

African American Patients' Perspectives on Medical Decision Making

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Background: The medical literature offers little information about how older African Americans view the medical decision-making process. We sought to describe the perspectives of older African American patients in a primary care clinic as they consider a medical decision.

Methods: We interviewed 25 African American patients older than 50 years who had discussed flexible sigmoidoscopy with their primary care provider. Interviews were analyzed using qualitative methods.

Results: Patients listed concerns about cancer and health, risks and benefits, their own understanding of the test, and the recommendation of the provider as the most important factors in their decision. Most patients wanted information about medical tests and procedures to increase their understanding and to provide reassurance rather than to guide decision making. Most patients ex-

plained that they wanted the provider to make medical decisions because of his or her training and experience. Despite this, many expressed a sense of ownership or control over one's own body. Patients thought trust was built by a health care provider's honesty, patience, kindness, interest, and continuity of care.

Conclusions: Although traditional models of informed consent have emphasized providing patients with information to guide autonomous decision making, patients may want this information for other reasons. Fully informing patients about their medical condition increases understanding and provides reassurance. Because many of these patients want their provider to participate in making medical decisions, he or she should not only provide information but should also provide guidance to the patient.

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ALTHOUGH DECISIONS ABOUT medical treatment are made daily between health care providers and their patients, our understanding of the patient's decision-making process is incomplete. This is especially true for populations that have historically been underserved by the medical system, such as African Americans in an urban setting. A clearer understanding of the perspectives of African Americans toward medical decision making will facilitate the delivery of care that meets the needs and goals of the patients.

Recent literature has focused on inequities in the health care system that may affect the way African Americans perceive their medical care and interact with health care providers. For example, many researchers¹⁻⁷ have commented on the long history of distrust of the medical system by African Americans. This distrust may reflect abuses such as the Tuskegee syphilis study, as well as other well-documented disparities in medical care.^{8,9} Distrust may

affect African Americans' access to medical care, their approach to decision making, and their needs for information about their health care. Furthermore, research to date has predominantly focused on white patients and may not have identified other variables that are important to African American patients. A first step in understanding the decision-making process of African American patients is to ask them in an open-ended fashion what factors are important in their decision-making process.

Current models of medical decision making have focused on patient preferences regarding their role in the decision and their desire for information. Researchers have found that individuals vary widely in how actively they wish to participate in making medical decisions. The proportion of patients who wish to take an active role in decision making has ranged from 6% to 64%.¹⁰⁻¹³ When other researchers separated patients' desire for information from their preferred decision-making role, they found that more patients want information about their condition

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Table 1. Interview Guide: Topics and Sample Questions

Medical decision making

- What were the most important factors you were considering in making the decision to have this test?
- Can you tell me how the decision about flexible sigmoidoscopy was actually made between you and your physician?

Elements of informed consent

- Disclosure. Physicians are told to go through all of the risks and benefits of a test. How do you feel about patients receiving detailed information about the risks of a test/procedure?
- Voluntariness. If your physician wanted you to have a test but you did not want to go ahead with it, would you feel comfortable saying no? Why or why not?

Trust in the patient-physician relationship

- What kinds of things should a physician do to build trust with his or her patients?

Sources of information used by patients/patients' information preferences

- Where do you commonly get your information about medical conditions?
- What is the best way for you to receive information you would need to make a decision related to your health?

than want to take an active role in making the decision.^{11,14} The desire for information has not been significantly correlated with patients' preferences for active roles in decision making.^{14,15} This divergence suggests that the desire for information and the preferred decision-making role are two separate constructs for most patients.

Several researchers^{10,13,14,16} have evaluated differences by race and ethnicity in decision-making preferences; however, their findings are not consistent. Cooper-Patrick et al¹⁷ found that although patients of all races were more satisfied with physicians who used a participatory approach to decision making, African American patients had less participatory visits than white patients. The results of this study suggest that health care providers may not be adequately meeting the needs of African American patients.

To explore the important issues for African American patients as they consider a medical decision, we conducted in-depth, open-ended interviews with patients as they were considering a medical procedure. We began by exploring the important factors in decision making in an open-ended fashion. Because most of the literature on patient decision making has focused on the topics of information and the decision-making role, we included questions on these topics. In addition, because recent literature on the perspectives of African American patients has focused on the issue of trust, we included questions addressing this issue.

METHODS

DESIGN AND PARTICIPANTS

We conducted individual, semistructured interviews with patients as they were considering whether to undergo flexible sigmoidoscopy as part of colon cancer screening. We considered a qualitative approach to be most appropriate since there is little information in the literature about the decision-making process of older African Americans, and, thus, the important variables for these patients may not have been identified. These are 2 situations in which a qualitative analysis can be most helpful.¹⁸⁻²⁰ We considered flexible sigmoidoscopy to be a useful target procedure for several reasons. First, it is a common medical procedure that is recommended for adults older than 50 years as a routine part of colon cancer screening. However, it involves some degree of risk and some discomfort, and so the de-

cision to undergo the procedure often involves an active discussion between provider and patient.

Interviews took place between August 13, 1999, and November 19, 1999, in the general medicine continuity clinic at Grady Memorial Hospital in Atlanta. Eighty-nine percent of the patients at this institution are African American.²¹ Many are uninsured or underinsured. The health care providers in the clinic include attending physicians, residents, interns, nurse practitioners, and physician assistants. This study was approved by the Human Investigations Committee of Emory University.

During half-day clinic sessions, each consecutive patient's medical record was reviewed by an investigator and flagged if the patient was eligible for flexible sigmoidoscopy. Eligible patients were at least 50 years old. Individuals were excluded if they had a contraindication to flexible sigmoidoscopy, including previous flexible sigmoidoscopy or colonoscopy within 5 years, a history of heme-positive stool samples or rectal bleeding, iron deficiency anemia, colon cancer, or a current unstable medical problem. Patients were also excluded from the present study if they had a history of dementia or did not speak English (owing to the lack of available interpreters).

A form was attached to the medical record of each eligible patient notifying the health care provider that the patient may be eligible for flexible sigmoidoscopy and asking the provider to indicate on the form whether he or she discussed the procedure with the patient. Any patient who had discussed the procedure with a health care provider was then approached for an interview.

DATA COLLECTION

Interviews were conducted by one of us (A.M.T.) using a semistructured interview guide. Each interview was conducted immediately after the clinic visit. The guide was designed by us to address the major aspects of medical decision making, using open-ended questions. Many questions were followed by probes to further explore the topic. Questions in the interview guide addressed the following general topics: medical decision making (which included questions addressing the decision to undergo flexible sigmoidoscopy and patients' general decision-making preferences), elements of informed consent, trust in the patient-physician relationship, and sources of information used by patients/patients' information preferences (**Table 1**). Interviews were audiotaped and transcribed. Each audiotape was reviewed with its accompanying transcription for accuracy.

DATA ANALYSIS

Data were analyzed using grounded theory,^{22,23} a method for analyzing qualitative data in which theory is generated from a

Table 2. Characteristics of 25 Participants

| Characteristic | Finding |
|--|--------------|
| Sex, No. (%) | |
| M | 7 (28) |
| F | 18 (72) |
| Age, mean (range), y | 60.6 (50-75) |
| Education, mean (range), y | 10.5 (0-16) |
| Insurance status, No. (%) | |
| Uninsured | 4 (16) |
| Medicare | 11 (44) |
| Medicaid | 6 (24) |
| Other | 4 (16) |
| Previous flexible sigmoidoscopy, No. (%) | |
| Yes | 4 (16) |
| No | 21 (84) |
| Patient had signed other consent form, No. (%) | |
| Yes | 14 (56) |
| No | 11 (44) |

systematic examination of the data. The systematic analysis involves coding, which helps to organize the data by labeling major themes and categories and organizing the data according to these categories.

Using this method, one analyst (A.M.T.) identified important statements in each interview and labeled each one. These labeled statements were organized into broader categories. Two of us (A.M.T. and G.M.C.-S.) met regularly to discuss emerging categories. Patients' statements with accompanying labels were sorted by category and reviewed to identify common themes. Research team meetings involving all of us (A.M.T., G.M.C.-S., and W.T.B.) were used to refine the categories, to develop theories from the data, and to identify representative quotes for each of the major topic areas. At each team meeting, we reviewed the interviews to determine whether we had reached theoretical saturation, or the point at which interviews yielded no new themes. We reached this point after 25 interviews. Our analysis identified 5 major categories: patients' considerations in making the decision, patients' desire for information, patients' desire to participate in decision making, importance of trusting the provider, and control over one's own body.

RESULTS

PATIENTS

Four hundred ten patient medical records were reviewed during 23 half-day clinic sessions. There were 202 patients whose medical records were flagged as being eligible for flexible sigmoidoscopy. Of these, 55 discussed the flexible sigmoidoscopy with their provider and were therefore eligible to participate. Twenty-six patients agreed to be interviewed. The most frequent reason for refusal to participate was not having enough time. Of patients who refused, the mean age was 64.38 years (vs 60.64 years for those who agreed to participate). Those who refused were 72% female (vs 72% females for those who participated), and 28% were uninsured (vs 16% of those who agreed to participate). Data on education and self-identified race was not available for individuals who refused. One interview was stopped after it became apparent that the patient was unable to understand the interview questions secondary to dementia.

Table 3. Major Factors in Deciding Whether to Undergo Flexible Sigmoidoscopy

| |
|---|
| Concern about cancer |
| Concern about developing cancer |
| Cancer in a family member or friend |
| Risks and adverse effects |
| Pain/discomfort |
| Fear of the test |
| Benefits/importance of the test |
| Desire for knowledge |
| Prevention of disease |
| Desire to diagnose a current symptom |
| Provider recommendation/provider information |
| Understanding/lack of understanding of the test |
| Concern about health |
| Need for the test at a certain age |

Twenty-five interviews were conducted (**Table 2**). Interviews took an average of 22 minutes to complete (range, 12-45 minutes). Two patients did not complete all the questions owing to time constraints. Patients ranged in age from 50 to 75 years. Although all patients attending the clinic were screened for participation, all interviewed participants were African American.

At the time of the interview, patients were at varying stages of the decision-making process. Some had definitively decided to accept or refuse flexible sigmoidoscopy, whereas others were undecided. Data were not available on which patients went on to undergo the procedure.

PATIENTS' CONSIDERATIONS IN MAKING THE DECISION

We categorized the most important factors listed by patients in their decision to undergo flexible sigmoidoscopy. We identified 6 different topic areas (**Table 3**). Concern about cancer was the most commonly listed reason. As one patient said:

The only way I can find out, do I have colon cancer, is to take this test.

Many patients raised concerns about pain and adverse effects. For example, one patients expressed feeling

frightened, you know, a little nervous [about] the feeling of it . . . whether or not it would hurt, which I wouldn't know because I never had one.

The recommendation of their provider was considered to be an important factor in decision making by many patients:

Dr ___ said it was time to have it again—checking for cancer and bleeding.

PATIENTS' DESIRE FOR INFORMATION

Most patients wanted to know all or most of the details about a test, as well as the risks and benefits. When we

explored the motivation for wanting to know these details, patients most often cited a desire for more knowledge and understanding about their own health:

I like to know what is going on with my body.

This is my body. I want to know what's going on inside of there.

Their other reasons included providing reassurance and alleviation of fear, finding out if any other tests were needed, and verifying that "things were being done right." Only one patient wanted to know details to guide decision making. A few patients who wanted to be told less than all of the information listed anxiety and fear as reasons for not wanting to know the details.

PATIENTS' DESIRE TO PARTICIPATE IN DECISION MAKING

We asked patients whether they wanted medical decisions to be made primarily by themselves, by their health care provider, or by both. Twelve of 25 patients wanted the decision to be made primarily by the provider. Many patients who wanted the decision to be made by the physician cited the physician's training and experience:

Well, she knows more about all that than I would . . . she's probably heard about it and knows about it, this is my first time knowing about it. That's why I'm here now because she makes all of the decisions and I go by what she says.

Five patients desired a joint decision:

Subject: I prefer to participate with my doctor.
Interviewer: Why?
Subject: Because this is my body and I love it.

Three patients wanted to make the decision themselves. Five patients gave responses that could not be classified.

IMPORTANCE OF TRUSTING THE PROVIDER

Patients were asked in an open-ended way to describe the role of trust in their relationship with their provider. Many responses demonstrated the importance patients placed on trust in the therapeutic relationship:

I like to trust someone, especially dealing with my life. Most of all I trust God, he is the highest over everything, but I have a nice doctor, I trust him and believe in what he says. He breaks it down to me where I can understand what is going on with my body or whatever. Just tell me the truth. I think I can survive just about everything if somebody is honest with me.

Well, I think trust is just as important as anything else. If you don't have trust and faith in a person, it's lost.

When asked what builds trust, patients mentioned truth telling most commonly. Other important concepts included patience, kindness, showing an interest in the patient, and continuity in the clinical setting. Patients listed perceived dishonesty or withholding information and ap-

pearing hurried or rushed as factors that broke down trust. Several patients mentioned that having to frequently change physicians in the medical clinic impeded the development of a trusting relationship.

When queried about trust, several patients recounted experiences that had either positively or negatively affected trust in the patient-physician relationship.

A woman having a positive experience of trust in her physician as she was treated for venous stasis ulcers:

. . . they were very good to me. Very good. They would explain to me from time to time what they were doing and had to do because that was a very, very painful procedure when they had to debride it, you know.

The negative experience of a patient hemorrhaging after childbirth and returning to a hospital for a dilation and curettage:

. . . I felt betrayed you know. He didn't tell me what was what because I never would have left . . . So, after that I kind of got scared to go back to the hospital. I wasn't the only one like that; it was a bunch more girls coming back with pieces of after-birth, back then . . . left up in them.

The negative experience of a patient feeling dizzy after a bone marrow biopsy and watching her physician leave the room and not return:

It unnerved her so that she left . . . I would like to ask her, what happened to you? Why did you as a doctor, I know that you are human just like I am and things will upset you, but why did you go away and you didn't return?

These vignettes illustrate that even today health care providers demonstrate varying levels of sensitivity to and understanding of their patients' experiences.

CONTROL OVER ONE'S OWN BODY

A consistent theme of patients was a feeling of control over one's own body or one's life. In fact, when we asked patients whether they would feel comfortable saying no to a procedure they did not want, only 3 said that they would feel uncomfortable refusing. One related his experience refusing a nephrectomy:

I wanted another opinion rather than letting the first doctor that come along just take it out. You know after all it's your body.

COMMENT

Overall, we believe that this group of older African American patients presented a coherent account of the factors that influence their decision making. Most important in the decision to undergo flexible sigmoidoscopy are concerns about cancer and health, comfort in knowing the characteristics of the test, including its risks and benefits, the patients' perception of their own understanding of the test, and the recommendation of the patient's personal health care provider. Although patients strongly

value the opinion of the health care provider, most still say that they would feel comfortable refusing a test or procedure that they did not want. Patients often express a feeling of ownership or control over their own bodies, although the provider's recommendation heavily influences them.

When asked in an open-ended fashion, patients did not mention trust as a factor in their decision-making process. However, when queried about trust, almost all agreed that it is an important feature in the relationship with their physician. We identified important elements in the development of trust from the patients' perspectives. Honesty and interpersonal skills such as patience and kindness are most often mentioned as important to developing trust. Disruptions in the continuity of the relationship, perceived dishonesty, and appearing hurried and unable to spend time with the patient are identified by patients as barriers to trust.

Our results are consistent with previous research, which showed that patients want their physicians to participate in medical decisions in a variety of clinical settings, including cancer (80%-90% of patients wanted either a physician-led or a collaborative decision)^{24,25} and hypertension (97%).¹³

Our findings also confirm that more patients want information about medical tests and procedures than want to play an active role in decision making.^{11,14} Previous studies did not explore the reasons for this difference in patient preferences. Our study identifies several reasons why patients desire information besides guiding their own decision. Many patients want to increase their understanding and knowledge about their own health. They feel that more information provides reassurance and alleviates fear. These additional reasons provide justification for fully informing patients even when they prefer to follow the recommendation of the physician or other provider.

This finding has implications for the concept of autonomy in the patient-physician relationship. Patient autonomy has been emphasized in recent years, largely as a response to paternalistic models of the patient-physician relationship that guided medical practice in a previous era.²⁶⁻²⁸ The modern focus on autonomy led to new models of the patient-physician relationship, in which the physician provides technical expertise and information but allows the patient to independently make decisions. The doctrine of informed consent has largely grown from such autonomy-based models of the patient-physician relationship.^{27,29}

These models exclude certain values that are important to the patient-physician relationship, such as the physician's guidance and caring. Several researchers^{27,28} have proposed alternative models that include the patient's and the physician's values and preferences. Results of the present study suggest that such models, stressing mutual patient and physician participation in decision making, better account for the wishes of patients like ours. In fact, many older African American patients in our study regard the recommendation of the physician as one of the most important factors in their decision making.

Nevertheless, our findings support fully informing the patient about his or her medical condition, tests, and

procedures for several reasons. First, autonomy is an important part of mutual decision-making models. We suggest that the physician has a duty to enhance the patient's autonomy to the greatest extent possible so that respect for autonomy balances caring and guidance. Our patients also indicate that they want health care providers to provide them with as much information as possible. This enhances their comfort with the procedure.

In addition, patients form opinions about their physician's skill and trustworthiness through discussions with their physicians. Our findings provide evidence that trust in the health care provider is built through the provider's honesty, openness, and willingness to provide information to their patients.

We used the findings of our qualitative study to identify the important factors for patients as they make a medical decision. Further research using quantitative methods will be important in better characterizing the preferences of patients like those in our study. A strength of our qualitative study is that we could characterize the patients' perspectives without imposing preconceived concepts about what they would find important. A possible limitation of this study is that all patients were interviewed by one of us (A.M.T.), a white physician. The race discordance between patients and interviewer may have affected the results because patients may have been less likely to express their negative views about physicians and the health care system to someone who they regarded as part of the system. Because all of our patients were African American, we could not determine which of our patients' beliefs or attitudes are more common in African Americans than in patients of other races. In addition to race, factors such as socioeconomic status and geographic location may play a role in the development of beliefs and attitudes about health care. Another limitation of this study is that our descriptions of patients' decision-making processes cannot necessarily be generalized to other patient populations. Patients who are middle class or upper class, younger, or from other racial and ethnic groups may approach medical decision making differently. Patient-physician relationships in private practice may also differ from the predominantly resident-based clinic in which this study was conducted.

The variables that we identified create a picture of the process of decision making for many older African Americans in an urban public hospital. Our findings can provide guidance for physicians as they counsel a patient about a medical procedure. Physicians should provide information about the medical condition at issue and the procedure itself, and they also should provide their own recommendation about how to proceed. Physicians must realize that the patient may give paramount importance to the physician's recommendation and yet still feel ownership over his or her body and expect to have his or her right of refusal respected. Factors that enhance trust, such as patience and kindness, should be incorporated into the physician's style of conversation. Our findings support mutual decision making that includes the guidance of a physician or other health care provider while respecting patient autonomy.

We also recognize that our patients expressed a variety of opinions and preferences. There were differ-

ences in each patient's desire for knowledge and participation that should be incorporated into the physician's approach. Rather than identifying a uniform decision-making protocol, our study suggests a framework within which a physician or other health care provider should consider working in settings like ours. Such an approach should remain flexible in responding to individual patient preferences.

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