developed a hypothesis on the basis of the qualitative conclusions: Barriers to hospice access and use exist to a greater degree in the African American population than in the European American population. This hypothesis was tested in the quantitative study described below.

Quantitative Study

The purpose of the quantitative portion of the study was to test the above research hypothesis statistically. A sample of 127 respondents was recruited to accomplish this, including hospice patients, churchgoers, and non-churchgoers. Hospice patients were recruited from four volunteer home hospices in the East, Southeast, and Midwest, and from one inpatient hospice in the Midwest. Churchgoers and non-churchgoers were recruited from a midwestern city of 100,000 population. An attempt was made to recruit equal numbers of hospice patients, churchgoers, and non-churchgoers, and equal numbers of African Americans and European Americans in each subgroup. Difficulty in recruiting African Americans and hospice patients, however, resulted in fewer respondents as well as a lack of probability sampling for these subgroups. African American churchgoers were recruited from the Protestant and Catholic congregations of the pastors who participated in the qualitative phase of the study. African American non-churchgoers were recruited from the telephone book and from a housing development in the same community. European American churchgoers and non-churchgoers were randomly selected from the rolls of one Protestant church and from the phone book in the same midwestern community.

The rationale for choosing respondents from church rolls was based on the importance of the church in African American society. First, we considered it important to have the help of the pastors in recruiting the African American sample. Second, we hoped that the sample of churchgoers would represent the traditional

African American perspective, which according to the literature is held by the vast majority of African Americans. We also were interested in learning the views of African Americans who do not attend church; thus, an attempt was made to control for the influence of church attendance by including subsamples of both churchgoers and non-churchgoers. The selection criteria for the subsample of non-churchgoers consisted of having attended church three or fewer times during the previous year. The rationale for this criterion was that many African Americans, who are not otherwise involved in churches, nevertheless attend church three times during the year to celebrate major holidays—Christmas, Easter, and Mother's Day.

The questionnaires were either read to respondents or self-administered, depending on their physical or reading ability. Two measures developed for this study were used—The Hospice Barriers Scale and The Hospice Values Scale. The Hospice Barriers Scale lists statements representing barriers to hospice care, with respondents circling "agree" or "disagree." Items included in this scale were derived from major themes resulting from the qualitative phase of this study. The scale itself was not tested for validity, but the barriers that made up the qualitative conclusions were taken to the African American pastors for their input. All participants agreed that these were the barriers to hospice access. The scale was tested for reliability (Cronbach's alpha = .64).

The Hospice Values Scale is a Likert-type scale that measures the extent to which respondents agree or disagree with statements representing the hospice philosophy regarding medical treatment in terminal illness. This scale was developed by the senior author for previous research (Ita, 1995–96), and has not been tested for validity, other than seeking feedback from colleagues regarding face validity. Reliability was tested (Cronbach's alpha = .75).

As mentioned above, ethnicity, hospice status (whether a hospice patient), and church attendance (whether a churchgoer) were controlled for through sampling. In addition, the demographic variables of gender, education, age, and income also were included to test for any possible effects.

Quantitative testing supported the research hypothesis—that barriers to hospice existed to a greater degree in African American than in European American respondents. Multiple regression indicated that ethnicity predicted the Hospice Barriers Scale score—African Americans had a higher mean score than European Americans. This result was true regardless of their gender, education, age, income, or hospice status ($R^2 = .18$, $F = 4.28$, $p = .000$). Higher income also predicted the level of hospice barriers, regardless of ethnicity—higher income predicted a lower score on the Hospice Barriers Scale (Table 1).

In addition to multiple regression on the Hospice Barriers Scale score, a second multiple

Table 1

Predictors of Hospice Barriers Scale and Hospice Values Scale Scores

	Hospice Barriers Scale			Hospice Values Scale		
Variable	**Beta**	***t***	***p***	**Beta**	***t***	***p***
Whether a hospice patient	.017	.156	.438	.260	2.753	.004
Ethnicity	.216	2.378	.010	–.401	–4.967	.000
Age	–.053	–.529	.299	–.007	–.074	.470
Education	–.124	1.338	.092	–.259	–3.144	.001
Income	.244	–2.617	.005	–.048	–.580	.282
Gender	–.080	–.948	.172	.008	–.112	.456

NOTES: Hospice Barriers Scale model statistics: $R^2 = .176$, $F = 4.280$, $p = .000$ one-tailed; Hospice Values Scale model statistics: $R^2 = .346$, $F = 10.591$, $p = .000$ one-tailed.
Variables were coded as follows: hospice patient = 1, African American = 1, female = 1.

regression test was conducted regarding effects of the same variables on the Hospice Values Scale score. In this test, ethnicity predicted the Hospice Values Scale score—African Americans disagreed with hospice philosophy. This again held true regardless of gender, education, age, income, or hospice status. Hospice status and level of education also predicted the Hospice Values Score, regardless of ethnicity ($R^2 = .346$, $F = 10.591$, and $p = .000$). Hospice patients and those with a higher level of education held values more similar to hospice philosophy.

Three *t* tests also were conducted to test for any possible effects of patient status, inpatient status, and church attendance. Results revealed the following:

- Patient Status—There was no difference on hospice barriers based on whether the respondent was a hospice patient ($t(125) = 1.397$, $p = .082$). As expected, however, there were significant differences in hospice values, with hospice patients having values more similar to hospice philosophy ($t(125) = 4.992$, $p = .000$).
- Inpatient Status—Whether the patient was an inpatient or home hospice patient did not influence the score on hospice barriers [$t(40) = 1.449$, $p = .155$] or hospice values [$t(40) = -1.252$, $p = .218$].
- Church Attendance—*t* tests were conducted to test for differences among the nonhospice patients only ($n = 85$), based on church attendance. Results indicated that church attendance did not predict differences regarding hospice barriers [$t(83) = -.519$, $p = .302$]. Church attendance did predict differences regarding hospice values [$t(83) = -5.036$, $p = .000$], with non-churchgoers holding values more similar to hospice philosophy.

Discussion

When considering the results of this study, it must be kept in mind that much of the African American churchgoing sample was selected from churches with a traditional religious perspective and will not reflect the views of more nontraditional African Americans. The small, nonprobability sample prevents generalizing even to the traditional African American population. Results of this study are consistent with literature about barriers to African Americans' access to hospice, however, documenting explanations presented in nonempirical discussion papers, providing a study directly with African Americans, and addressing a gap in our knowledge about the influence of African American religious beliefs on hospice access and use. Differences were found on hospice barriers and hospice values by ethnicity, even when controlling for a number of other variables. The demographic variables of income and education did influence barriers and values, supporting assertions in the literature about the influence of socioeconomic status on African American belief systems. Perhaps a larger sample would have produced a larger influence of demographic variables, but the literature also provides evidence of persistent negative African American views of the health care system regardless of socioeconomic status.

Perhaps because the measures in this study were driven by perspectives of respondents, the study did not examine policy issues at the state and private managed-care organization levels. In addition, reliability statistics for the Hospice Barriers Scale were not impressive ($\alpha = .64$). Further research is needed to clarify the influence of policy on hospice access and use barriers and to further develop measures of hospice barriers.

Implications for Social Work Practice

The model of participatory action research used in this project has several implications for practice. Such a practitioner–researcher–client partnership can benefit all involved. Practitioners often face great time and resource constraints that make it difficult for them to implement macro-level interventions. These constraints may be a source of frustration when the effects of larger social forces limit the impact of micro-level interventions. Practitioners may welcome a partnership with researchers who have resources to help them address a social problem on the community level. At the same time researchers may welcome practitioners' input about practice problems and help in facilitating access to data. Finally, the major purpose of participatory action research is to promote better services for clients by seeking their input about social problems and then using this input to influence social policy.

In this project, most African American respondents, especially those with lower socioeconomic status, expressed disagreement with hospice philosophy. Their spiritual beliefs precluded an acceptance of death. They preferred not to talk about death or to plan for it. They preferred not to be involved in the health care system, but rather to be cared for by their own people. They expressed agreement with the Hospice Barriers Scale item, "If I were dying, I would rather turn to my church and family than a hospice." Some might argue, based on this, that if African American people do not want hospice, it should not be forced on them.

We agree, nevertheless, with African American leaders who have emphasized a need for hospice care in their communities. Rather than concluding that African American culture and hospice philosophy have irreconcilable differences, we would urge the hospice community to find ways to adapt hospice to the needs of African Americans. As hospice moves toward the 21st century, it will need to learn how to reach this population more effectively.

This project indicates a need for social work practice with African Americans that honors diversity of belief, consistent with a growing body of social work literature calling for spiritually sensitive practice (Canda, 1988; Cowley, 1993; Smith, 1995). We must move beyond the ethnocentricity that characterizes African American beliefs as pessimistic and fatalistic, and views their traditional religious orientation with condescending amusement rather than respect.

We believe areas of convergence may be found between hospice philosophy and traditional African American perspectives. Rather than viewing their stoicism in the face of death, and reliance on God's will as "resignation," one might interpret these as an ability to transcend individual situations (Creel, 1991) and to accept one's own death without fear. Some African Americans may feel that since God is in charge, life-sustaining treatment may not determine whether one lives or dies. These views are consistent with the hospice philosophy of acceptance of death without great fear and of preference for palliative rather than curative care. The large supportive family network (Dowd et al., 1998) lends itself to the family support needed at home during hospice care, but Medicare regulations need to be changed to reflect the lack of full-time caregivers in the home. Considering that the African American church is the major social institution for the majority of African Americans and that pastors represent the leadership of this institution, it is reasonable to think that efforts toward social action and public education will be more successful if conducted collaboratively with pastors (Pipes, 1981) and organized through the church (Griffin & Bratton, 1995; Harris et al., 1996).

Recommendations for dismantling the barriers to hospice care for African Americans should incorporate the following:

- Respect cultural differences regarding medical treatment preferences
- Provide facts about reality of life-sustaining treatment, equal quality, and lower cost of hospice care
- Look for areas of convergence between hospice philosophy and African American beliefs
- Present hospice as compatible with caring for one's own, death as homecoming, God's will
- Conduct public education campaigns—television, community festivals, newsletters, church presentations
- Use churches as referral sources
- Develop programs to follow patients from active treatment to palliative care.
- Provide hospice care to African Americans in nursing homes.
- Train African American pastors to serve as community representatives.
- Keep patient and family informed, seek their input about every aspect of the treatment plan.
- Use realistic, practical language rather than communicating in a sterile and mechanical way.
- Acknowledge that there may be mistrust; address the issue directly rather than ignoring it.
- Involve African American pastors on boards of directors of hospices.

- Eliminate or make accessible the Clinical Pastoral Education requirement for hospital chaplains.
- Actively recruit African Americans for full-time positions as hospice chaplains and other staff. ■

References

Burrs, F. A. (1995). The African American experience: Breaking the barriers to hospices. *Hospice Journal, 10*(2), 15–18.

Canda, E. (1988). Spirituality, religious diversity, and social work practice. *Social Casework, 69,* 238–247.

Cooper-Lewter, N., & Mitchell, H. (1992). *Soul theology: The heart of American black culture.* Nashville: Abingdon Press.

Cowley, A. (1993). Transpersonal social work: A theory for the 1990s. *Social Work, 38,* 527–534.

Creel, M. (1991). Gullah attitudes toward life and death. In J. Holloway (Ed.), *Africanisms in American culture.* Bloomington: Indiana University Press.

Dignan, M., Michielutte, R., Sharp, P., Young, L., & Daniels, L. A. (1991). Use of process evaluation to guide health education in Forsyth County's project to prevent cervical cancer. *Public Health Reports, 106*(1), 73–77.

Dowd, S., Poole, V., Davidhizar, R., & Giger, J. (1998). Death, dying and grief in a transcultural context: Application of the Giger and Davidhizar assessment model. *Hospice Journal, 13*(4), 33–56.

Frazier, E. F., & Lincoln, C. E. (1974). *The Negro church in America/The Black Church since Frazier.* New York: Schocken Books.

Gallup Organization. (1997). *Special reports: Black/white relations in the United States.* Princeton, NJ: Author.

Glaser, B., & Strauss, A. (1967). *Discovery of grounded theory: Strategies for qualitative research.* Chicago: Aldine.

Gordon, A. K. (1995). Deterrents to access and service for blacks and Hispanics: The Medicare hospice benefit, healthcare utilization, and cultural barriers. *Hospice Journal, 10*(2), 65–83.

Gordon, A. K., & Rooney, A. (1984). Hospice and the family: A systems approach to assessment. *American Journal of Hospice Care, 1*(1), 31–33.

Griffin, L., & Bratton, L. (1995). Fewer black kidney donors: What's the problem? *Social Work in Health Care, 22*(2), 19–42.

Harper, B. C. (1990, Spring). Doing the right thing: Three strategies for increasing minority involvement. *Hospice,* pp. 14–15.

Harper, B. C. (1995). Report from the National Task Force on Access to Hospice Care by Minority Groups. *Hospice Journal, 10*(2), 1–9.

Harris, Y., Gorelick, P. B., Samuels, P., & Bempong, I. (1996). Why African Americans may not be participating in clinical trials. *Journal of the National Medical Association, 88,* 630–634.

Harwood, A. (Ed.). (1981). *Ethnicity and medical care.* Cambridge, MA: Harvard University Press.

Heckler, M. (1985). *Report of the Secretary's Task Force on Black and Minority Health* (Vol. 1, Executive Summary, U.S. Department of Health and Human Services). Washington, DC: U.S. Government Printing Office.

Hick, S. (1997). Participatory research: An approach for structural social workers. *Journal of Progressive Human Services, 8*(2), 63–78.

Infeld, D. L., Crum, G. E., & Koshuta, M. A. (1990). Characteristics of patients in a long-term care hospice setting. *Hospice Journal, 6*(4), 81–104.

Ita, D. (1995–96). Testing of a causal model: Acceptance of death in hospice patients. *Omega, 32*(2), 81–92.

Kalish, R., & Reynolds, D. (1976). *Death and ethnicity: A psychocultural study.* Farmingdale, NY: Baywood.

Klessig, J. (1992). The effect of values and culture on life-support decisions. *Western Journal of Medicine, 157,* 315–322.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage Publications.

Lowe, J., Barg, F., & Bernstein, M. (1995). Educating African-Americans about cancer prevention and detection: A review of the literature. *Social Work in Health Care, 21*(4), 17–36.

Lundgren, L. M., & Chen, S-P. C. (1986). Hospice: Concept and implementation in the black community. *Journal of Community Health Nursing, 3,* 137–144.

Mailick, M. D., Holden, G., & Walther, V. (1994). Coping with childhood asthma: Caretakers' views. *Health & Social Work, 19,* 103–111.

Malekoff, A. (1994). Action research: An approach to preventing substance abuse and promoting social competency. *Health & Social Work, 19,* 46–53.

Martinez-Brawley, E., & Delevan, S. (1993). Centralizing management and decentralizing services: An alternative approach. *Administration in Social Work, 17*(1), 81–102.

Miller, K., Miller, M., & Single, N. (1997). Barriers to hospice care: Family physicians' perceptions. *Hospice Journal, 12*(4), 29–41.

Mor, V., Hendershot, G., & Cryan, C. (1989). Awareness of hospice services: Results of a national survey. *Public Health Reports, 104,* 178–182.

National Hospice Organization. (1995). *Hospice fact sheet.* Arlington, VA: Author.

Neighbors, H. W., & Jackson, J. S. (1987). Barriers to medical care among adult blacks: What happens to the uninsured? *Journal of the National Medical Association, 79,* 489–493.

Neubauer, B. J., & Hamilton, C. L. (1990). Racial differences in attitudes toward hospice care. *Hospice Journal, 6*(1), 37–48.

Nobles, W. (1974). Africanity: Its role in black families. *Black Scholar, 5*(9), 10–17.

Penuel, W., & Freeman, T. (1997). Participatory action research in youth programming: A theory in use. *Child and Youth Care Forum, 26*(3), 175-185.

Pipes, W. (1981). Old-time religion: Benches can't say "Amen." In H. McAdoo (Ed.), *Black families* (pp. 54–76). Beverly Hills, CA: Sage Publications.

Raboteau, A. (1978). *Slave religion: The "Invisible Institution" in the antebellum South.* New York: Oxford University Press.

Rana, S., Knasel, A., & Haddy, T. (1992). Cancer knowledge and attitudes of African American and white adolescents: A comparison of two secondary schools. *Journal of the Association for Minority Physicians, 3*(1), 13–16.

Rapp, C., Shera, W., & Kisthardt, W. (1993). Research strategies for consumer empowerment of people with severe mental illness. *Social Work, 38,* 727–735.

Sarri, R., & Sarri, C. (1992). Organizational and community change through participatory action research. *Administration in Social Work, 16*(3/4), 99–22.

Smith, E. (1995). Addressing the psychospiritual distress of death as reality: A transpersonal approach. *Social Work, 40,* 402–412.

Wagner, D. (1991). Reviving the action research model: Combining case and cause with dislocated workers. *Social Work, 36,* 477–482.

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