

Preferences for African American PACE Participants at End of Life

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Introductions to Research Team

Objectives

- After this presentation the participants will be able to:
 - Have a greater understanding of African American PACE Participants' End of Life Preferences
 - Understand how themes emerged from the focus groups
 - Develop the beginnings of terminology to use when discussing End-of-Life Preferences in African American PACE participants

Introduction

- Understanding the African American perspective around end of life preferences, particularly around place of death, is a critical step in providing patient- and family-centered care within a PACE program.

Background

- Generally, African Americans view a good death through the lens of a good life that has been lived by faith in a family-centered environment.
 - Honoring one's preference for place of death is commonly considered a necessary component of a good death within African American culture (Borreani, Bruunelli, Miccinesi, Morino, Piazza, Piva, & Tamburini, 2008).
 - Anecdotally, institutionalization, or placement in a nursing home or any long term care facility, has historically been avoided and often shunned until family caregiving becomes impossible or too burdensome.

Background

- For many, “at homeness” or the condition of being in a place of the familiar is critical to a meaningful death; “at homeness”, or being home within the African American culture, is part of the cycle or continuum of a good life and a good death.

Background

- End-of-life and medical decision-making
 - The role of family and friends often supersedes the choice of the patient and impacts the ability of an African American elder to die at home, if they so choose (Varney, S. 2015) An earlier study conducted at our LIFE program found that African American elders relied on faith in God as central to medical decision-making (Nath et al., 2008)
 - Other than Nath et al. (2008), the majority of studies were conducted on patients in nursing homes or hospices who were terminally ill and received coordinated care, or imminently close to death

Study Purpose and Specific Aims

- Purpose of the study is to better understand values and attitudes associated with preferences for end of life care. The specific aims of this study explored:
 - African American elder preferences for place of death and the meaning attributed to their preference
 - Factors that either can help or hinder that preference of place of death from being carried out
 - Whether family attitudes influence African American elders' preferences on place of death

Methods

- Design: Qualitative Descriptive Study
- 3 focus groups with a semi-structured interview guide

Study Process:

- Approval - University of Pennsylvania IRB, PACE program
- Informed consent received and demographic forms completed by participants
- All focus groups moderated by 2 investigators with experience with qualitative research/focus groups
- Focus groups were audio recorded, transcribed professionally, and reviewed for accuracy by the team
- Transcripts uploaded into Atlas.ti qualitative software

Qualitative Methods

Analytical technique: Conventional Content Analysis

Process:

- Being immersed in the data
- Reading the data word by word to derive codes
- Codes were sorted and organized into clusters (categories) based on their relationship to one another
- The categories were then organized into clusters - which their relationships are identified as themes

Qualitative Methods

Trustworthiness

- 2 investigators coded together with in-depth review and consensus from the entire team regarding final themes and overall study findings
- Audit trail was kept – detailed account of initial codes, categories', and final themes, including a code book to account for decisions during ongoing data analysis
- Thick descriptions of the findings provided so that others can make a conclusion on their own about the transferability of the findings

Sample

- Inclusion criteria:
 - 65 years and older
 - Mini Mental Status Exam Score of 24 or greater (Random list generated from MMSE EMR report)
 - Agreed to participate in one of three focus groups
 - Self-Identified as African American
 - LIFE UPenn member
- Exclusion criteria:
 - Non African American
 - MMSE < 24
 - Younger than 65
 - Declined to participate

Demographics (N= 21)

Category	N	%
Age range		
65 to 75 years	9	42.7
76 to 85 years	6	28.3
86 years and older	4	19.0
Gender		
Male	4	19.0
Female	17	81.0
Race		
Black or African American	21	100
American Indian or Alaska Native	1	4.7
Ethnicity		
Hispanic or Latino	0	0
Non-Hispanic or Latino	21	100
Level of Education		
Grade School	2	9.5
Some High School	6	28.3
Completed High School	9	42.7
GED	2	9.5
Some College	4	19
Lives		
Alone	12	57.1
With Spouse	4	19
With Children	5	23.9
Type of Housing		
House	9	42.7
Apartment	10	47.6
Supported Apartment Living	2	9.5

Themes

4 Themes Identified

Four Themes

Take the Burden Off

Place of Death Depends on How You Are

I Am Ready

Rituals



Take the Burden Off

Some elders talked about ideally wanting a quick death or “going quickly” which they perceived would not be as burdensome on their family compared to a long and drawn out illness leading to their death.

“We’d go quickly and not lay around the hospital or nursing home.”

Take the Burden Off

For many members, having an insurance policy which covered burial expenses was a means of relieving their family of financial costs associated with their death.

“Oh no honey, I went through it, and that’s when I got my end of life situation straighten out, because I have [Insurance Company], and we discussed everything....how you wanted to be buried, or you want to be cremated, or everything --- I even wrote out my service, all of that. And, you do that, signed, sealed and it’s delivered.”



Take the Burden Off

Other elders voiced that they felt having written instructions removed the burden on their families.

“I got mine written in stone. So, I don’t worry about a thing. My children don’t worry about a thing because they know.”

Take the Burden Off

Other elders discussed wanting to have their wishes in writing to reduce anticipated future conflict among their family members and to ensure their own wishes were carried out once they die.

“I have a few more things to get set, when you have more than one child, have a conflict. They’re going to say, ‘She didn’t want this’. You know what I wanted but if I got it down, and you see what I want, don’t do more, no less. And so that’s why I have to do it and finish out on it... “

Take the Burden Off`

- Through the focus group discussions we heard both positive and negative experiences the elders had when preparing for their death and letting their end-of-life preferences known to their children and other family members
- We discuss it here in terms of facilitators and barriers

Take the Burden Off

Facilitators: Talking about their end-of-life preferences was embraced by some of the elders as a means of easing the burden on their families after their death.

This elder has chosen to do it gradually, as well as with a fair amount of humor to alleviate her children's reluctance to discuss death

"I had a good start talking to my children about it, and it started a few years back. And, this was after the situation with my uncle, my uncle and I. My son was going to Africa. He was taking 12 kids to Africa, and he said, 'If you...' he said, 'If you had died before that, I could've spread your ashes in Africa.' I said, 'Well, I'm sorry I didn't die in time. So, that started me to talk about it in a comical way.'

Take the Burden Off

One elder spoke about her children being reluctant to talk about her death, but her attitude and approach was to make her children talk about it now to reduce burden for them later when she does die.

“So my children don’t want to talk about it, but I talk about it with the two. I’m going if you all accept it or don’t accept it. Everybody got to go. So, you know, like just give me the respect that I would give you and all. I don’t want no arguing or fussing or nothing.”

Take the Burden Off

Barrier: Some elders shared how they wanted to talk about their end-of-life preferences with their children or other family members, but the other party has not been willing to discuss the topic

“I have tried to sit down with my children, talk to them about it, tell them what I wanted. They start crying. You understand what I’m saying? Sometimes you can’t get through to them and they say, oh, talk about it later mom, but see later may never come. I don’t know how I can get through to my children, if you can tell me how, that I can get through to my kids, my children talking to them about death, I’ll be happy to listen. I can’t.”

Place of Death Depends On How You Are

We heard from the participants that they were divided on wanting to die at home or die in the hospital. Some participants shared that their preference would be based on their condition when nearing death.



Place of Death Depends On How You Are

“I would rather be at home, I would much rather be at home. I don’t know, it’s a hard call to make, but if I’m not sick and to the point where it’s just a matter of time, let me be at home. If you get to the point where there’s nothing else you can do for me, let me be at home.”

Place of Death Depends On How You Are

“I don’t think I would like the hustle and bustle of the hospital and all the commotion and all of the ... But then again, it depends on how you are what condition you're in.”



Place of Death Depends On How You Are

“If it’s in the hospital, it’s okay. I don’t want to be home because I don’t know if I will be able to handle it or if the nurses will be there or nobody because it will be me and Jesus. Like I said, so I’d rather be in the hospital because they know what to do.”

Place of Death Depends On How You Are

No preference was also expressed

“I don’t care, I don’t care one way or the other. Because, I said, I’m going to die and that’s it, and I don’t care if I go to die in the hospital, I don’t care if I die at home. I don’t care if I die out there on the sidewalk. I know I’m going to die, and I’ve prepared my family for something like that...”

I Am Ready

Death was a common element in the lives of the elders. Often, the elders' perspectives on death were viewed from a spiritual, rather than a secular, stance. As a result, the African American elders referenced their end of life preparations to a spiritual preparation and acceptance of death, or lack of fear of death.

“When God calls me, all I’m going to be is ready. And is up to you all to do what you want with the body. Because my soul is going to rest with God. I don’t worry about the other part.”

“And when you belong to God, God has a right to come get you at any time he choose.”

I Am Ready

Other elders felt growing older and developing a closeness to God helped dispel the fear of death.

“I think the majority of people it doesn’t mean whether you Black, whether you Puerto Rican, it doesn’t really matter. I think it’s just that fear of should I step over this step, what’s going to be on the other side? I think that’s what it is, I think that’s what it is. I really do. But I think the older they get and the more closer they get to God, some of that fear will subside.”



I Am Ready

Some elders viewed fear of death as a part of the life cycle

“I do believe as you get older you don’t have a fear [of death]. I can remember coming up as a child, I sort of like feared it. And I did, I really did as I was coming up being raised up. And I guess I didn’t understand why people had to die and I really had a fear of it. I noticed as I got older...I don’t fear it anymore. In fact right now and I really get on my children’s nerves when I say this...I’m not afraid to die. My prayer is that it comes quickly more so that I won’t lay around and linger.”



I Am Ready

The African American Elders asserted a readiness for death, no matter how or when it came. Until the moment it came, they would continue to live their lives

“But I’m saying to myself that when and if the times comes, I’m already ready to go.”

“You are gone. No matter where you at it doesn’t matter, here or no matter where you at, you’re going to go. I can honestly say I’m not afraid and when my time comes, I am ready.”

“I’m not actually concerned about anything else, concerned about my death and my funeral it does not matter. I’m living my life while I am here.”

Rituals

Many of the elders shared detailed preparations for their funerals, including what they would wear, who would be present, and what songs would be sung.

“I got my little black dress, I got my little song I want them singing in church. And then I want my grandkids to be there. I want them to look good. And I want if I can help it I don’t want too much crying...I have lived my life and my life was beautiful. And the day I close my eyes they know what to do. When you say music, music is my thing, So I want good music. I want good music and I want the best and that is all I have to say because I am going on eighty eight years old and I know what’s going to happen after 87.”

Rituals

Most of the elders wanted their funerals to be a celebration of their lives, rather than a time for sadness

“Just like I go to church now and I praise God, I worship God. That’s the way I want the people to do. I don’t like dead funerals.”

“I told my pastor I don’t want no preaching just a few people saying a few words an’ nothing but gospel singing and having a good time that is my wish.”

“ I don’t want nobody to be sad because sad can last a long time.”



Rituals

In contrast, a few elders viewed funerals as a costly ritual.

“Because, I said as many funerals as I’ve seen, I haven’t seen a good-looking body yet. It’s not, to me, a dead body is dead, and it’s not-oh she looks so good, no she’s dead. Her soul is out of that body. That’s just an empty shell. So, why put thousands of dollars on this empty shell to put in the ground? Doesn’t make a bit of sense to me. That’s my personal opinion.”

Rituals

Singing was mentioned frequently by the elders as a form of celebration of life and also a form of catharsis during difficult times for African Americans

“Back in the slavery those women all they did was work, take care the family best way they could. They’d all get together and start singing that’s what brought those women through. Because they went through life to keep us alive.”

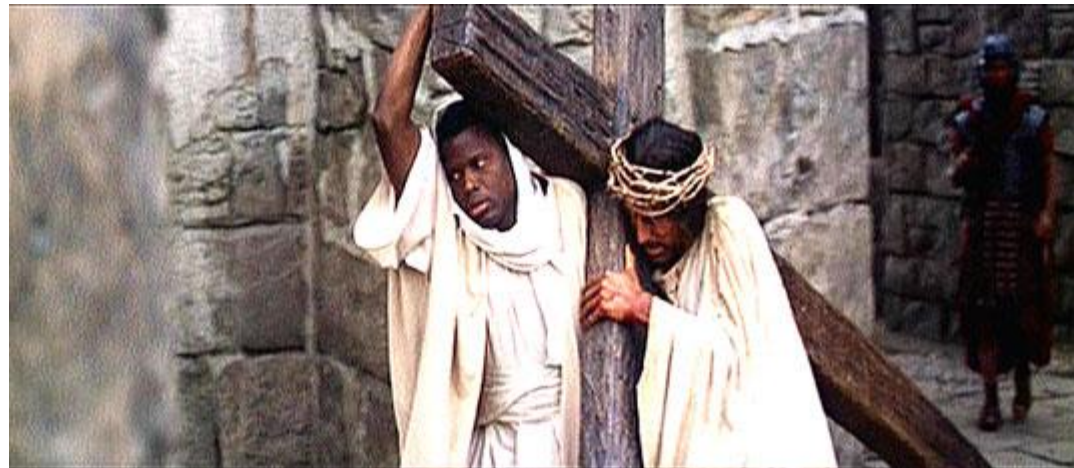


Discussion

- Perceived family burden
- Backward look/forward faith
- Faith carries them through their life experience



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Implications

- Since death and dying are an ever present part of the African American elder reality, advance care planning should be encouraged to ease perceived burdens and family conflict
- Members of the healthcare interdisciplinary team should be prepared to facilitate family end-of-life conversations, so elders' end of life preferences are properly heard and honored

Conclusion

- We learned that place of death was not as important as being prepared
- Being able to prepare their families helped the elder the have a more positive perception that their plans would be carried out at the end of life

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Questions?

Thank you!

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