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## Barriers to End-of-Life Care for African Americans From the Providers' Perspective: Opportunity for Intervention Development

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### Abstract

Research has shown that African Americans (AAs) are less likely to complete advance directives and enroll in hospice. We examined barriers to use of these end-of-life (EOL) care options by conducting semi-structured interviews with hospice and palliative medicine providers and leaders of a national health care organization. Barriers identified included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. Providers believed that acceptance of EOL care options among AAs could be improved by increasing cultural sensitivity through education and training initiatives, and increasing staff diversity. Respondents did not have programs currently in place to increase awareness of EOL care options for underrepresented minorities, but felt that there was a need to develop these types of programs. These data can be used in future research endeavors to create interventions designed to increase awareness of EOL care options for AAs and other underrepresented minorities.

### Keywords

African Americans; hospice and palliative care; underutilization; barriers; disparities; interventions

### Introduction

Although African Americans (AAs) make up 12% of the US population,<sup>1</sup> they make up only 8.5% of hospice patients.<sup>2</sup> Many studies have shown that AAs and members of other underrepresented groups tend to utilize hospice less often than their white counterparts,<sup>3–10</sup>

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and research suggests that AAs are also less likely to complete advance directives.<sup>11–15</sup> Still other studies report that AAs prefer more aggressive therapies at the end of life (EOL),<sup>16,17</sup> including mechanical ventilation and feeding tube use among the cognitively impaired patients.<sup>18,19</sup>

Barriers that may explain these racial/ethnic disparities in EOL care have been documented in the literature. Factors that contribute to racial differences in EOL care include lack of knowledge about hospice as an option for care, preferences for more aggressive therapies at the EOL, conflict between patients' spiritual beliefs and the hospice and palliative medicine philosophy of care, and mistrust in the medical system.<sup>17,20–23</sup> Although these barriers have been identified, few interventions have been designed to reduce the racial differences that have been observed.

The participants in these semistructured interviews are health care providers with experience in providing care for patients enrolled in hospice and palliative care programs. These providers had varying degrees of experience in hospice and palliative medicine—particularly with AA patients. They also came from a variety of disciplines, including social work, pastoral care, nursing, and medical practice. The primary objective of this study was to identify barriers to EOL care (advance care planning, palliative care, and hospice care) and possible intervention strategies to reduce disparities in EOL care from their perspectives. Data were collected as part of the formative research necessary to design targeted, culturally sensitive interventions that will increase awareness of EOL care options such as completion of advance directives, palliative care, and hospice among AAs and other underrepresented minorities.

## Methods

Following the approach of “typical case” purposeful sampling<sup>24</sup> and covering a diverse set of institutions and regions, 10 hospice and palliative medicine providers and 2 representatives of a national health care organization were identified and recruited to participate in the interviews. Participants were interviewed in person or by phone, and all 12 participants gave verbal consent prior to answering interview questions per institutional review board (IRB)-approved protocol. Before importation into online qualitative software, all identifying information was removed from transcripts, including mention of the participant's institution and a code assigned for each participant on the transcript of his or her responses. The IRB at UT Southwestern Medical Center University of Texas Southwestern approved all study procedures.

## Sampling Strategy

In qualitative research, purposeful sampling is intended for selecting *information-rich* cases for surveying in depth.<sup>24</sup> Typical case sampling is a strategy to identify typical cases within a population. The individuals interviewed, by sharing their views in response to a set of questions, help to develop a qualitative profile that includes the criteria best exemplifying the typical AA patient who faces choices for care at the EOL. The profile will assist in sampling members of the AA population for further knowledge generation regarding the obstacles and facilitators to the appropriate use of advance directives and hospice in EOL decision making

in this population. The data from this study will also inform the question guide for interview of members of the population of interest. Participants also contributed their relevant observations in interactions with AAs, as they relate to patient and family dynamics in EOL care.

### Question Guide

The interview guide was made up of 13 questions, including 1 regarding the typical patient seen by the practitioner/institution and others exploring the participants' experiences working with AAs patients at the EOL and their families. They were also asked their opinion of important considerations when developing interventions that will inform and support AAs as they make EOL decisions regarding advance directives, palliative care, and hospice.

### Data Collection

Participants participated in a semistructured interview. The interview guide was developed with input from all members of the study team and included open-ended questions about participants' experiences in caring for AAs at the EOL. Demographic information (race/ethnicity, years of experience in hospice and palliative medicine, discipline, etc) was collected, and initial questions were designed to examine participants' perceptions of barriers to EOL care among their AA patients. Additional questions were asked to examine assets to EOL care among AAs, the perceived amount of cultural sensitivity employed by their respective programs or organizations, whether they had programs in place to increase awareness of EOL care options among their AA patients or knew of programs, and suggestions for components of possible future interventions to address racial differences in EOL care. Patients were enrolled until thematic saturation was reached, and no more merging themes were identified.

### Coding of Data

All interviews were transcribed and coded by 2 individuals (RLR, KB) using the Dedoose qualitative analysis program. At periodic intervals, they discussed the data and refined the coding scheme. Disagreements were resolved through these discussions, and although a third individual was available to resolve any disagreements, the 2 coders were able to come to consensus on the coding scheme. A total of 70 codes were identified, many of which fell under the categories of assets and challenges to addressing EOL issues, including family dynamics, spirituality, and attitudes about the use of medications for pain management.

### Results

The health care provider participants included 6 physicians, 1 nurse practitioner, 1 registered nurse, a social worker, and chaplain all of whom worked in hospice and/or palliative medicine. They represented 1 hospice (in the northeast) and 2 palliative medicine programs (in southern states). The health organization participants were associated with the advocacy, public policy, and palliative care offices of a national health care organization that represents health care facilities across the country—including some hospices, home health agencies, and long-term care facilities. The average interview was 43 minutes (range 31–62 minutes).

There was 1 male physician participant, all other participants were female. Of the participants, 1 female physician participant self-identified as AA, while all other participants were caucasian. Years of experience in hospice and palliative medicine varied from 2 to 20 years, see Table 1.

## Types of patients

Health care providers reported that the percentage of AAs in their programs varied from less than 5% to 50%. Respondents reported that they mainly cared for adult patients, and cancer was the most common primary diagnosis. Some providers cared for more indigent patients that had no form of health care coverage or relied on county assistance programs for care, while others cared for patients who were mostly insured.

## Barriers to Hospice and Palliative Medicine for EOL Care

### Family Barriers

Providers felt that AA families were very supportive; however, the complexity of the family dynamic also proved to be challenging. When asked what barriers contributed to racial differences in use of hospice and palliative care among AAs, many cited family members' resistance to enrollment in hospice and use of palliative care as an obstacle. Providers often felt that though patients were ready to move toward comfort instead of cure, they did not because family members encouraged them to continue to seek more aggressive alternatives for care. One provider said, "I feel like the patient is very concerned about their family. They want to try. If the family wants them to try, they want to try. So they're not willing to give up in their eyes."

### Conflict With Spiritual Beliefs

Although spirituality and faith were strengths mentioned by hospice and palliative medicine providers, they noted that patients' spiritual beliefs often conflicted with their perceptions of the hospice and palliative medicine philosophy of care. Patients often expressed a desire to "leave it in God's hands" or believed that "God will take care of" them. A medical director of a hospice and palliative medicine program noted that though this did not apply to all AA patients, spirituality, an integral component of the dying experience for AAs, made having discussions about EOL care more challenging. She said:

It has sometimes been the case when I'm trying to have a conversation as a physician with a loved one and the patient. You have this wonderful, warm, comforting shield of faith that doesn't let them hear what you're trying to tell them or makes them feel that it's someone else that you must be talking about.

### Desire for Aggressive Care

Health care providers cited a desire for more aggressive care as a barrier to advance care planning, use of palliative care, and use of hospice. They described a sense that some AA patients felt that use of hospice meant that they were going to be denied treatment that others would be offered. They felt that patients did not like the idea of not being able to come back to the hospital, if their condition worsened. Changing goals of care from treatment to

comfort was particularly challenging. A provider said, “AAs seem to have more difficulties with changing goals of care to focus on comfort rather than cure . . . they’ve also had some difficulty in changing code status to do not resuscitate from being full code.”

### **Lack of Knowledge and Poor Perceptions of Hospice**

Lack of knowledge about prognosis, hospice, and palliative care, and poor perceptions of hospice and palliative care were additional barriers identified by providers. Providers sometimes felt that their AA patients were not aware of the severity of their illness. A provider said, “[Acceptance of palliative care or hospice] depends on if [providers] have told the family where they are in their illness, a lot of times they are in the dark, and then they’re hit all of a sudden with this.” Another provider also endorsed a lack of knowledge about prognosis as a barrier by stating, “I think it’s because of a lack of information about severity of illness given to those who have to make the decision to enroll.”

Providers also acknowledged a lack of knowledge about hospice and palliative medicine or misconceptions about hospice and palliative medicine. One provider believed that a barrier to hospice use was “myths about what [hospice providers] do that patients don’t understand.” Another provider reported, “I think there are some pretty popular misconceptions out there. I think one is that hospice sort of bumps people off.” Hospice was viewed by some AAs as “giving up,” and as such, one hospice physician chose to take a different approach to having discussions about hospice enrollment. This provider said, “I often have to present hospice as a mechanism of care. It can’t seem like a destination, it can never seem like we’re giving up.” Another identified theme dealt with fear of morphine or other opioids for pain and symptom management. Providers cited patients’ fears of addiction and an association with morphine as a “terminal drug” that hastened death. A hospice nurse reported “There’s very much a stigma to the ‘M’ word. I think that when they hear the word morphine, they think they’re going to die.”

### **Medical Mistrust**

Patients’ mistrust in the medical system was also a perceived barrier to EOL care options cited by providers, though some providers did not believe that they had been perceived to be distrustful themselves. They felt that some AAs and other under-represented minorities feel that they are being treated unfairly, not being offered what other patients might get, or “not getting their due.” A hospice medical director said the following

From what I’ve read and what conventional wisdom states, there is a great mistrust in the health care system. There is evidence that white upper middle class patients are more likely to get heart bypasses and high tech, more aggressive surgery than low income or minority patients . . . So that they may be less likely to accept what they feel as being turned away from the hospital gates for their care at the end of life.

A palliative medicine physician stated

My experience has been that patients come in trusting the medical system, then they get screwed, and then they cease to trust the medical system . . . When we do untrustworthy things—when we have a system that fails time and time again—it is

appropriate for people not to trust. If people don't get a follow-up appointment, if they can't reach anybody when they need help, that's how they should act. So until we create a trustworthy system, I'm not going to blame the patient for having issues about it. It's appropriate. I do have people who come in and they come in swinging, and that's okay because they are doing what they have to do to look out for their family. Then once we get to know each other and we work together, if I am trustworthy, then they trust me. But if I'm not trustworthy, they are right to be leery.

### **Acknowledgment of Illness Hastens Death**

Providers noted a pattern in attitudes about death and dying among their AA patients. They reported that in some instances, patients felt that any acknowledgement of illness meant that it would speed up the dying process. A palliative medicine physician noted the following, "Sometimes you have people who will not even admit that they're sick. I mean, I've had patients with fungating breast wounds that come in with duct tape and paper towels around their chest that say, "I can't own this." That is the hardest challenge for me—the hardest thing for me to take care of." Other providers felt that this also applied to completion of an advance directive. A palliative care social worker said, "I see that there is sometimes a superstition in actually writing an advance directive because I've heard "if I write it down, it makes it happen".

## **Ways to Improve Access to EOL Care Options for AAs**

### **Cultural Sensitivity**

All respondents believed that cultural sensitivity is needed to provide EOL care to AAs and members of other underrepresented groups. Most stated that they have had education and training in cultural sensitivity but believed that more education and training in cultural sensitivity are needed. They felt that education could come in the form of lectures, in-services, self-learning, and learning from colleagues of diverse racial/ethnic backgrounds. They believed that cultural sensitivity could also be increased by hiring staff of diverse racial and ethnic backgrounds, though hiring persons of diverse racial/ethnic backgrounds has been challenging. One provider stated, "When I've recruited in the past, I have not been able to find someone who wanted to do the clinic work. I don't know of any AA nurses that wanted to work in my role. I've talked to some of them and they say, 'I don't want to do what you do'".

### **Useful EOL Care Communication Strategies**

Many providers described approaches that they have used in caring for and communicating with AA patients and their families. Most providers believed that communication about the EOL was a gradual process that often required ongoing conversation. Given the strong influence of faith and spirituality among AA patients and their families, providers often felt that should be addressed. Some did not feel comfortable addressing that issue and relied heavily on a chaplain to provide spiritual support, while others were comfortable with including the topic in their conversations with patients. A palliative medicine physician described the approach to addressing spirituality and advance directives in the following manner:

Talking about advance directives is not against God's will. It's not anybody trying to take anything away from you. This is your chance. This is here to protect you. So here is what this can do. You tell your doctor what you want and that way we can make sure that's what you get. I think if it was sort of a self-empowering thing that would be helpful.

Another provider felt that though palliative care and hospice services are created, patients should not be pressured into choosing those services for care at the EOL. This provider said:

I think hospice is very useful for people who want hospice, but I don't think that everybody should be coerced into doing it. If it's not the right thing for the patient, leave it alone. It bugs me to ask people, "Is this what you want? Do you want comfort care or do you want aggressive treatment?" And if they want aggressive treatment, we try and talk them out of it. People should be allowed to do what they want to do. We have to meet them where they are.

### Possible Interventions

None of the participants had current programs in place to increase awareness of options for EOL care among AAs or other underrepresented minorities, and they could not identify programs sponsored by other programs or health care organizations. They did, however, acknowledge that they believed that AA patients would be receptive to educational programs—particularly if they were culturally sensitive and delivered in a way that patients could understand. They felt that AA patients would be receptive to informational videos that were culturally tailored, and they felt that specific barriers such as conflict with spirituality, lack of knowledge about EOL care options, and advance care planning should be addressed. A hospice physician stated:

If I were making tapes for educational purposes, they would be short and interactive, such as "here is the patient and here is the culturally appropriate doctor or nurse having the conversation about pain." Or about advance directives or something like that. I think I would have it in snippets and in a very short, well-acted interaction and not lecture style.

To address medical mistrust, respondents felt that having someone on the team with whom patients could identify culturally would be helpful. One respondent stated, "If you have somebody who comes in and is just like you—a normal person, speaking your language, having similar life experiences with good solid information—that would be helpful." Some felt that having someone who worked outside of the health care system, such as an AA lay health advisor with specific training in EOL care communication, would also address medical mistrust. Others, however, did cite concerns about the lay health advisor approach—particularly with regard to a lay person's lack of medical training as a potential barrier, and felt that the introduction of another individual may be overwhelming to patients. A hospice nurse said, "Patients can get to where they don't want to hear anymore, so somebody coming in to talk about advance directives is a step further down, but it's still along the same vein. It could be too much."



## Discussion

Using semistructured interviews of hospice and palliative medicine health care providers of various disciplines, we identified barriers to use of EOL care options including advance directives, palliative care, and hospice among AAs. We found that previously identified barriers continue to be associated with underutilization of hospice and advance care planning among AAs, including lack of knowledge about prognosis and EOL care options, conflict with patients' desires for aggressive treatment, and mistrust in the medical system.<sup>17,20–23</sup> The family structure and strong sense of spirituality have often been cited as strengths among members of the AA community; however, these constructs were also perceived by respondents to be barriers to their discussions about EOL care.

The interviews conducted in our study also revealed various methods that could be used to traverse those barriers that were identified. Providers felt that cultural sensitivity is needed when communicating with patients and families about EOL care, and cultural sensitivity could be enhanced through education initiatives, training, and hiring practices. They also believed that including spirituality in their discussions with patients or having pastoral care staff integrally involved would enhance these conversations.

Previous research has examined barriers to hospice and palliative care among underrepresented groups; however, few studies have been identified that evaluate interventions to reduce those disparities. Our study extends this work by not only evaluating underuse of EOL care alternatives from the points of view of a multidisciplinary sample of providers experienced in EOL care but provides some of the groundwork necessary to design and implement culturally sensitive, behavioral interventions with the goal of increasing knowledge and awareness of EOL care options (ie, advance care planning, palliative care, and hospice care) among persons who have historically underutilized these services.

There are certain limitations that should be taken into account. This study was conducted at 1 hospice and 2 palliative medicine programs. Although we tried to capture a sample that represented providers of multiple disciplines, years of experience, and regions of the country, the experiences of providers in other areas may differ. Finally, although multidisciplinary in scope, our sample was predominantly caucasian. As a result, we were unable to explore potential differences in perceptions of providers by race or ethnicity. Despite these limitations, common themes were identified that have been identified in prior studies, and targeted programs can be developed to address these barriers.

Intervention design and development is an important area that has been underutilized in EOL care research—particularly in disparities in EOL care; however, some educational interventions designed for use in EOL care and other domains have been successful.<sup>25</sup> Educational videos have been used to address health literacy about advanced dementia in the elderly patients,<sup>26</sup> and tailored audiovisual materials have also been used successfully in interventions designed to improve physician–patient communication.<sup>27</sup> Additionally, although not targeted at a specific population, EOL decision aids have been designed for patients facing advanced or terminal illness.<sup>28</sup> The lay health advisor model has also been



used successfully in intervention design to improve outcomes in various clinical conditions including pediatric asthma and cardiovascular disease.<sup>29,30</sup> Culturally sensitive interventions utilizing both audiovisual materials and the lay health advisor model could certainly be used to increase awareness of options for EOL care among the underrepresented groups, and the providers interviewed in this study believe that the patients they serve may be receptive to these methods.

The overall goal of this research was to identify barriers to care at the EOL among AAs and to perform the formative research necessary to design a culturally sensitive intervention to inform AAs with advanced illness of their end-of-life care options in a culturally sensitive manner. The providers interviewed believed that patient education programs could be effective—particularly if the program was delivered in a culturally sensitive way. They believed that AA patients would be receptive to audiovisual materials, though they would need to be tailored to fit the audience. They also felt that the lay health advisor model may be an effective method, though some expressed concern about the lay health advisor’s potential lack of medical knowledge. These factors should be taken into consideration for future research endeavors that center around EOL care among members of the AA community, and interventions should be designed to better inform AAs and other underrepresented minorities of their options for care at the EOL. We realize that barriers may continue to exist; however, efforts should continue to be made to improve the process of shared decision making. Health care providers must meet patients and families where they are and assist them with the often difficult transitions associated with the EOL.

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**Table 1**

## Sample Demographics.

<b>Role</b>	<b>Number</b>		
Physician	6		
Nurse practitioner	1		
Nurse	1		
Social worker	1		
Chaplain	1		
Health care organization representative	2		
	<b>Race/ethnicity</b>		
	Nonhispanic white	Nonhispanic black	Other
Physician	5	1	1
Nurse practitioner	1		
Nurse	1		
Social worker	1		
Chaplain	1		
Health care organization representative	1		
	<b>Gender</b>		
	Male	Female	
Physician	1	5	
Nurse practitioner		1	
Nurse		1	
Social worker		1	
Chaplain		1	
Health care organization representative		2	
Experience with hospice/palliative care, years			
<1	2		
1–2	3		
3–5	2		
6–10	2		
11–15	2		
>15	1		
Estimated percentage of AA patients seen			
<5	2		
6–10	1		
11–20	0		
21–30	2		
31–40	3		
41–50	2		
>50	0		

Abbreviation: AA, African American.

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