ASCRIBING MEANING TO HYPERTENSION: A QUALITATIVE STUDY AMONG AFRICAN AMERICANS WITH UNCONTROLLED HYPERTENSION

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Objective: The objective was to elicit patients' perceptions regarding the meaning of hypertension and to identify the personal, social, and environmental factors that might influence their perceptions.

Design: Qualitative study

Setting: Adult ambulatory care practice

Participants: African American patients with uncontrolled hypertension

Intervention/Methods: In-depth structured interviews were conducted with a purposive sample of 60 patients. Interviews were audiotaped, transcribed verbatim, and analyzed by using grounded theory.

Results: Patient descriptions of hypertension were grouped into three categories: 1) their thoughts on hypertension; 2) the consequences of hypertension; and 3) the impact that having hypertension had on their lifestyle. Factors that might have shaped how patients described hypertension were grouped into three categories: 1) the experiences of their social networks such as family and friends; 2) their personal experiences; and 3) information about hypertension that they might have gathered from the medical literature or during an encounter with a healthcare provider. Patients with family members who had experienced hypertension-related complications such as stroke were more likely to view hypertension as a serious condition. Patients who themselves experienced hypertension-related symptoms and who also had family members with a history of hypertensive disease were more likely to describe a willingness to make lifestyle changes.

Conclusions: In this study, personal experiences, experiences of family and friends, and encounters with the healthcare environment influenced patients' perceptions of hypertension and their willingness to make lifestyle changes. These findings can be used as a framework for helping to tailor effective and culture-specific interventions. (*Ethn Dis*. 2007;17:29–34)

Key Words: African American, Hypertension, Qualitative Study

INTRODUCTION

Approximately 17,000,000 African American adults have hypertension.[1–3] African Americans experience hypertension at an earlier age and have higher morbidity and mortality rates than do Whites. For example, compared to Whites, African Americans have almost twice the rate of hypertension-related fatal stroke, one and a half times the rate of heart disease death, and almost four times the rate of end-stage kidney disease.[4–8] One explanation for this disparity might be the discrepancies between the patient's and healthcare provider's understanding of hypertension and its management.[9–11] In order to effectively reduce the burden and adverse effects of hypertension among African Americans, healthcare providers must first understand the cultural and social factors that shape their perceptions of hypertension.

Patients have their own perceptions as to what hypertension means and how it should be treated. Eliciting patients' explanatory models of illness provides a basis for understanding the way in which patients conceptualize the cause, course, and appropriate management of an illness.[12,13] Explanatory models result from a myriad of social and cultural experiences that may, in part, influence health outcomes, health-seeking behavior, and adherence to recommendations.[11,12,14–16] Patients' explanatory models often differ from their physicians' biomedical models of disease and therefore may be unknown or less understood by the physician.[17] Patient explanatory models may also help to clarify the factors that helped to shape their understanding of an illness. Without an understanding of the patient's perception of illness, physicians may make recommendations that are incongruous with the patient's beliefs and that are inconsistent with their reality. Therefore, understanding how patients perceive illness and factors that influence their perception can improve the provision of quality care that is responsive to their specific needs.

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Among African Americans with hypertension, our objective was to elicit

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patients' perceptions regarding the meaning of hypertension. In addition, the personal, social, and environmental factors that might underlie how patients conceptualize hypertension were also identified.

METHODS

Study Design

This was a qualitative study conducted among 60 African Americans with poorly controlled hypertension who were patients in a primary care practice.

Sampling and Participants

Participants for this study were recruited from July 2003 through January 2004. The sampling technique used in recruiting patients involved a combination of convenience sampling and random purposive sampling. Purposive sampling is often used to recruit participants who are best suited to provide a full description of the phenomenon being studied.[18] During the study period, the charts of all patients who met the eligibility criteria were reviewed. Eligibility criteria were African American ethnicity, age $\geq$18 years, and uncontrolled hypertension as defined according to JNC 7 guidelines[19] (systolic blood pressure $>$140 mm Hg or diastolic blood pressure $>$90 mm Hg), despite having been prescribed an antihypertensive medication. All patients who met eligibility criteria and who gave informed consent were approached. From this convenience sample, purposive sampling was used to select the final participants by selecting only those patients who were able to describe their experiences with hypertension. Ineligible patients were those who were medically unstable or were unable to provide informed consent.

Data Collection

In-depth interviews were conducted by trained interviewers who used a standard guide. The standard interview guide consisted of an introductory question, which was followed by a series of open-ended question. Each interview began with the following probe: "While doctors have special ways of understanding illness, you may also have ideas, which may be different from what doctors think. It will help us to help people with high blood pressure if we understand how it affects you and what high blood pressure means to you." Patients were then asked the following series of open-ended questions:

1) What does high blood pressure mean to you?
2) What has been your experience with high blood pressure?
3) How has it changed your life (positively or negatively)?
4) What has made it easier or harder for you to take your medication?
5) What advice would you give to others with high blood pressure?

All interviews were audiotaped and transcribed verbatim. Informed consent was obtained before each interview.

Data Analysis

Transcripts were analyzed by open coding. Each transcript was analyzed line by line to create labels and generate preliminary concepts. Similar concepts were grouped to form larger categories, which were then examined for their properties and dimensions. Categories that shared similar properties and dimensions were grouped. After analyzing patients' understanding of hypertension, all transcripts underwent a secondary analysis to identify factors that might have influenced their descriptions. The Ethnograph (http://www.qualisresearch.com) software program was used for data management.

To ensure the trustworthiness of our data, several steps were taken.[20,21] First, we recruited a wide range of participants who had different hypertension experiences and who were from different age groups. Second, detailed notes of each interview were maintained and reviewed throughout the coding process, and weekly meetings were held to refine concepts and categories. When discordant views regarding the interpretation of findings arose, the raw data were reviewed and new categories were derived until a consensus was reached.[22,23] Finally, two independent corroborators, who were not part of the initial coding process, reviewed the original transcripts and decided whether they agreed with the final concepts and categories. The study methods and protocol were approved by the institutional review board of Weill Medical College.

RESULTS

Qualitative interviews were conducted among 60 patients. The mean age of participants was 61, with a range of 29 to 84 years. Of these participants, 92% were female, 54% were married, and 88% completed high school. The average duration of hypertension was 13 years. When patients were asked to describe the meaning of hypertension, their responses were ultimately grouped into three broad categories: 1) their thoughts on hypertension; 2) the consequences of hypertension; and 3) the impact that having hypertension had on their lifestyle. A fourth category was created for patients who were unable to ascribe a meaning to hypertension.

Thoughts on Hypertension

In their description of hypertension, patients often discussed what they believed hypertension was or how they acquired hypertension, which was further categorized into four subcategories: inherited, stress-related, behaviorally mediated, and biologically mediated. Table 1 describes the categories, subcategories, and key concepts that emerged from patient responses.

Patients often stated that hypertension was an inherited condition. One patient said "*My father has had high blood pressure. My family members had it.*

Table 1. Taxonomy of patients' descriptions of hypertension

Category	Subcategories	Concepts
Thoughts on hypertension	Inherited	Hypertension is passed on from other family members. Hypertension involves the entire family.
	Stress-related	Hypertension is induced by stress or by getting upset.
	Behaviorally mediated	Hypertension is a result of not adhering to healthy behaviors such as eating too much salt, not exercising, or drinking.
	Biologically mediated	Hypertension causes changes in the body that affects organs such as the heart.
Consequences of hypertension	Death	Hypertension can lead directly to death or is associated with other conditions that then lead to death.
	Other serious conditions	Other serious conditions can occur as a result of having hypertension.
	Symptoms	Certain symptoms are associated with hypertension that may indicate or be a clue to when the blood pressure is elevated.
Impact on lifestyle	Restriction	As a result of having hypertension, there are certain behaviors that one can no longer engage in.
	Adopt new behaviors	Hypertension is a life-altering condition that causes one to modify their health behaviors.

My uncle passed away from a heart attack.'' Many patients stated that hypertension was caused by stress. For example, one patient stated ''*High blood pressure means there is a lot of stress in my life. I really think it is a crazy thing, in my case, I believe it is all emotional, I had low blood pressure until my father died*.''

Patients also described hypertension as being associated with certain health behaviors. In particular, they believed that diet was associated with hypertension, for example: ''*High blood pressure means that I have obviously consumed too much salt*,'' Being overweight was also attributed to having hypertension. One patient stated, ''*I was not entirely surprised, it is hereditary. I am overweight; I expected it*.''

Some patients described hypertension in terms of the physiologic processes that occurred. For example, ''*Well, I think it's a resistance to the blood that flows through the body*.''

The Consequences of Hypertension

The consequences that patients attributed to hypertension were grouped into three subcategories: morbidity, mortality, and symptoms. Many patients believed that hypertension could lead to death. For example, a patient said, ''*Well, it is a very dangerous thing to have. It can cause stroke, cause a number of things, you know, you have to be careful with your salt intake and several other things. I mean, it's just something I would rather not have*.'' Other patients were more focused on the symptoms associated with having hypertension. Neurologic symptoms such as dizziness, lightheadedness, and headaches were most often described.

The Impact That Having Hypertension Had on Their Lifestyle

The impact that having hypertension had on their lifestyle was further categorized into two subcategories, restrictions patients thought it imposed on their lives and new behaviors that they decided to adopt. For example, ''*High blood pressure sort of hinders a lot of things that you would like to do and you cannot, like foods that you would like to eat. But you cannot because you know they do not agree with your pressure*.'' The most commonly described behavior change was having to ''watch what you eat.'' For many, hypertension meant other lifestyle changes: ''*It changed my life. Well I gave up alcohol, started exercising, and gave up really spicy food*.''

Unable to Ascribe a Meaning to Hypertension

Some patients had difficulty in ascribing a meaning to hypertension, possibly because their hypertension was actually diagnosed while they were receiving care for another condition. Some patients actually attributed the diagnosis of hypertension to the other condition, for example, ''*Well, I didn't know that I had blood pressure until I had this cancer thing in my neck and they gave me this chemo and radiation and that is when I got the high blood pressure*.''

The Factors That Shaped the Descriptions of Hypertension

The ways in which patients described hypertension were primarily by three factors: 1) the experiences of the patient's social networks, such as family and friends; 2) the personal experiences that the patient had with hypertension; and 3) information that the patient may have gathered from the medical literature or during an encounter with a healthcare provider.

The Experiences of Social Networks

Patients often described hypertension in terms of a death or a serious, nonfatal event such as heart attack or stroke experienced by a loved one. As one patient stated, ''*I had a niece that died from a hypertensive complication and she was only 28 years old. So you know, it's a very serious disease for me*.'' Patients whose social network members had an adverse experience with hypertension seemed to be worried that they would succumb to a similar fate. The experiences of their social networks were also associated with attitudes toward making

health behavior modification. For example, one patient said, "*I used to eat anything, but I changed after my sister and my mother had a stroke. I changed my own diet.*"

Personal Experiences with Hypertension

Having personal experiences with hypertension also shaped how patients described hypertension. For example, "*I describe it as an illness that affects the entire body, from the mental status to the function of the body. When my pressure is up, I have blurred vision. I feel very nervous, afraid.*" Conversely, patients who experienced few symptoms tended to describe hypertension as a less serious condition or expressed doubt about the actual diagnosis, as exemplified by the following: "*Going to the gym every day, I wanted to know how could I have it. I couldn't believe I possibly had high blood pressure.*"

The Influence of Medical Literature and Provider-Patient Encounters

Some patients described hypertension in terms of what they read in the literature and what they learned from their healthcare providers. One patient described hypertension as follows: "*Well, it is pretty much what I have read in the literature and what doctors told me. Elevated pressure, at one point anything over 140, was considered high but recently with pre-high blood pressure it's like 120/80 or something.*" Another patient said, "*What they (doctors) told me was that the pressure goes up for various reasons, you know, the kidneys and some other things might cause it.*" Another patient said, "*I have a chart about regular blood pressure; it should be 120/80.*"

DISCUSSION

Several studies have demonstrated that African Americans hold distinct knowledge, attitudes, and expectations regarding the causes and consequences of hypertension.[17,24] For example, Wilson et al reported that African Americans described hypertension as being caused by several factors, ranging from eating pork to evil spirits, and being associated with symptoms such as headache, dizziness, and weakness.[9] However, that study was conducted in a community-based setting, where only 10% of the participants actually had a history of hypertension. Another study by Ogedegbe et al looked at barriers and facilitators to medication adherence, but their study had less focus on patients' perceptions of the disease itself.[17] This study builds on previous work in this field by evaluating a population of hospital-based patients who had uncontrolled hypertension and by investigating the underlying factors that might have shaped patients' perceptions. Strategies for disease management in African Americans with uncontrolled hypertension are suggested in light of the findings of this study.

Patients' descriptions of hypertension were grouped into three broad categories: their thoughts on hypertension, the associated consequences of hypertension, and the effect that hypertension had on their lifestyle. As patients shared their thoughts on hypertension, stress was a common factor that was often linked to hypertension. Some patients associated a stressful situation or a recent stressful life event such as death in the family or financial stress with having hypertension. The fact that patients themselves attribute hypertension to stress provides an additional option to blood pressure management. Chronic stress has been implicated as a causative factor in hypertension, and stress reduction may be a culturally appropriate adjunct to medication in this population.[25,26]

Another finding that may have implications for the treatment of hypertension among African Americans is that hypertension was often associated with neurologic symptoms, such as headaches, feeling dizzy, or being light-headed. When patients describe these symptoms, physicians should instruct their patients to continue taking their medications even in the absence of symptoms and not to rely on their symptoms as an indication to take their medications.

The fact that patients themselves attribute hypertension to stress provides an additional option to blood pressure management.

Some patients may have difficulty ascribing a meaning to hypertension. Some patients attributed hypertension to unrelated conditions such as a finger laceration or head and neck cancer. This finding was limited to only 10% of the patients but is disconcerting. Patients who attributed their hypertension to another condition may not fully understand the significance of having hypertension. Patients who believe that hypertension is an incidental finding should be educated on the seriousness of this condition.

An understanding of factors that underlie patients' perceptions can also help to direct strategies for intervention. For example, the adverse outcomes experienced by a social network may reinforce the severity of the disease and the importance of treatment. Morisky et al found that providing family members with guidance that can enhance their ability to provide social support to their family members on health behaviors can be effective in modifying health behaviors.[27] However, because the experiences of social network members with an illness can also lead to unnecessary anxiety or fear, caution must be taken so that unrealistic fears are not perpetuated. The involvement of social support networks has demonstrated efficacy in improving outcomes.

Building on patients' personal experiences provides another strategy for improving hypertension control, which can be facilitated through motivational interviewing. Motivational interviewing involves open discussions about the patient's concerns, which offers the provider insight into factors that underlie the patient's motivation to change. By working with the patient to explore these factors, providers can help patients progress to change.[28,29]

Finally, this study reinforces the importance of the doctor-patient relationship in improving outcomes for patients with hypertension. The importance of the provider-patient interaction has been demonstrated in a study by Bosworth and colleagues in the Veterans Affairs hospital setting.[30] The components of their study included an interactive, telephone-based intervention that provided tailored education on hypertension and health behavior modification techniques to patients and feedback on blood pressure control to their respective physicians.

While our findings suggest strategies for the management of hypertension, limitations to the study must be noted. One factor that limits the generalizability of this study is that we interviewed relatively few men compared to women. Although this proportion reflects the higher ratio of women to men in this setting, future studies will need to oversample for men before making generalizations. Another limitation is that the hospital-based setting in which the interviews were conducted may have limited patients' responses to what they considered was socially desirable. However, the results of this study were similar to what Wilson found in a community-based setting.[9] In spite of these limitations, these results provide suggestions for interventions that may contribute to eliminating health disparities in hypertension. Engaging patients in discussions regarding their perceptions on causes, consequences, and personal effects of hypertension may help to dispel some misconceptions about hypertension and help to promote better disease management.

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