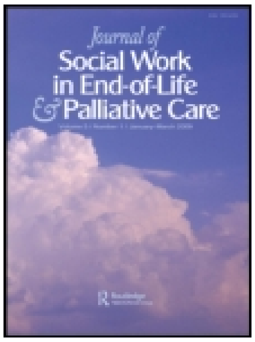

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PEER-REVIEWED PAPERS

What Matters to Older African Americans Facing End-of-Life Decisions? A Focus Group Study

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ABSTRACT. *Background*: To better understand what matters to African American elders who are faced with issues of death, dying, and end-of-life care, a qualitative study was conducted to elicit their perspective.

Methods: Focus groups were convened across the state of Connecticut. A total of 196 individuals participated in the 90-minute interview sessions. Using an interview guide, a trained moderator conducted the racially homogeneous discussion groups. Transcriptions of the group narratives with 22 older African Americans were coded to identify themes. Data were organized and analyzed using NUD-IST 4 and constant comparative method of qualitative data analysis.

Results: Five major themes emerged from the focus group data on older African Americans: (1) spirituality, (2) burden on family, (3) trust, (4) health insurance coverage, and (5) cultural concerns.

Conclusion: Recommendations are made for outreach education, involvement of informal helpers, and a level of acceptability in practice for diverse care needs.

KEYWORDS. End-of-life, African American elders, focus groups, death and dying

Although research has documented improvements in end-of-life care over the past decade, many older patients and their family members still report dissatisfaction with the quality of their care (Danis, Patrick, Southerland, & Green, 1988; Dawson, 1991; Field & Cassel, 1997; SUPPORT Principal Investigators, 1995). The literature on the quality of end-of-life care for African American patients reveals particular concerns in end-of-life care. According to several studies, African American elders are less likely than White elders to seek and to receive hospice and palliative care (Crawley, Marshall, Lo, & Koenig, 2002; McKinley, Garrett, Evans, & Danis, 1996; Reese, Ahern, Nair, O'Faire, & Warren, 1999; Garrett, Harris, Norburn, & Danis, 1993; NHPCO, 2001) less likely to receive adequate pain management (Anderson, Mendoza, Valero, Richman, Russell, & Hurley et al., 2000), and more likely to experience poor physician-patient communication (NHPCO, 2001; Burr, 1995; Caralis, Davis, Wright, & Marcial, 1993; Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000; Tulsky, Cassileth, & Bennett, 1997).

The absence of end-of-life services such as these is linked to poor quality care (Field & Cassel, 1997). Moreover, it characterizes a less than desirable dying experience (Hill & Shirley, 1992). Several studies have helped define key components of what might be termed a "good death" (Bradley, Curry, Williams, Van Doorn, Fried, & Fortinsky et al., 2002; Clark & Seymour, 1999; Emanuel & Emanuel, 1998; Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000), but these studies have typically lacked representation of the African American voice in articulating these components. Tong and colleagues (2003) looked at minority and non-minority groups as defined by religious affiliation to explore good death. This data did not focus specifically on race differences in end-of-life decisions. Yet, other studies (Dula, 1994; Caralis, Davis, Wright, & Marcial, 1996) have emphasized the need to understand the view of African Americans who are most likely to underutilize formal services for palliative care at end of life.

In the few studies that have examined African Americans' attitudes toward and acceptance of medical care, it has been noted that cultural factors including spirituality (Kumasaka & Miles, 1996), trust (Dula, 1994), and the perception of suffering (Black & Rubinstein, 2004; Johnson, 1992) affect health care decision-making. Although these studies addressed health care behaviors in general, and not specifically treatment at the end of life, they do highlight the influence that culture can have on beliefs and value systems. Moreover, these differences can manifest in various expectations about death and dying, role of the practitioner, the role of the family, and general preferences for care (Crawley, Marshall, Lo, & Koenig, 2002). The present study identifies themes that characterize what matters to African American elders who are faced with issues of death, dying and end-of-life care. Recommendations for improving care to the dying are made.

METHODS

Sample

The research was part of a larger study conducted by the Connecticut Coalition to Improve End-of-Life Care. Other end-of-life topics have been addressed with this rich data set, and have been reported elsewhere (Tong, McGraw, Dobihal, Baggish, Cherlin, & Bradley, 2003; McGraw, Dobihal, Baggish, & Bradley, 2002). The Coalition, which comprised 100 members representing community residents and more than 30 organizations and agencies, had as its charge the development of a comprehensive approach to improving the care of the dying in the state. In the larger study, 28 focus groups (with a total of 196 participants) were formed through a purposeful strategy designed to include individuals from various age groups as well as religious, ethnic and professional backgrounds. Participants were recruited from several types of organizations including senior centers, senior housing facilities, groups of religious leaders and institutions.

Some focus groups were racially homogeneous with African Americans. Two of which consisted of older African Americans (n = 22) and thus form the basis of the present inquiry. The focus group sessions were held in urban community centers in the Greater Hartford, Connecticut area in 1999. All participants in the present report self-identified as African Americans, were English-speaking and none had a diagnosis of dementia. The sample was approximately two-thirds female (n = 15) and one-third male (n = 7), with a median age of 64. Although no data was gathered on income for the participants, the sample was drawn from urban neighborhoods that tend to have moderately low to low-income households. Given the fact that many older African Americans live in resource-deprived communities (Taylor, Chatters, & Taylor, 1993), we felt that the sample frame was appropriate for exploration of this topic.

Data Collection

The focus group data collection method has been used in medical literature to explore various healthcare issues (Leape, Freshour, & Yntema et al., 1991; Morgan, 1994; Shmerling, Schattner, & Piterman, 1993). As recommended by experts in qualitative research (Krueger, 1994; Miles & Huberman, 1994; Mays & Pope, 2000), several methods were employed to enhance the validity and reliability of the findings, including use of a consistent discussion guide, and audiotaping and professional transcription of all focus group data. The standard discussion guide was used to guide the discussion about end-of-life beliefs, attitudes, and preferences [See Box 1 for Sample Questions].

BOX 1. SAMPLE FOCUS GROUP QUESTIONS

- Imagine that you were told that you could plan ahead for a time when you might be faced with an illness that could not be cured. What would be important for you in this planning?
- What if you had an illness that could not be cured, and you were unconscious/in a coma, and could not make decisions about your care. Would you want to be kept alive with the help of machines? Why? Why not?
- What do you think would worry you the most if you were faced with an illness that you were told could not be cured?
- Can you think about a time when you were effected by someone else's death or dying experience? What was that like? Please share good and/or bad experiences?
- What would tell care providers, such as social workers, doctors, nurses, clergy, and others, about how to help older African Americans like yourself, to get the care that you want and need when faced with death and dying?

Data Analysis

The first step in data analysis involved collecting, describing, and transcribing the raw data. Next, the researcher and two graduate research assistants coded the data. A "start list" of themes (Miles & Huberman, 1994; Glaser & Strauss, 1967; Crabtree & Miller, 1999) was created after the initial reading and review of the transcripts. Throughout this process, attention was devoted to sorting and coding of the words, themes, and meanings and what were construed as findings (Krueger, 1994).

Constant comparison analysis (Strauss & Corbin, 1990) was used to analyze the data. The procedure for such analysis involved identifying the major themes, and subthemes, then building the subthemes and linking them to each other. A coding paradigm model links subcategories to a category in a set of relations denoting phenomenon, context, and consequences. To enhance objectivity and reduce threats to validity and reliability in the development of categories, the following steps were taken: The first author conducted an independent analysis of the focus group transcripts. A "start list" was developed from the initial reading of the transcripts and used to code all subsequent transcripts as suggested by Strauss and Corbin (1990) in grounded theory methods. Research assistants participated in coding and comparing of respondents' statements. Efforts were made to reach agreement in coding and categorizing the various themes that emerged from the data.

RESULTS

The participants in this research reported various beliefs and concerns that influence end-of-life experiences. Based on the analysis of focus group discussion data, the following themes emerged (Box 2) as indicative of what matters to older African Americans when faced with death, dying and end-of-life care decisions.

BOX 2. COMMON THEMES OF WHAT MATTERS TO OLDER AFRICAN AMERICANS FACING END-OF-LIFE DECISIONS

- Theme 1: Spirituality
- Theme 2: Burden on Family Members
- Theme 3: Trust
- Theme 4: Health Insurance Coverage
- Theme 5: Cultural Concerns

THEME 1: SPIRITUALITY

The African American elders in this study frequently used spiritual references to characterize how they cope with illness and death. Empirical evidence and practice wisdom strongly suggest that the experience of living with illness increases an individual's awareness of the spiritual part of the self (Taylor, 2000). In discussing the dying process and preparation for death, these respondents provided spiritual insight about their belief in a higher power. For example one respondent, reflecting on death and God's dominance, expressed: *"There is no way to know when you're going to die and it's all in God's hands."* Another commented, *"I pray daily that if I die, I hope God takes me quickly."*

Spirituality, as expressed by these older adults can be best understood through the spiritual view presented by Crawley and colleagues (2000), which explains that African Americans view death as a transition and not as a final state. The belief is that during the dying process, one is to be hopeful because he/she is being prepared for a spiritual life, beyond earth. There was group consensus that a belief in God helped them to overcome fears as reported here: *"I don't worry about when I'm going to die. I'm prepared to meet my maker."*

Participants also described how religious rites were important at the time of imminent death, regardless of one's church attendance during life: *"My husband had a stroke and was in and out of the hospital. He was a church man, but never went to church. He asked to be baptized. I got my pastor to come and right after that, he passed away. So it wasn't suffering. He just wanted to be baptized before he died."* This comment suggests that spiritual practices are important in the preparations for the dying person to "pass on." Belief in God enables African Americans find hope when they are facing death. For this group of older African Americans, clearly death was not viewed as a final state.

These participants also explained how spirituality influenced their perceptions of what the dying person experiences and what is appropriate behavior during that process. There was a sense that the dying person could be well aware of their loved one's presence during this process. Therefore, death was a time to come together in the presence of the dying to show support. One person commented and others agreed, *"When a person is in a coma, they can hear the people around them talking."* Further comments included, *"My neighbor [had been] in a coma and I asked her what it was like? She told me that she heard every word and knew all the people in the room, all the time. Then, she got well and was well for many, many years. You just have to put your faith in the Lord."* Be at peace because, *"The good Lord is not going to put more on you than you can bear."* This comment is an example of what others (Crawley et al., 2000; Kumasaka & Miles, 1996) have linked to traditional religious views among many African Americans about death. The view is that pain and suffering is to be endured as a part of spiritual commitment. The African Americans in the present study were reticent about questioning their spiritual beliefs, denying that they did so. This was exemplified by the comment of one respondent: *"I don't question God. Never." "When my sister breathed her last sigh, I was happy with that. Because I knew she had gone on to be with the Lord."*

THEME 2: BURDEN ON FAMILY

The elderly participants were concerned about the burden that might be experienced by their loved ones during their dying process. They did not want to see them in grief and distress, wrought by medical decision-making, nor faced with financial stress as expressed here: *"I don't* *want my family sitting around grieving over my death."* Another elder commented: "*They don't need to worry about what to do with me when it's time to go. The doctor may come in and say, she's on her way out, but he's not going to be able to tell them she won't be here tomorrow, this is her last day. So, there's no need to worry your children with thinking about what to do at that point. What will happen, will happen in due time."* This woman's view is that care providers know not "the final hour nor the day," and therefore should not force end-of-life conversation upon family members, prematurely. A man said: *"I'm going to make sure I have enough money to have a decent funeral when I'm gone. My wife [and them] won't have to worry about paying it. I got it all taken care of."* Then a woman added: *"I've already told my son all the things to do so that when I'm gone, he'll know exactly where everything is and how everything goes [with the family].*"

THEME 3: TRUST

Although there was no specific question about trust, this theme was pervasive throughout the discussion. Many specifically wanted family in the room with them when being seen by medical staff. Some participants expressed concern that the doctor might withdraw or withhold treatment too soon.

One woman commented, *"When my sister had a very massive stroke and the doctor said to me that she was not going to live. It was just a matter of time. And he wanted to know from me what to do about the life saving machine and all that. And I said, well when she wakes up, ask her [what she would like to do]."* According to this report, the removal of life support would have been premature. The respondent's sister lived on. Another person added, *"My niece about two year ago. She got sick. . . . She was really sick. We had to put her on life support. And we thought she was going to be gone a couple of times. So they [the doctors] decided they was going to disconnect the machines and things she had on her. She [the sister] came out of it and she's walking around now. I don't know what would have happened if they'd taken them [life supports] off."* Trust was also pertinent to participants' views concerning pain management and whether they would receive optimal care. Participants expressed concerns about being ignored in care settings and not being given adequate medication for pain. *"I went to the hospital two weeks ago. My cousin was out there and she was in a lot of pain. I asked the nurse to give her something to ease her pain. She [the nurse] said, she can't have any right* *now. We were begging her to give something."* One person termed it "racist" and added *"Sometimes we who are not white have less coordination of services when we're in the hospital or in the clinics."* These comments are important to note because evidence (Caralis, Davis, Wright, & Marcial, 1993; Crawley et al., 2000) suggests cultural mistrust influences attitudes and behaviors toward end-of-life care decision-making.

In commentary about palliative care and African Americans, Crawley (2001) has made explicit statements about the less than optimal that these patients often receive. Furthermore, she argues that there is an enigma of inequities that is due "in part, to institutional racism" (p. 2).

THEME 4: HEALTH INSURANCE COVERAGE

In describing what is important to them, several participants revealed that they thought having health insurance coverage would determine whether they had a "good" death or not. The finding is strikingly distinct in that previous research on the domains of a good death (Hill & Shirley, 1992; Tong, McGraw, Dobihal, Baggish, Cherlin, & Bradley, 2003; Byock, 1996) that has not looked specifically at racially homogeneous groups, has not uncovered this sense of concern about the role of health insurance and its relevance to perceived quality of life at the end. These older African Americans felt that certain treatment options would not be available to them without health insurance. Therefore, one cannot have a "good" death without "good" insurance. A participant commented, *"I would say, God I know I'm going, so please let me have good insurance, so I won't have to suffer."*

Even though a person may be healthy with no need to see a doctor on a regular basis, it was believed to be important to have insurance coverage in the event there was a serious or terminal illness. A participant responded, *"If I do have to go in the hospital, I've already told my son what I want done; he knows everything. He knows about my [insurance] policies."* There was concern for those in their community who do not have insurance coverage. *"You had [at a time of medical crisis] good insurance, but what about those of us who do not have it? We're talking [about] the homeless; we're talking about low-income people and those on fixed incomes who don't have it? Those who don't have the insurance won't get the treatment." "When you've got insurance, its like gold, the sky is the limit."*

THEME 5: CULTURAL CONCERNS

In thinking about what a "good" death experience would be like, these older African Americans expressed their wishes to have family members and loved ones around them. There was consensus among this group of elders that it would be important to have extended family members at the bedside during death as reflected in this comment: *"My aunt was in a coma and she said, although she could not move or respond, she could hear and she knew that her family was visiting her." "You need somebody there who knows how you like things to go and that's gonna make sure it happens that way."* This need for family presence might also reflect underlying distrust of the health care system, as described earlier.

There was a sense of comfort in knowing that there would be people of their own race or ethnic group available to care for them during the time of death and dying. *"Usually black people are all one . . . if you don't belong to a church, then you have a friend. . . . We may disagree about things, but when there is a death they pull together to support one another." Another respondent added, "Very few people do not get any support from people within the black family."*

Participants' views about nutrition and hydration reflected a cultural element. One participant expressed a belief that people who are dying should certainly receive nutrition and hydration, as indicated by the following comment: *"When my husband was dying, I would come everyday to make sure he was eating and drinking. I didn't want him to be hungry at night. Believe me, some days I'm there for 4 hours on hot days and nobody, not an aide, a nurse or nobody, came in an offered the person next to him a drink of water."* African Americans may view the withholding or withdrawal of nutrition and hydration as giving up (Crawley, 2001). Even when formal care providers may deem such therapies as futile, collectively, African Americans have reported preferences for continuing this care (Blackhall, Frank, Murphy, Michel, Palmer, & Azen, 1999; Mebane, Oman, Kroonen, & Goldstein, 1999). Actively doing things for the dying had significance to the African American elders. A participant remarked with affirmative responses from other participants that, *"My family came every day, they brought flowers. Like I said, people don't visit the dying enough. In my family we visit and we sing with the [dying] and they enjoy it."*

Participants generally spoke about a "good" death as depending on one's spirituality and one's belief in God, although some questioned whether the clergy support desired was available to them when needed.

While one participant said, *"Most of us have ministers who will come around to the house to counsel the family,"* other participants voiced concerns of race influencing whether they received the clergy attention they desired: *"When I was in the hospital, the only people who got spiritual support from the hospital was the Catholics. I was in there 31 days and the priest used to always come around to various people. But, that priest, God bless him, he never said a word to me, bless me, nothing. And, they didn't have no other person that came around and offered those services all the 31 days that I was there. Only my minister and people from my church [came to me]; So, I didn't think that was good."*

Recommendations for Practitioners

Focus group participants made several recommendations for social workers to improve care for the dying based on what matters to them. Their recommendations were grouped into the categories of availability, accessibility, and acceptability of services.

Availability of Services. Participants described their feelings of being cut off from the information about available services that could assist them and their loved ones when faced with death. One person expressed, *"There's a lot of help out there that nobody tells you about."* Group members agreed and offered the recommendation that *"services should be out in the community at places that we go to like at the community center . . . not just at the hospital."* Some participants felt that family members should be informed as well because oftentimes family is engaged in coordination of care. This includes educating African Americans about end-of-life treatment options and the delivery of palliative care. *"They need to put the information out there because there is so much . . . that we don't know about." "Make it so that we can understand what we don't know." "I think maybe, if a group of people in our community could get together and tell us [that would be helpful]. I've learned a lot about what to do [when faced with death] from the people in this group today."* The availability of treatment options for a good death may be contingent upon one being appropriately informed about services.

Accessibility. While participants believed that health insurance was *"one sure way that they could have [access to] services"* when faced with end-of-life treatment decisions, several felt that social workers should go a step further to ensure access. For several participants, this meant allowing, *"family and other informal supporters"* to engage in the decision making. It was important for these older African Americans to be able to have someone whom they *"trust"* to help them to understand medical information and to affirm their treatment choices. This may be a neighbor, a church member, a friend, or some other informal helper. When medical services narrowly define family, and set limits on who can serve as a patient representative, these African Americans report that they are less likely to utilize the care. Accessibility for this population includes access for extended family members and other informal helpers in the caring process.

Acceptability. The degree to which one perceives being respected in a health care setting can determine where he or she has a good death. Participants commented that they would not utilize services in a setting where they did not feel as though there was equity across patients' racial groups. Historically, African Americans have been denied services because of their race and currently there is pervasive fear and concern among this population that they will be treated disparagingly, especially in medical care settings (Burr, 1995; Dula, 1994; Williams, Neighbors, & Jackson, 2003). It was recommended that practitioners treat patients and their family members with genuineness, empathy, and inclusiveness. A participant sums this up by saying *"If you're going to stop in and talk to the white patients, by God, do the same for the black patients. He [clergy] never said a word to me, nothing. I didn't think that was 'good'."* Participants expressed their feelings of not being accepted as equal to their white counterparts in medical settings. They felt over looked or ignored in the care setting.

DISCUSSION

The common themes that emerged from these older African American's reports of what matters when they are faced with end-of-life decisions included: spirituality, burden on the family, trust, health insurance coverage, and cultural concerns. While it is important to identify what matters to elderly African Americans who are faced with end-of-life decisions, it is equally important to understand how a lack of attention to these areas can result in barriers that influence service utilization. Patients' preferences for care are often guided by personal values, assessment of probable outcomes, and perception of quality of life (Neubauer & Hamilton, 1990). What mattered to the participants in this study was influenced by past experiences with the medical system, information passed on from others in their community, and the lack of information they have about medical care over all.

The findings support earlier work that calls for more attention to improving end-of-life care services for African Americans (Burr, 1995; Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000; Dula, 1994). The data contributes to our understanding of the role of spirituality in dealing with death and terminal illness. There was a sense among the group that death is not final and that a relief from suffering would come once they "passed on." This spiritual connection caused them to not feel it was necessary to plan ahead or make decisions about how they would like to prepare for death.

Trust and lack of trust in care providers were salient issues for older African Americans faced with end-of-life care decisions, according to these study participants. Although the view on a 'good death' for this group is comprised of concerns for their spiritual needs and limited burden to family members, previous experiences associated with trust of the medical care system, insurance coverage, and the involvement of family in care practices seem to produce a culturally specific phenomena for these elders. These results are consistent with earlier qualitative and quantitative work illustrating the importance of culture (Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000) and preference for life-sustaining medical treatment at end of life (Fried & Bradley, 2003).

Participants described their observations that African American patients were sometimes treated disparagingly in medical settings. These experiences led them to believe that African American patients might not receive appropriate pain management and coordinated care. These elders expressed concern about the burdens that a death can have on family members. The burdens can cause family members to experience financial burden and emotional burden. Health insurance seemed to be viewed as possible mediator of care disparities.

Our findings indicate that older African Americans have end-of-life care concerns that can be addressed through social work intervention. First, social workers can take steps to build trust and rapport between patients. Acknowledging that African Americans, historically, have valued collectivism and extended family involvement (Carlton-LaNey, 2001), practitioners can begin by assessing informal support networks, and the patients' desire to include additional helpers in the care process. It is a good idea to have family and/or members of the informal support network engage in the relationship building with medical staff. Informal support and social networks can augment the overall level of care that patients receive at end of life (Bradley, Curry, Williams, Van Doorn, Fried, & Fortinsky et al., 2002). Good relationship-building skills are imperative.

Second, there is a need for end-of-life advance care planning education. Helping individuals to understand how advance directives are intended to improve quality of care is imperative. African Americans can be empowered to educate their own communities and to promote change in the perceptions of care at end of life with the help of culturally-competent social workers.

Lastly, the acceptability of services and the degree to which African Americans are likely to utilize end-of-life care hinges upon the provider's sensitivity to diverse spiritual needs, burden of care to the family, trust issues, lack of health coverage, and culturally distinct beliefs about death and dying [See Box 3].

BOX 3. RECOMMENDATIONS FOR SOCIAL WORK PRACTITIONERS

- Develop and implement outreach education to increase the availability of end-of-life care information in African American communities.
- Increase accessibility to services through the engagement of informal helpers in care process.
- Create a level of acceptability in practice for diverse spiritual needs, sensitivity to burden of care on family, trust issues, lack of health coverage, and culturally distinct beliefs about death and dying.

These data are consistent with data showing that African Americans tend to prefer life-sustaining interventions when faced with end-of-life decisions (Garrett, Harris, Norburn, & Danis, 1993; Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000). Primarily, preferences seem to be influenced by spiritual beliefs, and a lack of trust for the medical profession. It is also possible that African Americans are experiencing discrimination in health care setting based on race (Williams, Neighbors, & Jackson, 2003). The issues raised here call for an agenda to address the barriers to effective end-of-life care for African Americans. Whether deterrents to access and services exist beyond this racial group is an important question for future research. Community studies that examine racial/ethnic discrimination can point to key issues to be addressed by service providers (Gordan, 2003).

As a qualitative investigation, the results of this study can only generate hypotheses and not confirm them. The absence of certain findings is noteworthy. Although we included broad open-ended questions about the dying process and what mattered to this population, we found no patient who would prefer hospice or palliative care to hospital care. It is possible that such older African Americans exist but were not included in this study. Further research is needed to determine whether what matters to African American patients are consistent with the care they actually receive at end of life.

REFERENCES

Anderson, K. O., Mendoza, T. R., Valero, V., Richman, S. P., Russell, C., Hurley, J. et al. (2000). Minority cancer patients and their providers: Pain management, attitudes, and practice. *Cancer*, *88*, 1919-1929.

Black, H. K., & Rubinstein, R.L. (2004). Themes of suffering in later life. *Journal of Gerontology*, *59B*, S17-24.

Blackhall, L.J., Frank, G., Murphy, S.T., Michel, V., Palmer, J.M., & Azen, S.P. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine*, *48* (12), 1779-1789.

Bradley, E. H., Curry, L., Williams, C. S., Van Doorn, C., Fried, T. R., Fortinsky, R. et al. (2002). Social support and social networks in the last year of life. *Journal of Mental Health and Aging*, *8*, 7-18.

Bullock, K. (2004). Family social support. In P. J. Bomar (Eds.), *Promoting health in families: Applying family research and theory to nursing practice* (pp. 142-161). Philadelphia: Saunders/Elsevier.

Burr, F. A. (1995). The African American experience: Breaking the barriers to hospice. *Hospice Journal*, *19*, 15-18.

Byock, I. R. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine*, *12*, 237-253.

Caralis, P. V., Davis, B., Wright, K., & Marcial, E. (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *The Journal of Clinical Ethics*, *4*, 155-165.

Carlton-LaNey, I. B. (2001). *African American leadership: An empowerment tradition in social welfare history*. Washington, DC: NASW Press.

Clark, D., & Seymour, J. (1999). *Reflections on palliative care*. Buckingham, U.K.: Open University Press.

Crabtree, B. F., & Miller, W. L. (1999). *Doing qualitative research*. Thousand Oaks, California: Sage Publications.

Crawley, L., Payne, R., Bolden, J., Payne, T., Washington, P., & Williams, S. (2000). Palliative and end-of-life care in the African American Community. *The Journal of the American Medical Association*, *284*, 2518-2521.

Crawley, L. (2001). *Palliative care in African American communities*. Innovations in end-of-life care: An International Journal and Online Forum of Leaders in End-of-Life Care, *3* (5), *www.edc.org/lastacts*

Crawley, L. M., Marshall, P. A., Lo, B., & Koenig, B. A. (2002). Strategies for culturally effective end-of-life care. *Annals of internal medicine*, *136*, 673-679.

Danis, M., Patrick, D. L., Southerland, L. I., & Green, D. N. (1988). Patients' and families' preferences for medical intensive care, *The Journal of the American Medical Association*, *273*, 703-802.

Dawson, N. (1991). Need satisfaction in terminal care settings. *Social science medicine*, *32*, 83-87.

Dula, A. (1994). African American suspicion of the healthcare system is justified: What do we do about it? *Cambridge Quarterly of Healthcare Ethics*, *3*, 347-357.

Emanuel, E., J., & Emanuel, L., L. (1998). The promise of a good death. *The Lancet*, *351*, S21-29.

Field, M. J., & Cassel, C. K. (1997). *Approaching death: Improving care at the end. Institute of Medicine Report*. Washington, DC: National Academy Press.

Fried, T. R., & Bradley, E. H. (2003).What matters to seriously ill older persons making end-of-life treatment decisions?: A qualitative study. *Journal of Palliative Medicine*, *6*, 237-244.

Garrett, J., Harris, R., Norburn, J., & Danis, M. (1993). Life sustaining treatments during terminal illness: who wants? *Journal of General Internal Medicine*, *8*, 361-368.

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

Gordan, A. K. (1995). Deterrents to access and services for blacks and Hispanics: The Medicare Hospice Benefit, healthcare utilization, and cultural barriers. *Hospice Journal*, *10*, 65-83.

Hill, T. P., & Shirley, D. (1992). *A good death: Taking more control at the end of your life*. Reading, Massachusetts: Addison-Wesley.

Johnson, J. W. (1992). Go down death. In M. G. Secundy (Eds.), *Trials, tribulations, and celebrations: African American perspectives on health, illness, aging, and loss* (pp. 171-173). Yarmouth, Maine: Intercultural Press.

Krueger, R. A. (1994). *Focus groups, A practical guide for applied research*. Newbury Park, California: Sage.

Kumasaka, L., & Miles, A. (1996). My pain is God's will. *The American Journal of Nursing*, *96*, 45-47.

Leape, L. L., Freshour, M. A., Yntema, D. et al. (1991). Small-group judgment methods for determining resource-based relative values. *Medical Care*, *30*, S28-39.

Mays, N., & Pope, C. (2000). Qualitative research in health care. Assessing quality in qualitative research. *British Medical Journal*, *320*, 50-2.

McGraw, S. A., Dobihal, E., Baggish, R., & Bradley, E. H. (2002). How can we improve care at the end of life in Connecticut? Recommendations from focus groups. *Connecticut Medicine*, *11*, 655-664.

McKinley, E. D., Garrett, J. M., Evans, A. T., & Danis, M. (1996). Differences in end-of-life decision making among black and white ambulatory cancer patients. *Journal of General Internal Medicine*, *11*, 651-656.

Mebane, E.W., Oman, R.F., Kroonen, L.T., & Goldstein, M.K. (1999). The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making. *Journal of the American Geriatric Society*, *47* (5), 579-591.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks: Sage Publication.

Morgan, D. L. (1999). Doctor-caregiver relationships: An exploration using focus groups. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research* (pp.17-48). Newbury Park, California: Sage.

National Hospice and Palliative Care Organization. *Facts and figures on hospice care in America*. Retrieved December 3, 2001, from *http://www.nho.org/public/articles/index.cfm?cat=60*

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

Reese, D. J., Ahern, R. E., Nair, S., O'Faire, J. D., & Warren, C. (1999). Hospice access and use by African Americans: Addressing cultural and institutional barriers through participatory action research. *Social Work*, *44*, 549-559.

Shmerling, A., Schattner, P., & Piterman, L. (1993). Qualitative research in medical practice. *The Medical journal of Australia*, *158*, 619-622.

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, *132*, 825-832.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, California: Sage Publication.

Support Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients (SUPPORT). *Journal of the American Medical Association*, *274*, 1591-1598.

Taylor, E. J. (2000). Spiritual and ethical end-of-life concerns. In C. H. Yarbro, M. H. Frogge, M. Goodman, & S. L. Groenwald (Eds.), *Cancer Nursing: Principles and Practice* (pp. 1565-1578). Sudbury, Massachusetts: Jones & Bartlett.

Taylor, J.S., Chatters, L.M., & Taylor, R.J. (1993). *Aging in Black America*. Newbury Park, CA: Sage Publication.

Tong, E., McGraw, S. A., Dobihal, E., Baggish, R., Cherlin, E., & Bradley, E. H. (2003). What is a good death? Minority and non-minority perspectives. *Journal of Palliative Care*, *19*, 168-175.

Tulsky, J. A., Cassileth, B. R., & Bennett, C. L. (1997). The effect of ethnicity on ICU use and DNR order in hospitalized AIDS patients. *The Journal of Clinical Ethics*, *8*, 150-157.

Williams, D. R., Neighbors, H. W., & Jackson, J. S. Racial/ethnic discrimination and health: Findings from community studies. *The American Journal of Public Health*, *93*, 200-208.

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