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Improving End-of-Life Care for Diverse Populations: Communication, Competency, and System Supports

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Abstract

Background: While disparities in end-of-life care have been well documented, explanations for the persistence of disparities are less clear. This study sought to examine diverse perceptions of end-of-life care, especially regarding how medical professionals can better serve all populations.

Objective: To investigate similarities and differences in end-of-life care preferences, across racial and ethnic groups.

Design: This work consists of a qualitative study utilizing in-depth focus group discussions.

Setting/Subjects: Six community-based focus groups were conducted with a total of 39 participants. Two groups were composed of African American participants; two had Latino participants; and two groups had white participants.

Results: Analysis produced three major themes: (1) Clear, comprehensive, and culturally relevant provider/patient communication regarding serious illness; (2) Provider characteristics & competency; and (3) Health system supports and barriers. While all groups had individuals who expressed a strong preference for direct communication, individuals varied within groups. All groups discussed concerns that the costs of care are high and that financial considerations are given more importance than high quality care. Groups diverged in their focus on provider characteristics and feelings of marginalization. African American and Latino groups emphasized a desire to match characteristics with providers, and African American groups discussed that their marginalization in the healthcare system requires hyper-vigilance to receive high-quality care.

Conclusions: Improvements in care would come from acknowledging diversity within groups, provider demonstration of comfort and competence, more effective care coordination, and recruitment of providers who share similar characteristics with the communities they serve.

Keywords

Healthcare disparities; health communication; terminal care; qualitative research; patient preference; cultural competency

Introduction

Racial and ethnic disparities in end-of-life care are documented across multiple research studies. When compared with white patients, racial and ethnic minorities experience greater barriers to quality end-of-life care, including lack of access to affordable care and limited cultural sensitivity within the medical establishment.^{1,2} Minority groups also receive lower quality of care when compared with whites, undergoing a greater percentage of aggressive life-sustaining treatment, and experiencing lower hospice and palliative care utilization.^{3,4} Minority patients and their family members also report lower satisfaction with care at the end of life.⁵⁻⁷

One way that disparities manifest is in patient/provider interaction. While studies have reported some differences in communication preferences, patients across racial and ethnic backgrounds often report a desire for openness and honesty from providers regarding diagnosis, prognosis and treatment. For example, a recent qualitative study of Hispanic families in hospice revealed a strong desire among patients and caregivers for education to understand the dying process and medical options.⁸ Despite this desire from patients, providers often report reluctance to discuss end-of-life issues. Explanations for this reluctance often include a focus on providing life-sustaining treatment, a lack of confidence with prognoses, lack of time, and concerns about distrust from patients.^{9,10}

Issues with cultural sensitivity also play a role in racial and ethnic disparities. Cultural values, such as level of trust in the medical system and spiritual beliefs, have been shown to influence care preferences and decision-making at the end of life.¹¹⁻¹³ Providers frequently lack understanding of these factors, and how they vary within and between groups.¹⁴ In one study, a palliative care team intervention focused on mediating distrust between patients and providers and emphasizing culturally specific values. This intervention was associated with an increase in formalized advance directives from one-third to more than 80% of patients, and earlier withdrawal of life-prolonging treatments in a large number of patients, demonstrating how stronger provider/patient understanding can lead to more informed decision-making for minority patients.¹⁵

Finally, systemic issues in health care create racial and ethnic disparities. Variations in access to and quality of care across groups have been well documented.^{2,3,16,17} Minority groups report more problems with finances and insurance and experience greater difficulty accessing services. For example, a recent qualitative study of Latinos on dialysis found that language barriers and health literacy were often compounded by socioeconomic disadvantage and logistical challenges to make chronic illness especially burdensome.¹⁸ Multiple studies have shown that African American populations experience lower quality pain management than whites, and are more likely to live in communities with limited access to opioids.^{19,20}

Given previous research demonstrating racial and ethnic disparities in end-of-life care, and provider difficulty with communicating about end-of-life issues, we sought to more closely examine attitudes regarding end-of-life care across racial and ethnic groups. In particular, we were interested in exploring perspectives on how medical professionals can better serve all

populations, regardless of race or ethnicity, at the end of life. Our research questions included: What similarities in care preferences exist across racial and ethnic groups? What preferences are unique to each group? What do these findings tell us about improving end-of-life care and reducing disparities?

Methods

Our approach included focus group discussions with community members who identified as African American, Latino, or white. Because we wanted participants to feel comfortable reflecting on ways their racial and ethnic group may differ from others, we organized groups to be racially and ethnically homogenous.

Participant recruitment

A total of 39 participants, across 6 groups (2 African American, 2 Latino, and 2 white), were recruited. Focus group participation was open to anyone over the age of 18 with the goal of capturing a wide variety of experiences and opinions. In order to recruit participants, we worked with community-based organizations serving African American and Latino adults. These organizations helped recruit and hosted the focus groups. To supplement, we posted an advertisement on an online community board to recruit white and Latino participants. Respondents emailed or called for screening to determine that they were at least 18 years of age, record their race/ethnicity, and gather other demographic information. Due to language, time, and budget restraints, all focus groups were conducted in English.

Data collection

Each focus group was held at a location convenient to participants in Los Angeles, CA, and lasted between 60–90 minutes each. Each participant received a \$20 gift card to a local retailer. The university institutional review board approved all research activities, and focus group participants provided informed consent in writing prior to the focus group.

All focus groups were moderated by an experienced member of the research team, with a second member taking written notes. The interview protocol is available in Appendix A. During the focus groups, we prompted participants to imagine themselves or a loved one dealing with a serious illness, and asked what they would want medical providers to know when caring for them or their family member. We probed for what supports they desired from doctors, what their care preferences entailed, and what they wished doctors would do differently.

Data analysis

We recorded all focus groups and transcribed them verbatim. An initial coding framework was created using literature on racial and ethnic diversity in communication preferences, cultural sensitivity, and access to healthcare, and guided by our research questions. We used ATLAS.ti to manage the coding process. Two members of the research team coded each transcript. Codes were reviewed and discussed during regular meetings between the researchers. Coding disagreement was reconciled as a group through conversation and

transcript review. The initial coding framework was revised and expanded throughout the coding process, and subthemes were generated inductively.

Results

Six focus groups were conducted with a total of 39 participants. Focus groups were divided by race/ethnicity – two groups included African Americans, two were composed of Latinos, and two had white participants. African American participants ranged in age from 30–80 years old, and most had completed some college. Latino participants had on average a high school education, and ranged in age from 25–92 years old. White participants ranged in age from 19–72 years old, and most possessed a Bachelor's degree (Table 1).

Focus group conversations produced three major themes: (1) The importance of *provider/patient interaction* when dealing with serious medical events; (2) the impact of *provider characteristics & competency* on patient satisfaction; and (3) *supports and barriers to care* within health systems. Table 2 provides an overview of themes and subthemes.

Provider/Patient Interaction

Focus group participants spoke frequently about their experiences with medical professionals, and the type of communication they desire from providers at the end of life. In our groups, several participants across racial and ethnic backgrounds said they preferred direct communication from providers regarding patient diagnosis, prognosis, and treatment options when facing serious illness. Honesty and openness from providers was highly valued by some participants, even regarding difficult subjects. A participant in the white group summed up a common refrain: “I personally wouldn't feel comfortable with a doctor who withholds information. I want to know everything.”

It is sometimes assumed that racial or ethnic minority groups do not prefer direct communication about difficult health-related news, but our findings show diversity within racial and ethnic groups.^{21–23} One African American participant explained: “I ask point blank, ‘Is he going to die?’ ‘Is she going to die?’ But they don't tell you that. [...] The relationship with the doctor is very important, you know, that you want to be able to talk freely with the person and get good care answers.” While direct communication from providers was a strong theme across all groups, the nature and amount of medical information a patient desires varied widely by individual, regardless of race/ethnicity.

Patient and family education was another important element of provider/patient interaction. Focus group participants said that the burden of health care education often falls on patients and their family members. Paperwork from providers can be cumbersome, and providers often do not have time to answer questions. One Latino participant said, “I had to personally educate myself about certain things about how they affected my mother, how they interacted with certain drugs she was taking. Just certain things that are pretty difficult.” This was echoed among white focus groups, with one participant suggesting more streamlined informational materials about different medical conditions. Notably, patient and family education was not specifically discussed among African American focus group participants.

Provider Characteristics & Competency

The personal characteristics and experience level of providers was an important theme, especially within the African American and Latino groups. Several African American and Latino participants stressed the importance of selecting a provider with whom they share similar characteristics, such as race/ethnicity, gender, and religious background. Matching with providers in this way provided a feeling of safety and shared understanding.

Cultural sensitivity of providers was frequently discussed among African Americans, and was also noted by some Latinos. Provider experience with different groups, and awareness and consideration of cultural values, was important in building trust among African American participants in particular. Participants pointed to personal experiences with providers who appeared to disregard their concerns based on racial bias. One African American participant explained:

I would want to know if they're culturally sensitive, if they have treated, for instance, the group here, the African American community. Because what I found is many instances of callousness in many doctors who treat African Americans as opposed to other races.

African American participants expressed feeling marginalized in health care settings, and spoke of a frequent need to advocate for better care for themselves and their family members. They believed that hyper-vigilance was required when interacting with providers. Said one African American participant, "We got to constantly mandate, monitor, and then challenge. That shouldn't have to be."

Participants in both the African American and Latino groups highlighted the importance of religious and spiritual beliefs, as well as emotional support. It was important to participants that providers consider religious values when discussing sensitive end-of-life care issues. Providers often presented information in a manner that felt disconnected or detached from the emotional experience of patients. One Latino participant suggested that a priest or chaplain should be in the room with providers when discussing end-of-life care, in order to ensure that religious and spiritual concerns are addressed.

Notably, white participants in our focus groups did not discuss provider characteristics or competency. Their primary concerns surrounded issues of access and quality within the health care system.

System Features

Issues with the health care system were mentioned across all groups. Access was a particularly important theme. Participants across all racial and ethnic groups discussed high health care costs, and described difficulties with health insurance. In all groups, participants felt that the cost of medical care was prohibitively high, and insurance companies had too much power in deciding what care they could receive. Many felt that financial considerations were prioritized above high quality care. Explained one white participant:

Insurance companies shouldn't be able to decide, 'Oh, well, we're going to cover this. If you twist your ankle we'll give an icepack, but you've got a terminal illness

and you're in severe, agonizing pain that morphine can't handle anymore, well, too bad.'

Quality issues within the health care system was another important theme across all groups. Participants spoke of subpar medical facilities, understaffed units, and poor care coordination. This was particularly salient among African American participants, many of whom described personal experience with dilapidated hospitals in their communities. Hospital staffing issues were also mentioned in all groups, with several participants discussing a need for more staff and better training for hospital personnel. Said one Latino participant, "The nursing staffs need to be increased, qualified nursing staff need to be increased for patients' care."

A lack of care coordination was frustrating to some. Participants in all groups described having to start over with each new provider, and keep track of complicated medical information themselves. They worried that this could result in something important being missed. Said one African American participant:

You may have fibromyalgia, you may have diabetes, you may have this, that, and the other, and the doctors are not communicating with the nutritionist. There's no wraparound care. [...] They say there is, but there's no care coordination, and that needs to happen. It needs to happen in a better way.

Discussion

We found that participants from diverse racial and ethnic backgrounds share common perceptions about end-of-life care, but differ in some key areas. All groups discussed a preference for direct communication from providers when facing serious illness, and spoke about high health care costs and difficulties navigating the health care system. The most prominent differences between groups arose in discussions about provider characteristics. African American and Latino groups described seeking out providers of similar race/ethnicity, and desired providers who demonstrate comfort in caring for people of color and sensitivity to the ways that culture matters. These themes were not discussed among white participants. Another key difference arose when African American participants spoke about feelings of marginalization within the health care system and the need to advocate strongly for themselves. This was a strong theme among African American participants, but was not specifically discussed among participants in other groups. These findings reinforce extant literature, but also highlight some new findings that require additional research.

First, in contrast to a common assumption that members of racial and ethnic minority groups do not prefer direct communication about their illness, we found that participants in all groups expressed a preference for open, honest communication.^{21–23} That is not to say that all participants agreed with this, or that these participants represented all people from these groups. However, it does show that there is diversity within racial and ethnic groups, and research and practice should acknowledge that diversity within groups. Additionally, providers should inquire about patients' current understanding and preferred knowledge about serious illness.²⁴

Second, our research shows that issues with high health care costs and difficulties navigating the health care system are concerns across racial and ethnic groups. Participants in all groups discussed the ways that care for serious illness is fractured, and expressed concern that financial considerations are placed above high quality care. A notable difference between groups arose when African American participants reported feeling a need to be hyper-vigilant to ensure high quality care. These feelings of marginalization were not specifically discussed in other groups, and may come in part from distrust of the health care system. It is important for providers to understand how feelings of marginalization and distrust manifest in patient and family members' experiences.^{11,16} Shifting the focus to partnering with patients and family members may help to improve trust as well as support coordination.²⁵

Finally, participants' perspectives on end-of-life care illustrate the continued need for interdisciplinary approaches and a focus on recruiting health care providers who share similar characteristics to the communities they serve. It is notable that while white participants did not discuss provider characteristics, this was a strong theme among African American and Latino groups. This suggests that end-of-life care would benefit from a focus on recruiting a more diverse workforce. Additionally, one participant felt that clergy should be involved in all end-of-life discussions while others talked about their concerns and questions as extending beyond medical concerns. While hospice care already takes an interdisciplinary approach, participants told stories of care in other settings – ICUs, long-term care, and primary care—that could benefit from a greater focus on interdisciplinary involvement.

Study limitations

Our qualitative approach is suited for understanding perceptions of end-of-life care, but does have some limitations. Our sample size is small and not necessarily representative. We recruited participants from Los Angeles, using community-based organizations and online postings, which likely produced a sample that is more urban, more involved in the community, or more technologically adept than average. Readers are cautioned not to assume these perspectives represent all persons from these groups. Additionally, our sample included people from a wide age range with various levels of experience with serious illness. We intentionally wanted a broad conversation, but some of the participants with less experience may have been less knowledgeable about care. Finally, focus groups were conducted in English only, due to time, budget, and language constraints. Conducting additional focus groups in a wide variety of languages would offer a more complete picture of end-of-life issues among diverse racial and ethnic groups. Even given these limitations, our contributions highlight the importance of examining perceptions of care.

Implications for clinical practice

Our research indicates that clinical practice could be improved through several recommendations. The first is to acknowledge diversity within groups. It is important to train providers in cultural competency, including the various ways that people make sense of serious illness.²⁶ However, tools and processes should be created to individualize discussions and not assume one's race or ethnicity alone reveals what is most important.²⁴ Second, part of that training for providers should focus on demonstrating comfort and

competence, no matter the background of the patient. Third, efforts should be made to more effectively coordinate care. While some perceptions of end-of-life care varied by race or ethnicity, all groups discussed problems in coordination. Finally, more effort should be made to recruit health care workers who share similar characteristics with the communities they serve.

Conclusion

Continued efforts to improve end-of-life care for all must integrate the perceptions and experiences of patients and their family members. Participants in this study came from a wide range of backgrounds, yet their discussions reinforced many of our current priorities in palliative care. Participants in this study were acutely aware of issues of disparities, cultural competence, access, and lack of coordination, and could be partners in attempts to improve care. Improving involvement of community members may also help to build trust across the continuum of care. As one African American respondent said:

Before doctors start throwing out pills [...], I want to know if they have a cultural sensitivity and how *they've helped our community to live* before they could tell me about what my options are in dying.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1:

Demographics of focus group participants

	Gender	Age range	Education range	N
African American (Group 1)	5 women 2 men	30–79	HS diploma – Professional degree	7
African American (Group 2)	6 women 2 men	40–79	Some college – professional degree	8
Latino (Group 1)	6 women 3 men	59–92	Below HS – HS diploma	9
Latino (Group 2)	1 woman 3 men	25–50	HS diploma	4
White (Group 1)	3 women 2 men	25–72	Bachelors – Professional degree	5
White (Group 2)	4 women 3 men	19–59	Some college – Bachelors	6

Table 2:

Themes & Subthemes

Theme	Definition	Example
Provider/Patient Interaction		
<i>Bedside manner</i>	Positive attitude & approach to patient	"My mother was ill for some time. I don't think the doctors were honest. Sometimes they would tell you the truth, but not all the time, and sometimes they didn't act as though they cared, even their bedside manners, to me, wasn't good and sometimes they weren't prompt enough about getting back a call when they know that the patient is seriously ill." - AA
<i>Patient & family education</i>	More & better education about diagnosis, treatment, prognosis	"I think on behalf of the physicians, what is needed more is just more interaction with the family, more education with the family in regards to, again, what to expect, how to deal with it, how to prepare yourself for it." - W
Provider Characteristics & Competency		
<i>Provider characteristics</i>	Characteristics of provider the same as patient, e.g. race/ethnicity, gender, etc.	"As I got older I felt I needed a female doctor and of my race, because now I could really talk in comfort." - AA
<i>Cultural sensitivity</i>	Provider awareness & consideration of the beliefs and practices that make up patients' value systems	"Focus on the patient in your face and talk to you in a way that you feel respected and heard. And when your family or loved ones are in the room, pay attention to what they're saying and not just dismiss them as if they're irrelevant." - L
<i>Religious & spiritual beliefs</i>	Provider awareness & consideration of spiritual concerns	"The doctor that performed the surgery on me that gave me the prognosis believed in Jesus Christ and [...] I feel comfortable with him performing surgeries on me." - AA
Health System Features		
<i>Access</i>	Barriers to health care access, including insurance/payment, pharmaceuticals, experimental/holistic interventions, etc.	"Is there anything available to her that her insurance company's going to authorize? Because that's another factor too. That's a real big factor if they don't authorize it." - L
<i>Quality</i>	Need for improved health care quality, including better facilities, more training of personnel, patient advocacy, etc.	"Perhaps if we are given priority as a patient, then it won't get to the pills. You won't get to the point where you do want to die if the patient is put first again, if the nursing staffs are increased." - AA
<i>Care coordination</i>	Need for better care coordination across the health care continuum	"A lot of the doctors don't look outside--they're there for their rounds, their two minutes or whatever; and then the quality of coordination of care is terrible." - AA