

## Original Article

**Cite this article:** Sanders JJ, Johnson KS, Cannady K, Paladino J, Ford DW, Block SD, Sterba KR (2019). From Barriers to Assets: Rethinking factors impacting advance care planning for African Americans. *Palliative and Supportive Care* **17**, 306–313. <https://doi.org/10.1017/S147895151800038X>

Received: 3 April 2018

Accepted: 15 April 2018

**Key words:**

Advance care planning; African Americans; communication; serious illness; qualitative

**Author for correspondence:**

Justin J. Sanders, M.D., M.Sc., Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, 450 Brookline Avenue, LW670, Boston, MA 02215. E-mail: [Justin\\_sanders@dfci.harvard.edu](mailto:Justin_sanders@dfci.harvard.edu)

# From Barriers to Assets: Rethinking factors impacting advance care planning for African Americans

Justin J. Sanders, M.D., M.Sc.<sup>1</sup>, Kimberly S. Johnson, M.D.<sup>2</sup>, Kimberly Cannady, PH.D.<sup>3</sup>, Joanna Paladino, M.D.<sup>4</sup>, Dee W. Ford, M.D., M.S.C.R.<sup>5</sup>, Susan D. Block, M.D.<sup>1</sup> and Katherine R. Sterba, PH.D.<sup>3</sup>

<sup>1</sup>Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, MA;

<sup>2</sup>Department of Medicine, Duke University School of Medicine, Durham, NC; <sup>3</sup>Department of Public Health Sciences, Medical University of South Carolina, Charleston, SC; <sup>4</sup>Department of Medicine, Brigham and Women's Hospital, Boston, MA and <sup>5</sup>Department of Medicine, Medical University of South Carolina, Charleston, SC

**Abstract**

**Objective.** We aimed to explore multiple perspectives regarding barriers to and facilitators of advance care planning (ACP) among African Americans to identify similarities or differences that might have clinical implications.

**Method.** Qualitative study with health disparities experts ( $n = 5$ ), community members ( $n = 9$ ), and seriously ill African American patients and caregivers ( $n = 11$ ). Using template analysis, interviews were coded to identify intrapersonal, interpersonal, and systems-level themes in accordance with a social ecological framework.

**Result.** Participants identified seven primary factors that influence ACP for African Americans: religion and spirituality; trust and mistrust; family relationships and experiences; patient-clinician relationships; prognostic communication, care preferences, and preparation and control. These influences echo those described in the existing literature; however, our data highlight consistent differences by group in the degree to which these factors positively or negatively affect ACP. Expert participants reinforced common themes from the literature, for example, that African Americans were not interested in prognostic information because of mistrust and religion. Seriously ill patients were more likely to express trust in their clinicians and to desire prognostic communication; they and community members expressed a desire to prepare for and control the end of life. Religious belief did not appear to negate these desires.

**Significance of results.** The literature on ACP in African Americans may not accurately reflect the experience of seriously ill African Americans. What are commonly understood as barriers to ACP may in fact not be. We propose reframing stereotypical barriers to ACP, such as religion and spirituality, or family, as cultural assets that should be engaged to enhance ACP. Although further research can inform best practices for engaging African American patients in ACP, findings suggest that respectful, rapport-building communication may facilitate ACP. Clinicians are encouraged to engage in early ACP using respectful and rapport building communication practices, including open-ended questions.

**Introduction**

The National Academy of Medicine recognizes advance care planning (ACP) as a key facilitator of high-quality end-of life (EOL) care (Institute of Medicine, 2015). ACP encompasses a broad range of activities, from identification of surrogate decision-makers to articulation of EOL care preferences (Sudore et al., 2017). Certain ACP activities (e.g., surrogate appointment) are relevant at all stages of health. However, ACP's greatest impact may be for the seriously ill (Billings & Bernacki, 2014), for whom evidence demonstrates improved healthcare outcomes: patients are more likely to receive care consistent with their preferences, enroll in hospice, and report greater care satisfaction (Detering et al., 2010; Mack et al., 2010b; Wright et al., 2008). Bereaved families have reduced distress and decisional conflict and higher quality of life (Chiarchiaro et al., 2015; Detering et al., 2010).

African Americans participate less in ACP than white Americans (Gerst & Burr, 2008). This may contribute to disparities in EOL care, such as lower use of hospice and palliative care (Carrion et al., 2012; Hanchate et al., 2009; Johnson et al., 2008a, 2010; Loggers et al., 2009; Mack et al., 2010a). Factors influencing ACP in African Americans are multidimensional and interrelated. Patient factors, such as religion and spirituality (R/S), interpersonal relationships, mistrust, and sociodemographics, interact with clinician and healthcare system factors to facilitate or impede ACP (Sanders et al., 2016). Significant gaps remain in our understanding about *how* these factors and their interactions affect ACP among seriously ill African Americans.

We conducted a qualitative study with multiple stakeholder groups, including seriously ill persons and their caregivers, to examine and compare perspectives on ACP among African Americans.

## Methods

### Overview

As part of a larger study to assess acceptability of a tool to assist clinicians in conducting ACP discussions, we conducted a series of interviews and focus groups with (1) disparities experts (researchers and a palliative care clinician) with experience studying and/or caring for seriously ill African Americans (experts); (2) community-dwelling African Americans (community); and (3) seriously ill African Americans and their caregivers (patient-caregiver). Informed by social ecological theory, we used group interviews to qualitatively explore systems, community (interpersonal), and patient and caregiver (intrapersonal) perspectives, respectively, on barriers and facilitators to ACP (Crabtree & Miller, 1992). We conducted a focus group, small discussion groups, and a joint interview given participant time and interviewer resource constraints (Polak & Green, 2016).

### Recruitment

Institutional review boards at the Medical University of South Carolina (MUSC) in Charleston, SC, and the Dana-Farber Cancer Institute in Boston, MA, approved this study. For the “expert” groups, we recruited MUSC academic and medical professionals to participate in one of two small discussion groups. To represent community perspectives, we invited a convenience sample of African American church members who meet regularly to discuss health-related issues to participate in a single focus group. For the patient-caregiver group, we used electronic health records to identify and recruit from MUSC specialty clinics African American patients with stage IV cancer, New York Heart Association class III/IV heart failure, or chronic obstructive pulmonary disease with more than three hospitalizations. Patients and their named caregivers were invited to participate in one of two in-person focus groups at MUSC. Refreshments and a \$25 gift card were provided to groups 2 and 3.

### Data collection

We developed a structured interview guide reflecting a social ecological model, which posits that individual behavior is shaped by intrapersonal, interpersonal, and societal factors (McLeroy et al., 1988). We used a literature review to inform guide development, with different versions for each group (researcher/clinician, community, patient/caregiver). Medical literature alone may be insufficient to understand expert opinion because researchers and clinicians also derive knowledge from personal experiences. Therefore, we asked experts with research or clinical expertise in the academic community to comment on systemic and local factors that informed their perspectives on ACP among African Americans. We incorporated a church-based group of community participants because of clear evidence of the role of R/S in shaping EOL care for African Americans (Balboni et al., 2007; Johnson et al., 2008b; Sanders et al., 2016). Church members and patients-caregivers were asked to share their own experiences communicating with clinicians about goals and preferences for EOL care, to reflect on their priorities about EOL planning, and to consider barriers to and enablers of ACP.

All focus groups and interviews were audiorecorded, lasted 45–90 minutes, and were cofacilitated by team members experienced in moderating focus groups (JS and KS). Participants completed a demographic survey after sessions. Moderators collected narrative process notes to document observed interactions and conversation subtext.

### Data analysis

Interviews were transcribed verbatim for content analysis. We employed template analysis, which uses both inductive and deductive approaches, to facilitate coding and theme identification (Crabtree & Miller, 1992): we developed a preliminary code framework drawn from the literature (deductive), which we augmented in an iterative fashion with themes derived directly from focus groups (inductive).

Our initial coding template was organized, in accordance with our interview guide, to reflect anticipated barriers to and facilitators of ACP derived from the literature in a structure that reflected intrapersonal, interpersonal and systems levels. Using this template, two authors (JS and KS) independently coded transcribed data and reconciled differences by consensus. We refined evolving codebooks as data analysis proceeded by collapsing overlapping and unused themes.

As highlighted in Figure 1, in addition to our seven *a priori* codes, 12 additional codes emerged in data analysis and contributed to a final set of seven themes capturing participants’ descriptions of ACP barriers and facilitators. After coding data from each group, we combined all data in a final codebook to identify group consistencies and differences. JS and KS compared process notes following groups to further contextualize findings.

## Results

### Participant demographics

The “expert” group ( $n = 5$ ) comprised four disparities researchers (two African American) and a palliative care clinician. The “community” group consisted of nine African American community church members (mean age, 50; range, 25–66), eight of whom were female and had experience as a caregiver, and seven with at least some college education. The patient-caregiver group consisted of 11 participants, seven with serious illness and four caregivers (mean age, 58.5; range, 49–73). Four participants were college graduates, three had completed some college, three had a high school education, and one had not completed high school. Two participants rated their health as “poor,” six as “fair,” and three as “good” or “very good.”

### Thematic findings: from barriers to assets

Participants described several key factors that shape participation in ACP. They highlighted the role of R/S, mistrust, family, and patient-clinician relationships, and identified beliefs and preferences regarding prognostic communication and care preferences that influence ACP. However, perspectives on how these factors impede or enable ACP among seriously ill African Americans differed by group. Next we describe themes and highlight similarities and discrepancies by group, presenting illustrative quotations in Table 1. Overall, findings fit a pattern in which factors traditionally identified as barriers in the literature were seen as assets, particularly by patient-caregivers.

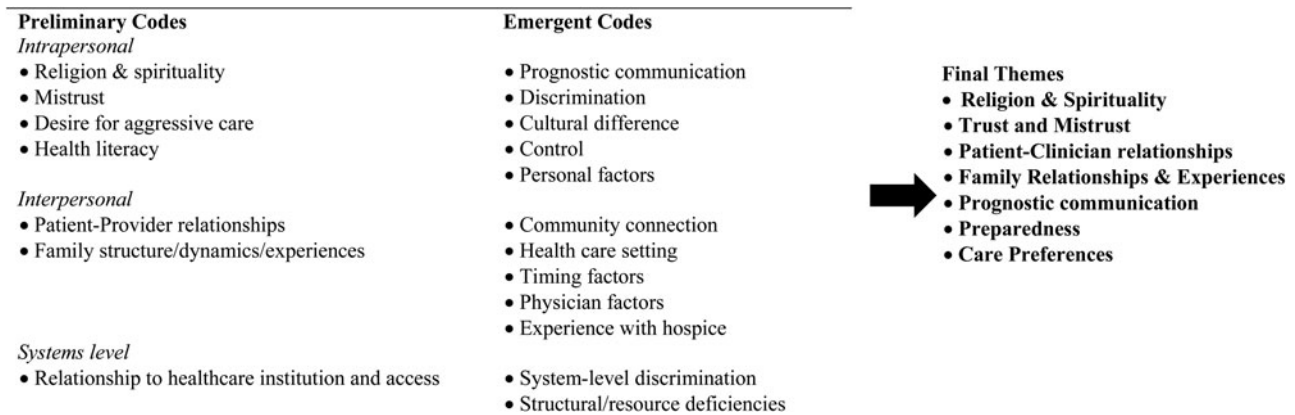


Fig. 1. Predefined and emergent codes and subsequent themes.

### Context: rarity of ACP

One finding from interview notes contextualize the results described here: participants' clinical, family, and personal experiences reflected a culture in which African Americans rarely participate in ACP. Perceptions about barriers and facilitators to ACP, including among experts, often reflected communication challenges experienced in the last days of life (e.g., in the hospital), which timely ACP might help overcome. Expert participants, in particular, were sensitive to this issue. As one said, "This has got to happen before a person experiences the major issues of needing palliative or EOL care" (group 1, #2).

### Religion and spirituality

Participants described ways in which R/S help patients make sense of disease and its trajectory, and thus indirectly influence ACP. Experts stressed the potential for R/S to impede ACP. They agreed that the common patient and family belief in God's control over prognosis fostered a sense of fatalism that precludes ACP: "Trusting that God has that in his control...pushes them to let go of care decisions" (group 1, #5).

Some community members echoed this sentiment, noting of Christians: "we feel like...if we get sick God will heal us and we'll all live forever," and are thus "the worst people to prepare for what's to come" (group 2, #7). This was accompanied by a nuanced understanding of divine healing: that death itself could represent divine healing, as when one described the death of her uncle: "God said, 'I told you that I was going to heal him. I never told you I was healing him for this side of the earth'" (group 2, #1).

Patient-caregiver participants agreed that, as one said, "the Man up there is the one who determines everything," (group 3, #P6) including prognosis, and that God's ability to heal supersedes that of physicians. However, in contrast to expert participants' framing of R/S as a potential barrier to ACP, they focused predominantly on positive aspects of R/S in supporting coping, by providing "strength." This was coupled with an acceptance that, as one said, "when the Lord is ready for you, They are ready for you" (group 3, #P3).

### Mistrust and trust

Participants cited historical events and personal experiences within the healthcare system that perpetuated impressions about inadequate care for African Americans. Expert participants cited historical examples of trust violations by clinicians and

healthcare systems. One noted that "Talking about EOL is not a priority; getting healthcare is" (group 1, #4), suggesting that any discussion of care limitations might be overshadowed by perceptions that care is being unfairly withheld. Similarly, community and patient-caregiver participants cited memorable negative experiences with clinicians as evidence that African Americans receive lower quality healthcare across the spectrum of illness and sometimes highlighted these as obstacles to productive health interactions. As one noted, "half the time we don't know if what they're telling us is the truth or not... We're going by what they tell us, but then we see something else" (group 2, #1).

Expert participants viewed mistrust as an unmitigated barrier to ACP, limiting the acceptability of discussing prognosis, for instance. By contrast, community and patient-caregiver participants were more likely to emphasize the positive impact of trusting relationships on discussion of prognosis and treatment recommendations, an integral part of ACP. They also described interactions with trusted physicians that eased acceptance of prognosis and preparation for loss. For example, one church member described an experience with her mother, in which a trusted family doctor helped the family prepare by stating directly that she was dying. All patient-caregiver participants described trust in current clinicians.

### Patient-clinician relationships

Participants highlighted the importance of rapport with clinicians involved in EOL planning and respect demonstrated through kind, direct communication, and equal regard for African American lives. Rapport and respect might facilitate ACP by enhancing trust, whereas their absence reinforced ACP barriers.

Expert participants emphasized societal aversion to discussing death, whereas community and patient-caregiver participants focused more on their own patient-clinician experiences. Community members had experienced poor communication (e.g., victim-blaming for health problems and discourteousness) and felt that this both conveyed disrespect and impeded openness to future communication. Patient-caregiver participants also commented on positive effects of good communication. As one caregiver noted: "the doctors have been very pleasant. ... They not only ask about [patient's] health. They want to know how I am...and how everybody doing at home...And that's good when you have that relationship with the doctor because it does make it easier" (group 3, #F4).

**Table 1.** From barriers to assets: quotations illustrating variation by group in common themes around ACP among African Americans

Group 1: experts	Group 2: community church members	Group 3: patients/caregivers with serious illness†
Religion and spirituality		
<ul style="list-style-type: none"> <li>“Families believe that a doctor should not be in control: God will decide...when that person’s time of death is, God will decide when the time is not to offer chemotherapy...or dialysis.” (#4)</li> </ul>	<ul style="list-style-type: none"> <li>“So God has healed me many a times, but it’s the doctors who I run into that are either faith doctors, doctors who are man of faith, who believe in Christ, who pray with me and the nurses that I come in contact with that said...‘I feel God has healed you already.’ And so I’ve had encounters with a lot of people who are believers and it makes a big difference, and you are healing.” (#6)</li> </ul>	<ul style="list-style-type: none"> <li>“You have to have faith to be able to make it... You find that you draw strength from places that you don’t even know where you got it from.” (#P3)</li> </ul>
Mistrust and trust		
<ul style="list-style-type: none"> <li>“History is key and lack of trust in healthcare institutions, because they haven’t traditionally been seen as advocating on the part of the patient... just a perception that doctors give up too easily on African American patients and don’t try hard to save people and about the perceived value of life...may be seen as less.” (#1)</li> </ul>	<ul style="list-style-type: none"> <li>“We felt like there should have been more done to save him. We asked the doctor, but they said that they have done all they could do according to the condition of his heart. But I just kind of felt and my children kind of felt like we were just kind of cheated in that way, it felt like they could have done more even if it was his time to die, I kind of felt like they should have done more.” (#1)</li> </ul>	<ul style="list-style-type: none"> <li>“They say cancer has come back again...but I still have trust in on them, I still going to follow what they say.” (#P6)</li> <li>“Her oncologists were wonderful. They explained it to us so that we can all understand it. So, she knows. And it’s not saying it could be today – it could be three years from today – but we’ve come to terms with it. So we have made arrangements for those final days.” (#F6)</li> </ul>
Patient-clinician relationships		
<ul style="list-style-type: none"> <li>“It has to be done very caretakingly – developing rapport...and setting it up right.” (#4)</li> <li>“You have to build trust before having this conversation. ... They can see that you are wanting to do this [ACP] so you can advocate for them so it gives them some control over some things they have little control over.” (#5)</li> </ul>	<ul style="list-style-type: none"> <li>“I’ve only had good experiences with doctors. The doctor was a good friend of the family. He knew us.” (#3)</li> <li>“Your manners will turn me around real fast. I’m already going through enough, so when I’m coming for help, I’m already humbling myself. It’s already a struggle to do that because I already know my wall is up because of what I’m going to expect – ‘I don’t have time for this’ or ‘you’ve had this for how long and you just coming back for it.’” (#6)</li> </ul>	<ul style="list-style-type: none"> <li>“That’s good when you have that relationship with the doctor because it does make it easier. ‘Cause a lot of times, if he is in the hospital, I am his voice.” (#F1)</li> <li>“That made me feel bad because that was the first cardiologist she went to and some people don’t listen to you. By that time, she was out of breath. He said, ‘You need to lose weight.’ ... She had pneumonia. If he had only listened to her.” (#F2)</li> </ul>
Family and decision-making		
<ul style="list-style-type: none"> <li>“When you bring family into the discussion... that’s next to God. It’s a very important space. ... will be a way of giving it a context that would give [ACP] a better space.” (#4)</li> <li>“Training in medical school trained [doctors] for interacting with one decision-maker; they are not sure how to work with African American families, in which there are multiple decision-makers.” (#1)</li> </ul>	<ul style="list-style-type: none"> <li>[RE: the death of an uncle] “When [his daughter was] around...she had to be the one to make that decision, because I’m only a niece; the rest of us were nieces and nephews. But though he had her and he had two sons, they had to make that decision and I told her, what ever decision you make we’re going to stand by. So that’s when she made the decision to pull the plug.” (#1)</li> <li>[RE: the experience of her deceased mother] “She wasn’t sick for a long time. I mean it was just all of a sudden, but he had already had that conversation...So we, and pretty much my family, we all try to get together and talk about what we want; my brothers, they weren’t wanting to hear any of that. But so I had to be like the voice of reason for them, because it wasn’t anything else that they could do for her. And they didn’t want her to come off the vent and I said, ‘well, she already told us what she wants, so we need to comply with what she wants...’” (#8)</li> </ul>	<ul style="list-style-type: none"> <li>“I didn’t want [my wife] to worry about what she needed to do... We set it up: if this happens, this is the cutoff point.” (#P1)</li> <li>“There it is in black and white. It’s signed, it’s notarized – everything. So nobody have anything to say because we gonna go with what he wants and if they can’t deal with it then they just can’t deal with it.” (#F2)</li> <li>“[He] has already done his advanced directive. We did that from the beginning and I know what he want and he does not want. Anything like that, so we discussed it.” (#F4)</li> </ul>

(Continued)

Table 1. (Continued.)

Group 1: experts	Group 2: community church members	Group 3: patients/caregivers with serious illness†
<ul style="list-style-type: none"> <li>• “It took (a friend) dying and put me to realize, okay, I’m not going to do this. .... So, I sat them all down and we had that discussion. That’s what I need to do. That’s how I ended up getting my peace, because I’ve seen so much that my mother, my father, my brother, all along with cancer, all of this stuff. It’s horrible.” (#6)</li> </ul>		
Communicating poor prognosis		
<ul style="list-style-type: none"> <li>• “There is mistrust and a superstition that talking about illness could bring it about... I’ve experienced this first-hand” [described example of a patient’s husband believing that telling his family that his wife was going to die “poisoned her mind.” He said: “Black people do not talk about death and dying.” (#5)</li> </ul>	<ul style="list-style-type: none"> <li>• I kind of feel like your first response when doc just start asking questions like this will be ‘are you giving up on me already? Why are you asking me this? You’re not God. Are you giving up on me?’ I think that I would feel it if my doctor was asking me questions like that. Not if I was in a terminal state, then maybe those [ACP] questions would be good. (#7)</li> </ul>	<ul style="list-style-type: none"> <li>• “I see limited time frame for here, and the Man up there is the one who determines everything. So what I do is I try to keep a positive attitude. Try to stay happy and smile. ... So, like I said, when I look at it and when I think about it to myself, I say “Damn, I don’t have much time.” But y’all, I got a whole lot of time and I’m gonna do my bucket list thing and I will be happy. (#P2)”</li> </ul>
Care preferences		
<ul style="list-style-type: none"> <li>• “...being perceived as receiving inferior care throughout the course of life so at the end you want everything done. It’s the one time that you can say ‘don’t stop, keep going.’ (#1)”</li> </ul>	<ul style="list-style-type: none"> <li>• So I mean this is a conversation that I’m going to need to have and then I’m going to have to tell my husband what it is I want, because there are some things I just don’t want. I don’t want long suffering. I don’t want to be on any machines. I don’t want to be without my limbs. I don’t want to be without my kidneys, there are things I don’t want. I don’t want to live my life with somebody else having to take care of me. (#1)</li> </ul>	<ul style="list-style-type: none"> <li>• “...if she chooses not to do the chemo anymore because it’s not working for her. We don’t want her to suffer anymore. We’ll wish she’s already gone too. You know, so that’s what she wants to do.” (#F4)</li> </ul>
Preparation and control		
<ul style="list-style-type: none"> <li>• [Discussing barriers to MOLST or advance directive completion] “It’s not wanting to prepare. If you document something for your death, are you hastening your death by doing it? It’s the claiming it. That’s a lot of ministers are really trying to talk to the congregations to say doing well does not mean – they always – I mean, I’ve heard several say death is coming and you don’t have control over when it comes so doing it well doesn’t impact when death comes to you because it’s we don’t know. So they’ve tried to reinforce that.” (#1)</li> </ul>	<ul style="list-style-type: none"> <li>• “I think I would like to plan mine, too. I want to plan the way I go out. ... When my mom died, she had a smile on her face and she didn’t worry about us because we told like she went home in peace. There is something we can be a hinder [sic] and this is good that you’re going to write out different things that you want your loved ones to do whatever before you pass, because sometime when family pass you have so much arguments and stuff over things. So lots of time that have to be taken care of before one individual died.” (#5)</li> </ul>	<ul style="list-style-type: none"> <li>• “Just like I said, this journey to be made as pleasant as possible because it’s a journey all of us are gonna take. That’s inevitable. Unfortunately for them, is they have a disease but we all are going to die. Just like I said, it’s inevitable. So, we let [speaker’s sister, the patient] do her planning now while I give her a notepad so she can write. ... So she can make her own decisions. And it’s like ‘Well, mommy makes decisions when you can’t make them,’ but as long as she can make her own decisions, she makes them. She just have to write them down because she forgets sometimes. I’ve got the pad and her pen and write down what you want done and how you want it done. (#F6)”</li> </ul>

\* In reporting participant quotations, ellipses are used to minimize superfluous speech and enhance clarity of meaning. †P and F in ID# reflect status as patient or family caregiver. MOLST, Medical Orders for Life-Sustaining Treatment.

**Family and decision-making**

Participants uniformly validated the importance of family to ACP. Expert participants strongly emphasized the breadth of family—“it’s not just sons and daughters; it can be brothers, sisters, aunts, uncles” (group 1, #2)—the importance of family decision-making and how this challenges ACP processes focused on autonomous decision-making. These participants also highlighted clinician

training gaps in communication and cultural competency that leave them unprepared to engage multiple decision-makers.

Without deemphasizing practical aspects of family decision-making, community and patient-caregiver participants added that excluding family from decision-making—“Some people don’t want their family to know” (group 2, #8)—was a way to both minimize burden for surrogates and protect themselves



from family disagreement about limiting care. Family members' experiences of personal loss and conflict made them more receptive to participating independently in ACP: "...this is good that you're going to write out different things that you want your loved ones to do before you pass, because sometimes when family pass you have so much arguments and stuff over things. So lots of time that have to be taken care of before an individual dies" (group 2, #5).

### Communicating poor prognosis

Participants differed by group in their perceptions about how willing African Americans are to engage in discussions that include disclosure of poor prognosis. Expert participants highlighted "superstition" related to potential negative consequences of discussing dying. "Fundamentally, there may be a concern that bringing up the issue of EOL care is kind of 'speaking it' and that's something that will happen to the person" (group 1, #1). As a result, one expert said: "Don't ever give a timeframe. ... I err on the side of just giving a generalization (because) we don't know and we're not God. Me saying a timeframe breaks down trust and I'm not honoring their view of God and his power" (group 1, #4).

In considering prognostic communication as a part of ACP, community participants described the potential impact of such "negative talk," which might cause a frail person to "give up." For example, one participant stated: "Lots of times people don't want to die, but when you speak with negative talk around people when they are on a sick bed and they see you – you're crying like you don't have no faith for them" (group 2, #5). Patient-caregiver participants, by contrast, did not equate ACP or prognostic discussion with negative thinking. There was agreement among participants when one caregiver noted:

I appreciate a doctor being candid. ... you can't make an informed decision if you haven't been informed.... We were very fortunate to have one of the residents that came in there and, then Doctor X, they were so wonderful that we didn't go out. We left feeling positive, very positive and knowing what stages, you know, what this journey's gonna be like (group 3, #F3).

### Care preferences

Participants' descriptions of care preferences, along a spectrum from comfort- to cure-focused care, and their impact on ACP varied between groups. Expert participants emphasized a culturally normative desire for aggressive care among African American, obviating ACP unless they wished to limit treatment. As one noted: "People will not accept a recommendation to stop treatment at the EOL..." (group 1, #5). Community and patient-caregiver participants, by contrast, suggested that concerns about quality of life drove care preferences. Definitions of quality varied. One community participant said, referring to intensive EOL therapies: "there are some things I do not want" (group 2, #1); another commented in response that "if I ain't got nothin' but a head, then let me live" (group 2, #7). Participants described a difficult balance between a desire to fight and awareness of risks of invasive care. As one noted:

And I wouldn't go through (life-sustaining) measures. I told my mother I wouldn't, no matter what if the one treatment didn't work, I refuse to keep going on. I wanna have a good quality of life. Not longevity. I don't consider the longevity if I'm always in the hospital. They stare at me like a pin cushion and I gotta get this test and that test and nothing's working. ....

I'm done. My faith is what's going to get me through. So, that's what I'm counting on. (group 3, #P4)

### Preparation and control

Community and patient-caregiver (but not expert) participants emphasized preparation and control as ACP motivations. They valued EOL preparation and associated it with a personal sense of peace and peaceful death in family members. One described ambivalence about completing a living will: "I was really frightened about doing that, but I went and did that will and after I did [it] I felt so good" (group 2, #7). Another patient described not feeling prepared to complete an advance directive, despite awareness of terminal prognosis, ultimately ceding control to his daughter:

He explained it to me as what it was...and I was comfortable. I just did not – I didn't feel that I was ready to sign for it. ... It was more like an advanced directive-type...my daughter: she is mostly in charge of when I'm sick that I can't answer it, you know, I get – I have permission in my chart for them to ask her. But I just...not really legalized it paper-wise. I was just not ready for that yet. (group 3, #P4)

### Discussion

This study was designed to elicit multiple perspectives on ACP processes among African Americans, from those with a broad systems outlook to those for whom ACP is a proximate concern. It is the first to examine and compare barriers and facilitators to ACP from multiple perspectives. We anticipated different viewpoints. Although the identified influences on ACP echo those described in existing literature (Sanders et al., 2016), our data highlight divergent perspectives of experts with those of community members and seriously ill patients and caregivers. Although our methods limit generalizability, patients, caregivers, and some community members described attitudes and behaviors that defy or complicate stereotypes endorsed by experts and evident in the literature about ACP barriers. This suggests opportunities for alignment of practices to meet patient and family preferences in ways that enhance completion and impact of ACP.

Expert participants highlighted R/S as a barrier to ACP, because faith in God's control over the timing and circumstances of death obviates EOL planning. By contrast, patient and caregiver participants emphasized the strength derived from R/S. Although participants did not directly associate R/S with ACP, when taken with an expansive definition of religious healing described by community participants, which includes death itself, our data suggest that R/S need not necessarily impede ACP. Existing literature also suggests this possibility with work highlighting that efforts to engage clergy in ACP suggests that R/S communities may add value to ACP improvement efforts (Bullock, 2006; Medvene et al., 2003). Additionally, although one study of advanced cancer patients demonstrated that patients who receive a high degree of spiritual support from religious communities are more likely to undergo more intensive EOL interventions, those who received spiritual support from medical teams were less likely to do so (Balboni et al., 2013).

Many presume that agreement to withhold life-sustaining treatments is the predetermined outcome of ACP. Therefore, logic holds that mistrust born of historically valid concerns about withholding treatment might limit ACP acceptability. Whereas expert and community participants emphasized the role of mistrust as a barrier to ACP and unwillingness to engage

in prognostic communication because of mistrust or superstition, patient-caregiver participants described trusting relationships with clinicians that enabled discussion about sensitive issues, including prognosis. The nature of serious illness, and the frequency and intensity of relationships with clinicians, may foster trust in ways that more ad hoc engagements with the healthcare system undermine.

Participants uniformly validated the importance of family in ACP. However, where experts emphasized the presence of multiple decision makers in African American families as a barrier to ACP, community and patient-caregiver participants described the importance of independent decision-making in advance that could either protect family from decision-making, or protect themselves from family decisions that controvert their preferences. Evidence supports the viability of ACP in family-centric communities from other cultures (Tay *et al.*, 2017).

Patient-clinician relationships have a profound impact on illness and can enable ACP when characterized by rapport and respectful communication. Although long-standing relationships enabled rapport, participants felt that open-ended elicitation of goals and values and clinician kindness demonstrated respect.

These findings augment existing literature on ACP among African Americans. It is not the first study to demonstrate a lack of familiarity with ACP in the African American community (Daaleman *et al.*, 2008; Nath *et al.*, 2008). A recent systematic review modeled complex interactions between factors along a historical continuum of discrimination in ways that directly impact African American's ACP preferences (Sanders *et al.*, 2016). Consistent with studies of older adults or patients with poor health or serious illness (Bullock, 2006; Carr, 2011; Ford *et al.*, 2010; Johnson *et al.*, 2008b; Loggers *et al.*, 2009; Smith *et al.*, 2007), our results suggest that R/S shapes perceptions about control, the meaning of healing, and coping, and subsequently influences ACP. Likewise, our results complement other studies examining the role of interpersonal relationships (Braun *et al.*, 2008; Dupree, 2000; Hauser *et al.*, 1997; Hwang *et al.*, 2003; Mack *et al.*, 2010a; Rhodes *et al.*, 2015; Smith *et al.*, 2007; Volandes *et al.*, 2007; Wenger *et al.*, 2001; Williams *et al.*, 2008; Zapka *et al.*, 2006) and highlight both positive and negative influences on decision-making. Where some qualitative studies have highlighted the theme that "death is not an option" (Waters, 2001), our community-based and seriously ill patients and caregivers suggested a more realistic approach. Although other studies highlight the impact of mistrust on ACP (Sanders *et al.*, 2016), our findings suggest that the sole focus on mistrust as a defining characteristic likely oversimplifies the relationship that African Americans have with the healthcare system. This and other studies suggest the possibility that clinician-patient relationships provide the greatest influence on ACP for African Americans (Narasimhan *et al.*, 2014).

What are the potential implications of our findings? African Americans have a diversity of preferences. Seriously ill African Americans may have preferences regarding ACP that differ from those commonly highlighted in the medical literature. Such evidence risks being used to teach cultural competence, when in fact it may undermine it by inadvertently and inappropriately discouraging some clinicians from initiating ACP or disclosing prognosis to African Americans. Second, our findings suggest the need for an approach to improving ACP that emphasizes high-quality communication between clinicians and patients. The history of African Americans in the United States is characterized by systematic marginalization by healthcare and

other institutions (Tucker, 1994). Religion and family have developed unique importance to African Americans in response to their unique history (Ruggles, 1994; Sobel, 1979). The current study highlights that religion and family should also be seen as assets that can be engaged by healthcare systems and clinicians to enable and enhance ACP.

How might this be achieved? Our findings reinforce others' suggestion that ACP and prognostic disclosure should be offered to those with serious illness (Ahalt *et al.*, 2012; Smith *et al.*, 2011). This research raises the possibility that specific communication practices may lead to improved ACP with African Americans with serious illness, including enquiry about R/S beliefs and how they inform patients' illness understanding, acknowledgment of patients' and family's difficult experiences in the healthcare system, respectful exploration of individual goals and values, and exploration about the desired role of family in ACP (Kagawa-Singer & Blackhall, 2001). Exploring these beliefs, experiences, and goals demonstrates respect for patients and families and builds rapport by helping them feel known.

This study has limitations. We engaged a small sample in one southeastern US city. The number of participants and interviews likely preclude data saturation and present the possibility that themes are over- or underrepresented (or absent), and that comparisons are over- or understated. However, the themes highlighted by participants and patterns across groups align with what is historically known about African American engagement with healthcare and challenge common perceptions in ways that carry face validity. There is the potential for selection bias and response bias among participants providing feedback to race-discordant facilitators; the presence of eight women of nine church-member participants means that we may have missed additional male perspectives; and caregivers and patients may not have felt able to express themselves honestly in each other's presence. However, whereas previous qualitative studies are limited by nonrepresentative groups (young or healthy adults) (Sanders *et al.*, 2016), we included participants from key stakeholder groups identified by applying current (socioecological) theories regarding health disparities among African Americans. Also, evidence suggests the potential benefit of eliciting the shared perspective of patients and caregivers (Morgan *et al.*, 2013). We used multiple analysts with different academic backgrounds to address potential evaluative invalidity related to a subjective analytical process. Nonetheless, these findings require further exploration and testing in future research. Finally, despite our attempt to clearly frame the discussions about ACP, lack of familiarity with ACP meant that participants may have referenced other types of clinician-patient communication when commenting.

In conclusion, African Americans in our sample appear willing to discuss prognosis and comfort-focused treatment, expect to do so with trusted clinicians, and prefer to determine family engagement in decision-making based on their perceptions of personal and family needs. Clinicians must avoid making assumptions about patient preferences regarding ACP based on race or other cultural attributes and elicit individual beliefs and values. Efforts to improve ACP must be multipronged, with physicians and health systems taking an active role in improving communication and trust in a community of seriously ill Americans deeply touched by personal and structural impacts of racism.

**Author disclosures.** JJS's work on this project was supported by the Richard A. Cantor Fund for Communications Research in Palliative Care and KRS is

supported by a Mentored Research Scholar Grant in Applied and Clinical Research, MRSG-12-221-01-CPPB from the American Cancer Society. The authors report no conflicts of interest.

**Acknowledgments.** The authors thank Florine Johnson, R.N., for her gracious assistance in planning a focus group. JJS acknowledges the support of the Cambia Health Foundation, Jonathan Gass, and the faculty and staff of the Serious Illness Care Program.

## References

- Ahalt C *et al.* (2012) "Knowing is better": preferences of diverse older adults for discussing prognosis. *Journal of General Internal Medicine* 27(5), 568–575.
- Balboni TA *et al.* (2013) Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life. *JAMA Internal Medicine* 173(12), 1109–1117.
- Balboni TA *et al.* (2007) Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology* 25(5), 555–560.
- Billings JA and Bernacki R. (2014) Strategic targeting of advance care planning interventions: the Goldilocks phenomenon. *JAMA Internal Medicine* 174(4), 620–624.
- Braun UK *et al.* (2008) Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of General Internal Medicine* 23(3), 267–274.
- Bullock K (2006) Promoting advance directives among African Americans: a faith-based model. *Journal of Palliative Medicine* 9(1), 183–195.
- Carr D (2011) Racial differences in end-of-life planning: Why don't Blacks and Latinos prepare for the inevitable? *Omega (Westport)* 63(1), 1–20.
- Carrion IV, Park NS and Lee BS (2012) Hospice use among African Americans, Asians, Hispanics, and Whites: Implications for practice. *American Journal of Hospice & Palliative Medicine* 29(2), 116–121.
- Chiarchiaro J *et al.* (2015) Prior advance care planning is associated with less decisional conflict among surrogates for critically ill patients. *Annals of the American Thoracic Society* 12(10), 1528–1533.
- Crabtree BF and Miller WL (1992) *Doing qualitative research*. Newbury Park, CA: Sage Publications.
- Daaleman TP *et al.* (2008) An exploratory study of advance care planning in seriously ill African-American elders. *Journal of the National Medical Association* 100(12), 1457–1462.
- Detering KM *et al.* (2010) The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ* 340, c1345.
- Dupree CY (2000) The attitudes of black Americans toward advance directives. *Journal of Transcultural Nursing* 11(1), 12–18.
- Ford D *et al.* (2010) Factors associated with illness perception among critically ill patients and surrogates. *Chest* 138(1), 59–67.
- Gerst K and Burr JA (2008) Planning for end-of-life care - Black-white differences in the completion of advance directives. *Research on Aging* 30(4), 428–449.
- Hanchate A *et al.* (2009) Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites? *Archives of Internal Medicine* 169(5), 493–501.
- Hauser JM *et al.* (1997) Minority populations and advance directives: Insights from a focus group methodology. *Cambridge Quarterly of Healthcare Ethics* 6(1), 58–71.
- Hwang SS *et al.* (2003) Knowledge and attitudes toward end-of-life care in veterans with symptomatic metastatic cancer. *Palliative and Supportive Care* 1(3), 221–230.
- Institute of Medicine (2015) *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.
- Johnson KS *et al.* (2008a) Racial differences in hospice revocation to pursue aggressive care. *Archives of Internal Medicine* 168(2), 218–224.
- Johnson KS, Kuchibhatla M and Tulskey AA (2008b) What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of the American Geriatric Society* 56(10), 1953–1958.
- Johnson RW *et al.* (2010) Differences in level of care at the end of life according to race. *American Journal of Critical Care* 19(4), 335–343; quiz 344.
- Kagawa-Singer M and Blackhall LJ (2001) Negotiating cross-cultural issues at the end of life: "You got to go where he lives." *JAMA* 286(23), 2993–3001.
- Loggers ET *et al.* (2009) Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *Journal of Clinical Oncology* 27(33), 5559–5564.
- Mack JW *et al.* (2010a) Racial disparities in the outcomes of communication on medical care received near death. *Archives of Internal Medicine* 170(17), 1533–1540.
- Mack JW *et al.* (2010b) End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology* 28(7), 1203–1208.
- McLeroy KR *et al.* (1988) An ecological perspective on health promotion programs. *Health Education Quarterly* 15(4), 351–377.
- Medvene LJ *et al.* (2003) Promoting signing of advance directives in faith communities. *Journal of General Internal Medicine* 18(11), 914–920.
- Morgan DL *et al.* (2013) Introducing dyadic interviews as a method for collecting qualitative data. *Qualitative Health Research* 23(9), 1276–1284.
- Narasimhan D *et al.* (2014) Advanced directives (AD) implementation is difficult near to end-of-life: Efforts must be directed while healthy and with capacity. *Journal of the American Geriatric Society* 62, S195.
- Nath SB *et al.* (2008) A place called LIFE: Exploring the advance care planning of African-American PACE enrollees. *Social Work in Health Care* 47(3), 277–292.
- Polak L and Green J (2016) Using joint interviews to add analytic value. *Qualitative Health Research* 26(12), 1638–1648.
- Rhodes RL *et al.* (2015) Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development. *American Journal of Hospice & Palliative Care* 32(2), 137–143.
- Ruggles S (1994) The origins of African-American family structure. *American Sociological Review* 59(February), 136–151.
- Sanders JJ, Robinson MT and Block SD (2016) Factors impacting advance care planning among African Americans: Results of a systematic integrated review. *Journal of Palliative Medicine* 19(2), 202–227.
- Smith AK, Davis RB and Krakauer EL (2007) Differences in the quality of the patient-physician relationship among terminally ill African-American and white patients: Impact on advance care planning and treatment preferences. *Journal of General Internal Medicine* 22(11), 1579–1582.
- Smith AK, Williams BA and Lo B (2011) Discussing overall prognosis with the very elderly. *New England Journal of Medicine* 365(23), 2149–2151.
- Sobel M (1979) *Trabelin' on: The slave journey to an Afro-Baptist faith*. Westport, CT: Greenwood Press.
- Sudore RL *et al.* (2017) Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management* 53(5), 821–832.
- Tay K *et al.* (2017) Cultural influences upon advance care planning in a family-centric society. *Palliative and Supportive Care* 15(6), 665–674.
- Tucker RT (1994). Patient Self-Determination Act: An African American perspective. *Cambridge Quarterly of Healthcare Ethics* 3(3), 417–419.
- Volandes AE *et al.* (2007) Using video images of dementia in advance care planning. *Archives of Internal Medicine* 167(8), 828–833.
- Waters CM (2001) Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qualitative Health Research* 11(3), 385–398.
- Wenger NS *et al.* (2001) End-of-life discussions and preferences among persons with HIV. *JAMA* 285(22), 2880–2887.
- Williams SW *et al.* (2008) Communication, decision making, and cancer: What African Americans want physicians to know. *Journal of Palliative Medicine* 11(9), 1221–1226.
- Wright AA *et al.* (2008) Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 300(14), 1665–1673.
- Zapka JG *et al.* (2006) Care at the end of life: Focus on communication and race. *Journal of Aging and Health* 18(6), 791–813.