


“You Have to Be Part of the Process”: A Qualitative Analysis of Older African American Men’s Primary Care Communication and Participation

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Abstract

The objective of the current study was to understand older African American men’s perceptions of and experiences with patient–provider communication during primary care medical visits. Fifteen African American men age 50 and older participated in individual semistructured interviews. Open-ended questions focused on their primary care therapeutic alliance, preferences for decision-making, self-efficacy, patient satisfaction, communication, and companion participation during primary care medical visits. Emergent themes included the perception of rushed and inattentive care related to low socioeconomic status, inadequate information exchange about medical testing and follow-up care, welcoming the help of highly engaged companions, and proactively preparing for medical visits. Participants’ assertiveness, confidence, and persistence with health providers regarding agenda setting for their care were most prevalent and contradict extant literature portraying African American men as less engaged or informed patients. Older African American men, particularly those with low socioeconomic status, may benefit from additional support and advocacy to consistently receive patient centered care and communication.

Keywords

men’s studies, health communication, health inequality/disparity

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Background

Ineffective communication between older African American men and their health-care providers plays an important role in perpetuating the health disparities that affect this population (Epstein, Fiscella, Lesser, & Stange, 2010; Hawkins & Mitchell, 2018; Miller & Bennett, 2011; Mitchell, 2011). The availability of research focused specifically on patient–provider communication with older African American men is often limited to experiences with prostate cancer, HIV, or hypertension, common diseases with disproportionate incidence, and suboptimal outcomes in this population (Saha & Beach, 2011). However, patients encounter primary care settings most often to manage both

minor health-care needs and common chronic illnesses, making primary care an important setting for assessing experiences with patient-centered communication. African Americans and other people of color in the United States

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have a long and storied history of experiencing unequal health-care treatment due to their race or ethnicity (Arnett, Thorpe, Gaskin, Bowie, & LaVeist, 2016; Chandler, 2010; Thompson, Mitchell, Johnson-Lawrence, Watkins, & Modlin, 2017). Racially biased health-care encounters have been linked to poorer health outcomes, shorter medical visits, reduced patient satisfaction, lower likelihood of returning for follow-up medical visits, less effective patient-provider communication, and insufficient adherence to treatment recommendations for African Americans (Hall et al., 2015). Moreover, while patients of every racial and ethnic background, gender, age, socioeconomic status, and geography experience varied barriers to engaging with health-care systems and providers, African Americans face particularly pernicious difficulties in navigating the health-care system due to racial bias, such that perceived discrimination in medical encounters has been consistently linked to lower access to life saving treatments such as cancer screenings (Rogers, Mitchell, Franta, Foster, & Shires, 2017) and kidney transplantation (Lockwood, Bidwell, Werner, & Lee, 2016). In addition, the burden of discrimination is associated with unhealthy lifestyle behaviors such as smoking, getting fewer hours of sleep, and intake of dietary fat that places African Americans at increased risk for morbidity and mortality (Sims et al., 2016)—potentially bringing them in more frequent contact with primary care settings and subsequently, inequitable treatment.

Patient-Centered Communication and African American Men

Patient-centered communication is the health-care standard for patient-provider interactions that emphasizes trust, rapport building, and shared decision making between patients and their families, and physicians. It has been empirically associated with greater patient satisfaction, adherence to physician recommendations, and improved health outcomes (Greene, Hibbard, Sacks, & Overton, 2013; Miller & Bennett, 2011; O'Quin, 2013). Studies report that patients who are willing and capable of actively participating in medical visit communication receive higher quality communication from their provider than less engaged patients (Cegala & Post, 2009). Cegala and Post (2009) defined active patient participation as a patient's ability to seek information, present detailed information, act assertively, and express concerns during medical interactions. When patients actively participate in their medical visits, they can indirectly influence their health providers to reciprocally demonstrate increased patient-centered behaviors (Blendon et al., 1995; Cegala, Street, & Clinch, 2007; Morgan & Yoder, 2012).

African American patients do not experience the same degree of patient-centered communication during medical visits as White patients (Collins et al., 2002; Williams,

Haskard, & DiMatteo, 2007). Disparities in the content and quality of health communication during medical visits stem in part from unconscious racial bias among health providers, cultural differences in how health providers and some African American patients communicate, and lower utilization of health-care services among some African American patients (Cooper et al., 2012; Griffith, Ober Allen, & Gunter, 2011; Smedley, Stith, & Nelson, 2003; Street, Gordon, & Haidet, 2007). African American patients have reported communication from their physicians that is less informative, less supportive, verbally dominant, nonempathetic, and paternalistic (Adams et al., 2015; Williams et al., 2007). African American patients are also less likely than White patients to use active communication behaviors such as question asking and assertiveness in medical visits (Levit, Balogh, Nass, & Ganz, 2013; Schouten & Meeuwesen, 2006; Williams et al., 2007). These challenges in tandem with provider behaviors that are less patient-centered contribute to disparities in African Americans' health help-seeking and health communication, leading to poorer health-care processes and outcomes (Beach et al., 2011; Cooper et al., 2012; Hall et al., 2015).

African American men, in particular, face distinct challenges with health help-seeking, and accessing and participating in patient-centered communication in health-care settings. Specifically, experiences of everyday racism in combination with the salience of masculine norms are strongly associated with increased barriers to health help-seeking in large samples of African American men (Powell, Adams, Cole-Lewis, Agyemang, & Upton, 2016). Furthermore, unmet health information needs (e.g., the inability to get one's questions answered) during primary care visits are most pronounced among older African American men with less education and income, more concurrent chronic conditions, and poorer access to primary care via insurance and provider relationships (Perry, Mitchell, Hawkins, & Johnson-Lawrence, 2018). Although a few extant studies explore the impact of sociodemographic, interpersonal, and psychosocial factors on health help-seeking and health communication in primary care, they have largely failed to fully illuminate African American men's own perspectives and experiences with communicating and participating in primary care medical visits.

Extant research on how health communication impacts the health-care outcomes and experiences of African American men is mostly confined to specific illnesses that disproportionately affect them, namely HIV (Beach et al., 2011), hypertension (Beach et al., 2011; Martin, Roter, Beach, Carson, & Cooper, 2013), and cancer (Friedman, Corwin, Rose, & Dominick, 2009; Song, Hamilton, & Moore, 2012). The aim of this work is to provide missing details on older African

American men's first-hand experiences with primary care communication and participation, including their perceptions on how patient-provider communication, physician behaviors, and other health system factors influence the quality of their care.

Methods

This study employed semistructured qualitative interviews conducted by phone and audio recorded. Conducting qualitative interviews by phone is a common and viable data collection option, and phone interviews are chosen over in-person interviews often due to the ability to reach geographically or otherwise isolated participants, convenience in scheduling, lower cost, increased privacy for participants, the potential to neutralize power dynamics that can occur during researcher-participant interactions, and the relative emotional safety of discussing potentially traumatic experiences by phone instead of in person (Drabble, Trocki, Salcedo, Walker, & Korcha, 2016).

In the current study, each participant was interviewed once by phone for between 45 and 60 minutes. The semistructured interview guide was comprised of questions adapted from Donald Cegala's extensive research on active patient participation in both oncology and primary care settings (Cegala & Post, 2009; Cegala et al., 2007), and the work of Richard Street on patient communication skills (Street et al., 2007). Specifically, communication-related questions and follow-up probes were developed that were informed by both Cegala and Street's prior studies demonstrating that the style of a patient's communication during medical visits can influence how much and what type of information physicians offer to patients, and race plays a role in how African American patients are treated communicatively. Relevant research on patient activation also provided a lens for developing qualitative questions related to empowerment and self-efficacy during medical visits (Greene et al., 2013). The interview guide included additional supporting questions to qualitatively probe preferences for communication during medical visits.

Sample and Data Collection

Participants were African American men in a Midwest city, age 50 and older, English-speaking, and who had at least one (1) nonemergency interaction with a health-care provider in the prior 12 months. Initially, 35 men were recruited from a research registry of older African Americans managed by a research partnership between The University of Michigan and Wayne State University, and 15 men agreed to complete the phone-based interview. The institutional review board of The University of Michigan (IRB HUM00102185) and the community

advisory board that oversaw the research registry both approved the study. Selecting a sample of participants from an existing research registry helped to more quickly establish trust and rapport, as participants were aware that only researchers with approved and vetted studies through the registry would have access to their contact information for research purposes. Many registry participants were accustomed to and comfortable with phone-based research participation due to advanced age, lack of transportation, and flexibility in scheduling (Hall et al., 2016). Participants provided verbal consent over the phone to be interviewed and recorded by phone; participants' consent was audio-recorded. Three graduate research assistants in social work conducted interviews; they were trained and supervised by a social work researcher (PhD). Research assistants further sought to build trust and rapport with participants by using a telephone script to clearly communicate the purpose of the study and emphasize the importance of participant contributions, offering to answer any questions or terminate the interview at any time during the call, reassuring participants that any personally identifying information revealed in the course of the interview would not be retained during the transcription process, engaging in relevant small talk, and using probes to encourage participants to elaborate on brief responses. In addition, research assistants received pre-interview training and had access to a resource toolkit on qualitative interviewing to continually refine their skills. Interview quality was assessed on an ongoing basis by the leading social work researcher who listened to interview recordings and provided specific and ongoing feedback to research assistants on interviewing techniques and areas for improvement. In the absence of nonverbal cues, research assistants were trained to probe for richer details, move the conversation along as needed when participants were consistently uninterested or the question was not relevant to them, and ask for clarification when responses were inaudible or otherwise difficult to understand. Participants received a 20-dollar gift card incentive. Recorded interviews were encrypted, transcribed, and de-identified by the research team.

Coding. The overall approach to the data can be characterized as qualitative thematic analysis beginning with initial broader questions, including "How do the older Black men in the study exhibit confidence, assertiveness, express concern, and provide personal health information during primary care visits?" These questions were grounded in the specific behavioral components of patient active participation, such as asking questions, volunteering information, articulating preferences for care, expressing concern, or displaying affect or emotion that characterizes a patient's active involvement in the delivery, planning process, treatment, and follow-up of their

own care. The conceptual framing of active participation has been published in the literature (Cegala & Post, 2009; Cegala et al., 2007; Levit et al., 2013). The research team was comprised of the three graduate social work students who conducted interviews and the social work researcher. The research team coded assigned transcripts separately using Dedoose 7.6.21, an encrypted web application for managing, analyzing, and presenting qualitative and mixed method research data.

The research team then met at the completion of coding to discuss data analysis in a process designed to limit subjective bias in interpreting the qualitative data (Guest, MacQueen, & Namey, 2012; Saldaña, 2015). Each interview was conducted separately, such that the interview protocol was not altered based on prior interviews. The research team then met regularly during the data analysis phase to discuss and develop codes, deliberate over several coding methods, and work toward consensus, including discussing and agreeing upon when saturation was reached for particular themes that emerged. Dedoose 7.6.21 provided several qualitative data visualization tools, specifically interactive 3D word clouds that automatically developed as research team members separated coded their assigned transcripts in the broader linked data set. This word cloud, among other tools, were employed by the team to guide initial discussions about frequently coded categories and how several salient categories that were relevant to one another could be grouped into broader themes. The word cloud and other data visualization tools available in DeDoose were also linked to the segments of text they represented; this allowed the research team to easily return to coded segments and discuss the application of codes and labels, discuss and reach consensus on anchoring definitions of each code, develop rich descriptions for each broader theme, and select several participant excerpts to represent each theme. The qualitative themes that follow result from an extended iterative process and represent the research team's consensus regarding themes on men's lived experiences with navigating primary care communication and participation.

Findings

The final sample of 15 older African American men had a mean age of 65.9 years. Seven participants were both married and seven men reported a household income of \$40,000 or more. Eleven participants had some college education or higher, while only three participants reported having less than a high school diploma and one preferred not to reveal this information. Ten men out of the fifteen were retired, one reported being disabled and unable to work, and four reported engaging in full or part-time employment though their specific occupations were not recorded. Men's names and contact information were

provided by a registry of potential African American research participants age 55 and older; who reside within the city of Detroit or immediate surrounding metro areas.

Two of the primary themes identified, perceptions of rushed care and racial or ethnic bias in care and communication, focused on important reasons for dissatisfaction with the primary care health experience stemming from the perceptions of bias and larger structural issues with health-care delivery. The theme regarding companions as a source of support highlighted how older African American men in this study viewed and valued the contributions of their significant others who accompanied them on medical visits. The final theme concerning participants' confidence, assertiveness, and self-advocacy, revealed the salience of men's self-perceptions. Specifically, this theme demonstrated how men in the study felt fully capable of speaking up for themselves during health-care interactions, articulating their agenda as patients during medical visits, and seeking second opinions and new health-care providers if they felt their needs were not being met. These themes are summarized in further detail in the following sections.

Racial/Ethnic Bias in Care and Communication

The perception of bias in health care and communication focused on men's views that one's race has continuing significance for and impact on health-care experiences and outcomes. For example, participants reported feeling that their physicians treated them differently, or they witnessed physicians treat others differently based on what they believed was the patient's racial/ethnic identity, socioeconomic status (SES), or type of insurance. It is notable that almost all participants ($n = 14$) discussed at least one experience of perceived discrimination by physicians or hospital staff due to their racial/ethnic identity. Five men explicitly discussed racial discrimination as a consistent problem in health care.

There are proven disparities even today, within the medical community in relationship to the care and services provided to African American men and women, and the care and services related to Caucasians. (69-year-old African American male)

Participants also discussed how in their experience and opinion, physicians or health-care systems often do not adequately address health conditions and needs most pervasive among African American men.

I do think that there are certain conditions and diseases prevalent in the Black community and specifically to Black males that a general practitioner for the most part is not going to pay a whole lot of attention to. (66-year-old African American male)

It is an atmosphere where no Black people are represented and therefore, they don't know how to how to speak our language, and we may not know how to speak their language, so it affects how the care and services are given. (65-year-old African American, self-employed male)

Racial/ethnic bias, though often unconscious among providers, is relevant to perceptions of trust and treatment among medically underserved populations such as older African American men. Indeed, perceived racism in health-care interactions is the most powerful correlate of medical mistrust among African American male patients, even more so than masculine norms or sociodemographic factors (Hammond, 2010).

Perceptions of Rushed Care

In this theme, perceptions of rushed care served as a signifier for a broader health-care system that was inattentive to patient needs. Specifically, eight men in the study discussed being unsatisfied with the patient-provider communication specifically in relation to rushed care. Men reported feeling as if they were being treated as an impersonal number or as a box to check off rather than being seen as a person in need.

Some practicing doctors have a tendency to get into a routine of you being a number. (51-year-old retired athletic trainer)

Participants also discussed feeling as if their concerns expressed during medical visit communication were not being fully considered. One participant spoke at length about a situation in which he repeatedly described physical symptoms that he thought were indications of a potential cancer diagnosis. He strongly felt as if his treating primary care physician did not listen to his opinion, consider his own knowledge of his body to be legitimate, and that the physician was not responsive to his stated concerns. Within the context of inattentive and rushed care, six men discussed financial incentives or disincentives physicians may receive to move quickly through medical appointments and how these practices may negatively impact the quality of care received by patients.

They're more interested in making the money and patient care is not a concern or major concern as long as they get the money. (66-year-old African American male retiree)

The majority of the older African American men in this study did not feel that the appropriate time or attentiveness was given to their overall or communicative needs during recent primary care medical visits. These findings are supported by other qualitative studies of medically underserved patients who seek primary care interactions where they are not rushed through the

encounter, but rather they feel seen and listened to (Hammond, 2010).

Companions or Important Others as Sources of Support

The older African American men in this study offered pointed perspectives on the presence of important others during their primary care medical visits, underscoring how these individuals often play an important role in facilitating health communication and decision making. Specifically, twelve participants reported that they had brought a companion or important other with them to a primary care visit in the prior year; all indicated that they planned to continue doing so. Older African American men in this study were forthcoming about their reliance on companions or important others, including spouses, to support them during even routine medical visit communication. Among men who discussed a prior cancer diagnosis and associated medical visits, companions or important others were noted as important sources of support that aided in navigating complex care management.

He was my support system, when they told me I should have somebody with me, I knew it was serious and so he was my support system during the visit. (75-year-old single African American man, describing his fraternity brother who accompanied him to a medical appointment during which he received a cancer diagnosis)

She plays a large role, I mean she asks questions as well, and she has full participation. She can be supportive and bring up issues that I may have forgotten. (81-year-old married African American male referring to his wife)

Companions or important others were often discussed in the context of their role as communication facilitators. Six participants discussed the ways in which they relied on companions or important others to articulate their medical symptoms or concerns to a physician. Relatedly, men described how companions assisted during medical visits by clarifying physician instructions or recommendations to the patient.

My wife is like my second brain at visits. She would always ask questions, research what doctors said, have questions written down... if there are things I didn't understand or something got by me, she gets it. (51-year-old former athletic trainer)

Confidence, Assertiveness, and Self-Advocacy

A sense of self-assurance or confidence in men's ability to communicate with primary care providers was the third theme; it emphasized the sense of agency men

brought to the health-care encounter. Participants repeatedly emphasized their willingness to be assertive in advocating for the best health care. In nine interviews, participants discussed bringing their sense of agency to the medical visit, including having the confidence to shift the conversation if necessary, to better meet their needs. Some men felt confident that they could and would find a new health provider if their current physician or health team was not a good fit or was not delivering what they perceived as high quality care.

I always have control of the direction of the visit. (69-year-old married and retired African American male)

These doctors know me and they know if I say something, that's what I want. (85-year-old retired widower)

There are some people who may not have a good knowledge of or a good understanding of the language or terminology, they would need someone to help them pose questions to the doctor or get a better understanding of what the doctor was trying to explain to them. But, I don't need, you know, that kind of help. (60-year-old African American male)

Participants spoke frequently about advocating for themselves during medical visits, and referenced not being intimidated about speaking assertively when necessary in order to voice their concerns.

You have to be assertive. I don't feel that I have to be overly assertive, because my doctor responds to my feelings. But it's important to be assertive. (69-year-old married African American male with technical/trade education)

Being willing to step outside of patient-provider relationship to obtain additional expertise or confirm a health provider's diagnosis, which can be inconvenient and costly, demonstrates a high level of commitment to self-advocacy when necessary. Several participants indicated a willingness to do just that.

If I do not agree with my doctor's advice, I feel comfortable seeking a second opinion from another doctor or medical professional. (65-year-old married African American male, employed full time with a college degree).

Discussion and Implications

This article reports findings from a qualitative study designed to spotlight the primary care communication and participation experiences of older African American men in their own words. This study provides formative data about how some older African American men perceive the impact of racial bias and financially driven models that perpetuate rushed care, as significant barriers to engaging with primary care. Specific to racial bias, the

literature is clear on the harmful impact of perceived racial discrimination on African American's trust and utilization of health care. For example, one study on racial bias and medical mistrust among low-income urban African Americans found that medical mistrust accounts for the significant difference between African Americans' preferences for using the emergency department or outpatient clinics in contrast to Whites who utilized primary care as their main usual source of care (Arnett et al., 2016). It is also clear that African Americans broadly, and older African American men in particular, may feel that their health-care communication and treatment is hampered by a sense of being judged by who they are or what they can afford, which certainly engenders mistrust in the health-care provider and system. Such mistrust could discourage older African American men from engaging in routine care or obtaining the knowledge and tools from health providers to prevent or manage health conditions.

According to men in this study, trusted companions or important others also play an active and central role in facilitating medical visit communication, and in helping men to exercise self-advocacy and agency in navigating their primary care visits. Literature establishes that spouses, adult children, and other companions accompany more than a third of all adult medical visits in the United States (Wolff, Clayman, Rabins, Cook, & Roter, 2015). Companions and important others often aid in information recall, facilitate information exchange, advocate for patient needs, and motivate patients to adhere to treatment recommendations during medical visits (Wolff & Roter, 2011). However, most research on patient-provider and companion interactions has neglected to capture the experiences of African American patients and their supportive care needs and resources. More recently, one study has utilized novel archives of medical visit communication to observe, analyze, and characterize the communicative role that African American companions and important others play specifically on behalf of African American men with cancer (Mitchell, Hawkins, Williams, Egely, & Albrecht, 2019). Additional research is needed to illuminate the doctor-patient-family or important other communication and participation dynamic during primary care medical visits for this African American men.

While recognizing that older African American men as a population are not homogenous, it is important to contextualize, in men's own words, their explicit sense of agency and self-determination in contrast to popular narratives about their engagement in health care. Interviews with men in this study revealed a deep sense of health self-efficacy or self-assurance in the ability to take care of one's health. Self-assurance, assertiveness, and self-advocacy are not common narratives in public health and media portrayals of African American male patients, who are often portrayed as underserved under-utilizers of

routine and specialty health care (Dean et al., 2015; Hammond, Matthews, Mohottige, Agyemang, & Corbie-Smith, 2010; Thompson et al., 2017). However, these findings are well aligned with other studies on older African American men who consistently demonstrate high health-related self-efficacy, even when hampered by poor health-care access and other socio-environmental and health system barriers to care (Thompson et al., 2017). While confidence and assertiveness were prominent themes among this small sample of men, it is also important to consider that other subgroups of African American men may not have the resources or capability to exercise the degree of self-advocacy demonstrated by men in the current study.

Limitations and Conclusions

This study has some limitations that are important to note. First, the time-limited nature of the semistructured interviews means that the researchers may not have been able to fully capture the context behind men's narratives. Also, it is to be expected that the qualitative experiences of the men in this study may not be reflective of the broader population of older African American men. Also, it is beyond the scope of this study to determine or confirm the degree to which these findings are similar across diverse patient populations in primary care or are attributable to race. Finally, qualitative research is meant to study a specific phenomenon in context, and is not designed to be generalizable in the same sense that quantitative research is evaluated. Even still, the small sample size of the current study is a potential limitation for drawing implications from this work. These considerations notwithstanding, this study has the potential to contribute to the primary care of older African American men in several ways. First, this work clarifies the perceptions of patient-provider and companion communication during primary care medical visits for a small sample of older African American men and helps to shed light on their experiences with health-care bias in addition to their preferences for engaging with health providers in this context. Further, findings from this study have the potential to educate clinicians by dispelling harmful generalities about African American men's willingness to actively engage in primary care communication and decision making, while also foregrounding African American men's inherent strengths, including self-efficacy and advocacy.

These findings may also serve as a springboard for future research with larger samples and increasingly rigorous designs. Specifically, future investigations may reveal the dynamics whereby older African American men welcome their companions' inputs and active engagement in the patient-provider communication dynamic, and how

primary care providers respond to this dynamic—important issues that this study was not able to capture. Additional research on which subgroups of African American men are most likely to engage in self-advocacy could support the development of practice interventions to better support older African American men who may need assistance during medical interactions with identifying and speaking up about their informational needs, including ensuring that patients' questions are asked and answered. Research to undergird these types of interventions could improve older African American men's adherence to treatment recommendations and support their uptake of behavioral adaptations that improve the length and quality of their lives. Implications for clinicians might also include strengthening training on reducing bias in health care and engaging in culturally competent care with diverse populations, and continuing to promote self-advocacy and active participation among medically underserved populations in particular.

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