



Older African Americans' Perceptions of the Congruence between Cultural Preferences for Care at the End of Life and Hospice Services Received

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Statistics

- Racial and ethnic inequality persists for hospice care
- Minority elders 65 + comprise about 13% of the general population
- Among 65+ hospice care patients, only 6% are minorities



Benefits of Hospice Care

- Better pain management for hospice patients than non-hospice patients
- Better quality of life and of death than non-hospice patients
- Emotional and spiritual support for patients and family caregivers



Previous Approaches & Knowledge



Previous Approaches

- Conduct opinion studies with minority individuals
- Conduct interviews and focus groups with caregivers of minority patients
- Secondary data analysis



Previous Findings

- Access Barriers

- Minority Elders' Preferences
 - EOL care preferences not consistent with hospice philosophy
 - *Cultural preferences in receiving health care*



Barriers to Access

- Lack of Health Insurance
- Limited Income
- Immigration Status
- Lack of Knowledge of Hospice Care
- Low Referral Rate by Physicians
- Other Logistical Barriers



Minority Elders' End of Life Care Preferences

- Differences in spiritual/religious beliefs
- Acculturation
- Attitudes toward EOL health care choices
- Family-centered culture of care
- Reluctance to burden families with receiving in-home services
- Mistrust and medical racism



Minority Elders' Cultural Preferences in Receiving Healthcare

- Lack of cultural diversity among health care providers
- Language Differences



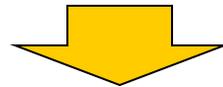
Research Gap

Understanding of
why terminally ill minority elders
do use hospice care



Limitations in Study Design

- Second-hand information
- Respondents not all hospice patients
- Only a few respondents terminally ill
- Secondary data analysis & opinion studies



Leads to a Need for a Prospective Study



Research Questions

*R1: Why do terminally ill
minority elders choose to use
hospice care?*



Research Questions

R2: What structural barriers do terminally ill minority elders face and how do they overcome them?



Research Questions

R3: What cultural preferences do they have in receiving health care services and what are their experiences like in having them respected by hospice staff?



Methods



Sampling Criteria

Purposive sampling of minority elders

- ~ Currently receiving hospice care
- ~ 50 years of age or older
- ~ Of racial or ethnic minority origin (other than non-Hispanic white)
- ~ English/Korean speaking
- ~ Deemed by hospice care provider as mentally competent to participate



Data Collection

- Face-to-face interviews
- Recruited from 3 hospice agencies
- Participant referrals made by hospice staff



Survey Development



Survey Instrument

- Section 1: Demographic and SES
- Section 2: Choice to receive hospice care
- Section 3: Structural barriers and ways to overcome them
- Section 4: Cultural preferences and experiences in having them respected



Quantitative Measures

- Gender
- Age
- Marital Status
- Religion
- Race/ethnicity
- Education
- Income
- Occupation
- Diagnosis



Qualitative Question 3

“Would you please talk about any traditions or values that are important to you when you receive health care services?”

“What are your experiences in having them respected by your hospice staff?”



Qualitative Question 3

Followed by questions on impacts of:

~ Diversity among health care providers



Data Analysis



Data Analysis

- Descriptive Statistics for Quantitative Data Analysis
- Content Analysis for Qualitative Data Analysis



Reliability

- Independent coding by two additional researchers followed by comparison and discussions to reach a consensus



Findings



Demographics

- Terminally ill African Americans
- Protestant
- Less than 12 years of education
- Low prestige job
- Majority (20 out of 28) of them under the Poverty Threshold



Themes

- Dying at home
- Independent decision-making
- Autonomy in daily life
- Unwillingness to be a burden
- Open Communication
- Relationships
(with family/friends, with hospice staff)



Dying at home

“I wanted to be home and I am going to die at home...”

“It (hospice) worked for me because I didn’t want to leave home. They (hospice staff) don’t tell me where I (should) stay. They are fine with me being here.”



Independent decision-making

“I decide what’s best for me. I ask for facts and think them over and make my own decision. When to have them (hospice staff) come in and what to take or what not. (I) need those pills and oxygen but not the hospital bed. It’s all upon my decision, and they (hospice staff) never push.”



Independent decision-making

“I can feel when a person is forcing things on me and when they force things on me, it makes me angry... I decide what I want and what I need. I've always been this way. Seeing doctors and what treatment I get or don't get, hospice or no hospice, it's no exception. You see, like the physical therapy, they (hospice staff) offered but the decision was mine, to go out there (hospice house) and get it or not. They (hospice staff) left it (decision-making) on me.”



Independent decision-making

“They (hospice staff) don’t try to force anything. Any of it. They let me decide. I feel good about it.”



Autonomy in daily life

“They asked if I needed them to come by and bathe me and shave me and stuff. I told them I don’t need that and I can do that myself. And I just need the nurse to come out and they just send the nurse and my social worker. I mean I don’t want to waste nobody’s time. If I can do it myself, that’s my job to do it. Somebody else come out here and do it for me when I can still do it - I don’t think it (is) right.”



Autonomy in daily life

“I’m sick sure enough, but I’m not helpless. I can walk up that street but once I get up to that little hill right up there, I have to stop and rest for a little while. But, I can still walk and when I go to the store, I walk a little bit further or I can drive that green car over there.”



Autonomy in daily life

“I appreciate their (hospice staff) worries about me being by myself here, but, I tell you what, I can hold on to the stove and can carry my stuff on wheels. I try to keep myself up and keep going.”



Autonomy in daily life: not respected

“There’s room for improvement if they had a program of exercise that they could pass on to the Hospice patients - especially those that request it. I know a bunch of folks would be just as glad to forget about it, but there are others of us that – excuse me, that would enjoy doing something besides walking around that church.”



Autonomy in daily life: not respected

“It looks to me, hospice is something that they put you in your house – in your house (to) just sit down and look at the walls and die. They (are) not making my life better. I know there are people that I know, they go to the YMCA. They go to different places. They have a center that they have transportation come and takes you there for activities to get you move.”



Unwillingness to be a burden

“I became a burden to him. They had to look out for me. The pain in my legs was so bad that I couldn’t sleep at night. They put me in the wheelchair and took me down to the ER. I really didn’t want to be a burden.”

“I’m asking for a volunteer because my granddaughter’s young but she stays in the house with me 24/7. It’s a hard job to do. They (hospice staff) understood and said they’ll get somebody.”



Open communication

“I just like, I feel about anybody – I mean if you want to tell me something, tell it to me. If you (are) not gonna be honest with me and tell me lies, don’t even mention it. If you are gonna tell me something bad, tell me something bad. If you are gonna tell me something good, tell me something good. I want to know. And don’t beat around the bush.”



Open communication

“They (hospice staff) don’t hold back nothing (anything) from me. They let me know what’s going on, and I appreciate it.”



Open communication

“You're the one who's feeling the pains and the problems, so you have to let them know what you feel, because they can't guess everything about you, so you have to let them know what's what. And, I let them know if I'm feeling bad or something.”



Open communication

“I love a person going to sit down, take some time to explain things to me. Just don’t close it out to me and then leave me hanging and I’m trying to figure out what’s what.”



Open communication: not respected

“I feel rejected when I think they (hospice staff) are hiding something from me. They try to look out for me...but I wish they are more open with me.”



Social support from family and friends

“That’s (having visitors) keeping me alive. I may be sick and weak but I really enjoy seeing them and talking with them. It gives me good energy and keeps my spirit up.”



Caring and friendly attitude from health care providers

“When people treat you like you’re a human-being that goes a long way with me.”

“It’s (hospice care) like family, better than family, better than family. They are, what I like is, they are ‘concerned’, ‘concerned’ about you, and they do their best to see about you. It’s what I (am) always looking for in doctors and nurses. They (hospice staff) do their very best to see about you.”



Dependability

“You know they always come the day they said they gonna come. And come in the morning and they gonna come - call when they gonna be late. Just in case my wife or somebody is here, they don’t have to wait on them coming. They call and let you know what time we (they are) coming. That means a lot when you receive care from somebody. My physical therapist (from hospice care), she does the same thing.”



Dependability: not respected

“I wish they could improve with answering their phones at late hours. They’re supposed to be at desk all time, somebody to pick up the phone all time, but, sometimes it’s hard to get them on the phone. I don’t want to be in no emergency if I can’t get nobody on the phone.”



Diversity among healthcare providers

- Disinterest
- No preference due to religious beliefs
- Competency more important
- Have previous knowledge on availability of black staff



Disinterest

“I’m a human being and they’re human beings, so I didn’t think it was necessary for me to ask that question.”

“I didn’t think about asking that, but I feel one might not be any nicer than the other. You find some nice and white and some nice and black. And just the opposite.”



No preference due to religious beliefs

“The color was not even a big interest to us. The color, race, or the local...as long as they were people who would enter the spirit of Christ.”



Competency more important

“I didn’t think it mattered as long (as) you knew you’re getting good care from someone who knows what they’re doing. If we (are) black or white or what, it don’t made no difference.”



Conclusion



Limitations

- African Americans only
- United States citizens only
- Respondents willing to participate
- Cognitively intact respondents only
- Respondents residing in urban areas



Practice Implications

- Health care providers' support for open communications and informed decision-making
- Need to assess patients' preference for independence and autonomy in their daily life and personal care
- Training for hospice health care personnel about cultural values and beliefs



Comments? Questions?