

National Kidney Disease Education Program

African Americans and Kidney Disease

Findings from a Focus Group Study

March 2002

Project Background

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is developing a new education program—the National Kidney Disease Education Program (NKDEP)—to reduce the morbidity and mortality caused by kidney disease and its complications. Prior to launching a nationwide program, a pilot program is planned to reach out to African Americans, a group at very high risk for diabetes, hypertension, and kidney disease. These focus groups were conducted to allow NIDDK to learn more about the target audience's knowledge, attitudes and behaviors related to kidney disease.

The findings of this research will help NIDDK develop the pilot program by providing insight into channels, intervention strategies, and messages that will be effective in increasing awareness of kidney disease. In addition, the groups will provide vital insights about how African Americans who are at risk for kidney disease or who have end-stage renal disease (ESRD) perceive kidney disease and screening. This information will be used to develop culturally appropriate and meaningful materials.

Methodology

Research Design

Focus groups were held in early 2002 with people at-risk for kidney disease (e.g., diagnosed with diabetes and/or hypertension), family members of ESRD patients, and ESRD patients. At-risk participants were recruited by a professional recruiting agency following a screener developed by NKDEP staff. Groups with at-risk patients were conducted in a focus group facility in the Baltimore area equipped with a one-way mirror to allow for client and research team observation. Participants for the family member and ESRD patient groups called in to a toll-free number in response to a recruitment flyer distributed to dialysis units. NKDEP research staff answered these calls and screened respondents to determine if they qualified for participation. These groups were conducted over the phone with persons residing in the NKDEP pilot site locations (e.g., Jackson, MS, Atlanta, GA and Cleveland, OH). All groups were audio- and video-taped (when possible), and the audiotapes transcribed. All groups were mixed with respect to gender, race, education and income, and were led by a professional focus group moderator using guides developed by NKDEP staff.

Organization of the Discussion

The focus group discussion with hypertension and diabetes patients was organized into five parts. The discussion first probed the effect of diabetes and/or hypertension on patients' lives. This was followed by a discussion of kidney disease knowledge and awareness. Next was a discussion of kidney disease screening. Participants were then asked to indicate sources of health information and rank those of greatest importance. Finally, the participants were asked to examine a number of potential messages about kidney disease and rank these in importance.

The discussion with family members was organized around four subjects. The discussion first probed family members' knowledge and awareness of kidney disease. Next, they were asked about their behavior and attitudes toward being screened for kidney disease. Participants were then asked to discuss sources of health information. Finally, the discussion focused on sources of kidney disease information.

The discussion with ESRD patients was also organized around four subjects. The discussion first probed the management and impact of kidney failure on patients' lives. Next, they were asked about their perceptions of kidney disease and kidney failure. Participants were then asked to discuss how their kidney

failure had impacted members of their family. Finally, they were asked to describe sources of kidney disease information.

Limitations of the Research

Focus groups allow the researcher to explore the range of opinions on a particular topic and reveal people's reasons for thinking a particular way. Due to the small number of participants and the recruitment procedures used, these results cannot be interpreted quantitatively or generalized to the target population of African Americans.

Research Results

At-Risk Focus Groups

Coping with Diabetes/Hypertension

Hypertension/diabetes had affected participants' medication use, eating habits, and daily routines.

Changes in eating habits were mentioned by several participants who described having to avoid certain foods (e.g., potato chips, salt, fried foods, hot and spicy foods), "reprogramming" their habits, cooking separate foods for themselves and other family members, or remembering to eat several meals a day. A few participants also mentioned the need to take medication every day. Also mentioned was the need to make frequent visits to the doctor, not being able to do everything one was accustomed to, and needing to monitor one's body more carefully.

Diabetes and hypertension were considered serious illnesses. Several participants indicated these were very serious and/or life threatening illnesses. For some participants this realization did not occur until they or a close family member had a serious health episode (stroke, hospitalization for high blood pressure, etc).

Genetics and lifestyle were thought to contribute to the development of hypertension/diabetes. Some participants indicated that genetics played a large part in whether one developed hypertension/diabetes. For example, one participant said that his wife came from a "bionic family" that rarely experienced illness. Several participants mentioned other relatives (parents, grandparents, great grandparents, or siblings) who had been diagnosed with hypertension or diabetes and some indicated that these were illnesses that "ran" in their family. Lifestyle factors, both in terms of dietary habits and lack of activity/exercise, were also cited as contributing to illness.

Knowledge and Awareness of Kidney Disease and Screening

Knowledge of kidney disease was low. Participants had a poor understanding of what caused and what could prevent kidney disease. Medication, mixing Tylenol with alcohol, alcoholism, and not drinking enough water were cited as factors that could lead to kidney disease. Only a few respondents accurately cited hypertension and diabetes as risk factors for kidney disease. Drinking plenty of water was thought to help prevent kidney disease. Participants also had a poor understanding of what function the kidneys performed.

Kidney disease was considered a serious illness. AIDS was named as a comparable disease.

Most participants did not perceive themselves at risk for kidney disease and few had been tested for kidney disease.

There was no clear consensus as to the importance of being tested for kidney disease. Some respondents believed it was important to be tested for kidney disease, or at least as important as monitoring other organs or body functions. Several respondents noted that there would be no reason to be tested if they were not experiencing symptoms or did not believe themselves to be at risk. Some respondents indicated that they did not want to dwell on or stress about their health. For example, one noted “I do not want to be a hypochondriac” and others indicated that worry or stress could lead to illness or death. However, near the end of one of the groups the respondents generally agreed that being tested for kidney disease was important if one had diabetes or hypertension and several said they would ask to be tested for kidney disease at their next doctor’s appointment.

Fear—of needles, hospitals, doctors, or the results—was the most common reason cited for why someone would not be tested for kidney disease. Other respondents indicated that a lack of medical insurance or the expense involved in caring for diabetes could prevent some people from being tested. Doctors also played an important role as some respondents expected their doctor to know what tests were appropriate and suggest that patients take them.

Sources of Health Information

Every participant indicated their doctor and/or doctor’s office was an important source of information and more than half rated the doctor as one of the most important sources of information. A few indicated that their doctor helped them to realize the seriousness of their condition and that they needed to change their behavior.

Time and feeling comfortable contributed to patients’ perception of their doctor as a useful information source. Time, both in terms of how much they could spend with their doctor and in terms of how long they had been seeing their doctor (e.g. continuity of care), impacted how useful respondents perceived doctors to be as information sources. Some respondents said their doctor was not useful because they felt the doctor did not have or did not want to spend time talking with them. Others considered themselves lucky that they did have a physician who would spend time talking with them and answering their questions. As one noted, “I have a doctor who I feel comfortable talking [to] about anything and she gives me good ideas and tries to help me when it is difficult.” Another said, “I’m comfortable. I just tell him what I’ve got to say and I want him to explain to me in the terminology that I will understand.” Some respondents seemed very frustrated by their physician. One stated, “My doctor does absolutely nothing. I go in, he writes me medication and sends me out the door.” A relationship also existed between time and feeling comfortable talking with one’s doctor. Patients felt more comfortable talking with doctors who made time to do so, and with whom they had an established relationship.

Trust in advice from one’s doctor varied. Some participants indicated that they took their doctor’s word because he or she was more knowledgeable or a professional. One stated, “I’m no doctor. That is why I go to him. If he tells me this is wrong, I take his word for it. This is right; I take his word for it.” Another said “He’s my doctor, I consider him working for me.” Others had disagreed with or attempted to verify recommendations by their doctor. Some openly resisted the recommendations of their physician. As one said, “I’ve taken my blood sugar and it’s been way up, and he’s said I’m going to put you on insulin. I’ve said “Oh, no!” I know it’s something I just did and my blood sugar went up but it’s going to go back down. I’m not going to let him arbitrarily put me on insulin just because it’s up this time.” As

another said, “I should be the one to make the final decision on what I should or should not do, unless it’s a matter of life or death.” As noted above, trust was also related to how much time doctors spent with them and with how established their relationship was.

Pharmacists, nurse practitioners, medical clinics, emergency rooms, and health education classes were also sources of health information. One respondent spoke to her pharmacist to receive a second opinion and to verify information from her physician. She felt comfortable with the pharmacist because she frequently went to that pharmacy. Another relied on a nurse practitioner because the nurse spent more time explaining things than did the doctor. Another took a class at the local Giant grocery store.

Every participant named some form of mass media as a source of health information.

Approximately two-thirds indicated a television show or news program as an information source. A majority of respondents also used magazines, books, or newsletters for information. Approximately half named the radio as a source of health information and a third named the Internet.

Most respondents had used the Internet in the past. Nearly all of those who used the Internet for health information rated it as an important source of health information. Ease of use was one reason cited for using the Internet. One respondent noted, “It is a lot easier to me to pick up than having to go to the library to pick up a book because I’m at the computer all day. If I need to know something I can pull it up real quick.” Other respondents noted that the Internet allowed them to check what they had been told by their doctor. The Internet was mentioned in very general terms; no one named a particular source of information. This also suggests that all sources may be regarded as equally credible (e.g., a sense of “If it’s on the Internet it must be true” could exist).

Family members and family members with a particular illness were cited by the majority of respondents as an important source of information. In fact, family members were cited by more than half as one of the most important sources of information.

Co-workers or family members with the same condition were cited as sources of information. Respondents indicated that those with the same condition had a greater understanding because they experienced the same things.

Barber shops and hair salons were not regarded as useful information sources.

Few respondents were familiar with kidney disease agencies and organizations. No one was familiar with the NIDDK acronym and only one respondent recognized the agency by name. None were familiar with AAKP and only a few recognized NIH and NKF by either name or acronym.

Evaluation of Kidney Disease Messages

Participants in the focus groups were asked to rate several messages about kidney disease in terms of their importance. The results indicated that:

Messages perceived as personally relevant were regarded as more important. A number of respondents indicated that messages that contained information relevant to them—because the message noted their age, race or health condition—were more important. One noted, “To me that [race and health condition] is a flag. That would trigger me to look into it. That is the type of information that I need to even look. Otherwise I won’t go down that road.”

Messages with shock value were regarded as more important. A number of respondents indicated that the message written as a fear appeal was the most important. For others, statistics about incident rates stood out.

Messages that stress incidence and prevalence rates among African Americans may not be effective. A few respondents indicated they were tired of hearing that certain diseases affected African Americans more than other persons. One noted, “They always says it’s the Black people; there are a lot of White people that have diabetes, too.” Another said, “I think we just think that we have everything so what is one more added to the list?”

Family Member Focus Groups

Knowledge and Awareness of Kidney Disease

Family members reported that their family member’s kidney disease had affected their daily routine, interaction patterns, and provision of care. Several respondents noted that they had to provide care for their family member either by transporting them to the doctor’s office or dialysis, preparing food, monitoring food or fluid intake, or helping with other day-to-day needs. In some cases the needs of their family member had impacted the caretaker’s ability to work. Some also said that seeing their family member ill was distressing and others found they had to work on keeping their family member motivated and/or following a treatment regimen. Others noted that they had changed their behavior as a result of seeing their family member’s health deteriorate. A few said that their family member’s kidney disease did not affect them.

Most family members did not think about kidney disease or consider themselves at risk. The majority of respondents indicated that they did not think much about kidney disease. The majority also said they were not at risk or were unsure about their risk level. Some believed that because they drank a lot of water or were watching their diet that they were not at risk. One respondent believed that her faith in God would protect her from illness. A few stated that diabetes or kidney disease ran in their family and they were uncertain about whether anything could prevent it.

Knowledge of kidney disease was low. In one group the majority of respondents knew that high blood pressure and diabetes could affect the kidneys. However, few realized this in the other group. Respondents said that alcohol, soda, certain foods (e.g., tomatoes & potatoes), medication, dietary habits, and heredity caused kidney disease. Some believed that drinking plenty of water could prevent kidney disease. The symptoms of kidney disease were thought to be problems with urination (too much or too little), swelling in the arms or legs, and back pain. Most thought kidney disease was common but did not believe it affected certain people (by age, gender or race) more than others. A few thought that Black people were more likely to get kidney disease. Most thought there was no way to prevent it and that dialysis was the only treatment. Several agreed that a transplant could cure it but one respondent said that because a transplant required a person to take medication for the rest of his/her life it was not really a cure. These perceptions related to symptoms and treatment suggest that family members make no distinction between kidney disease and kidney failure. In fact, they may believe that kidney failure *is* kidney disease.

Most respondents said their doctor had never discussed kidney disease with them. A few who had discussed kidney disease with their physician said that their kidney function had been discussed because they were diabetic. One respondent made sure that his physician knew his mother and sister had kidney disease and checked him for it as a result.

Kidney disease was perceived as a serious illness. Most reported that kidney disease was serious. Some said it was as serious as cancer or AIDS since there was no cure for it. Others compared it to diabetes.

Screening for Kidney Disease

Most respondents knew that they could be tested for kidney disease but most had not done so. Some did not know what kind of test was used. Most agreed that being tested was important but several thought it was important only if there were signs of kidney disease or a family history of it. Those who had been tested had done so because they had other health problems or believed they were at risk because of diabetes or family history.

Fear of the results was thought to be a reason that some people would not be tested for kidney disease. Others noted that if they did not believe they were at risk than they would not think about taking the test. As one said, “If there is nothing broke, don’t fix it.” Others said that someone might not be tested because they did not have insurance and could not pay for the test. One said that a belief in God prevented some people from being tested because these people believed God would cure them.

If diagnosed with kidney disease most respondents said they would try to get additional information. Several agreed that they would “do a lot more than I’m doing now” and would discuss kidney disease more seriously with those family members who had it. A few said they would seek a second opinion to make sure the diagnosis was not an error or misunderstanding.

Sources of Information

Most respondents relied on their doctor for health information but not everyone was satisfied with the information they received. Some respondents complained that doctors did not have enough time to spend with them. Others said that they had a particular physician they did trust or had trusted and this doctor had provided very useful information. A few said that when information was presented in layman’s terms it was helpful. Other professional sources of health information included a health hotline (Ask a Nurse), health seminars and a pharmacist.

Several respondents said they picked up pamphlets to get more information. Some picked up pamphlets on illnesses they were concerned about and some picked them up just because they were interested in the topic.

A few respondents turned to the Internet for health information but not all respondents had access to the Internet. Specific websites that were mentioned included cdc.gov, publichealth.gov, metacrawler.com, msnhealth and pharmaceutical websites.

Few respondents relied on health organizations or government agencies for health information. The only government agency mentioned was the Centers for Disease Control; however, many of the participants in these groups were from Georgia and their proximity to the CDC may have influenced their response. When asked specifically about agencies such as NIDDK, NIH, NKF and AAKP, most respondents had not heard of these organizations either by name or acronym.

Several respondents indicated that someone who has the same problem is a useful source of information. They believed these people could share information in a way that others could not.

Barber shops and hair salons were not regarded as useful information sources.

Sources of Kidney Disease Information

Some respondents received information from their family member or by taking them to dialysis.

Most respondents indicated that they had discussed kidney disease with their family member. A few said that they had learned some things about kidney disease by going to the dialysis unit or from observations they had made while there.

Family members were not necessarily regarded as good sources of information about kidney disease. A few respondents indicated that their family member was a good source of information but others said their family members were reluctant to discuss it and/or did not know very much about it. Nearly all, however, agreed that if their family member tried to give them advice about kidney disease they would take it.

Family members with kidney disease, physicians, specialists and the Internet were named as key sources for advice/information about kidney disease.

ESRD Patients Focus Groups

Management of Kidney Disease

Kidney disease had significant effects on the lives of ESRD patients. Most patients reported that kidney failure had changed their life radically. Some had been forced to quit working and many now lived on limited or reduced incomes. They also had initial difficulty adjusting to their diagnosis and coping with their fear and the fear of their family members. The time required to undergo dialysis made it a central feature of their lives and required that all other activities be planned around it.

Few of the patients knew they had kidney disease before having kidney failure. A few mentioned warnings from or discussions with their physician about kidney disease but none had acted on these. One respondent had been diagnosed with kidney disease as a child and been told her kidneys would fail. However, even before her kidneys failed she seemed to have no knowledge that this was going to happen. This patient admitted she had been in denial and had a particularly difficult time accepting her diagnosis.

Most patients had not thought they were at risk for kidney disease and most had not thought about kidney disease before their diagnosis.

Perception of Kidney Disease and Kidney Failure

Patients indicated that Tylenol, lupus, congestive heart failure, medication, high blood pressure, and diabetes could cause kidney damage. As with the other groups, some patients thought that medication they had taken for another condition (such as high blood pressure) had caused their kidney disease.

Symptoms of kidney disease were thought to be protein in the urine, urinating too much or too little, puffiness or swelling in the face, a bad taste in one's mouth, swelling in arms or legs, congestive heart failure, shortness of breath, a dark puffy look under the eyes, backache, headache, and fatigue. These symptoms were thought to indicate the beginning stages of kidney disease.

Most of the patients knew very little about kidney disease before their diagnosis. A few knew that it was serious, could result in dialysis, or could be fatal. One knew that blood pressure and diabetes could lead to kidney disease, and one knew that hypertension could damage the kidneys.

Most of the patients saw a difference between kidney disease and kidney failure. Kidney failure was described as a type of kidney disease. Kidney failure meant that the kidneys no longer functioned and dialysis or a transplant were the only treatments.

Some patients indicated that kidney disease was inevitable. One noted that “if you’re African American or any nationality, if you have hypertension that goes untreated or undetected, it will take your kidneys in the long run.” Another noted that in her situation she did have treatment of kidney disease before her kidneys failed. However, she said, “Eventually, you will have end stage regardless. This [treatment for kidney disease] will just buy you some time.” Another said “I don’t think it can be prevented, especially if you have diabetes.”

Most patients thought it was common and could affect someone of any age. Most of the patients also thought that ethnicity played a part and several said they thought African Americans had more kidney disease. Some of the greater kidney disease among African Americans was attributed to diet. Some thought that those with high blood pressure and diabetes were more likely to develop kidney disease.

Kidney disease was regarded as a very serious condition that was life-threatening.

Since being diagnosed most patients realized that high blood pressure and/or diabetes could contribute to kidney failure.

Patients wished they had had a greater understanding of the causes of kidney disease before they developed it. Several wished they’d known that high blood pressure and diabetes caused kidney disease. Some wished they’d known how serious the consequences of being overweight, not exercising, and eating improperly could be. One said his stressful lifestyle contributed to his kidney disease and he wished he would have lived differently. One believed a blood pressure medication had caused her kidney disease and she wished she would have known it could damage her kidneys.

Impact on Family

The primary impact on family members seemed to be their increased concern for the patient’s well-being. Several patients said that at diagnosis most of their family members thought the patient would die. Several said their family members still monitored them closely.

Most of the patients had never heard that close family members were at increased risk for kidney disease because the patient had it. When asked if they believed their children to be at increased risk, all patients said no. One said “I don’t want to badmouth my kids. I ain’t gonna say that.” Nonetheless at many times throughout the discussion patients indicated that certain illnesses such as hypertension or diabetes did run in families.

Nearly all of the patients had discussed their kidney disease with others. Most had discussed it with family members. Others discussed it with friends, co-workers, church members, or anyone who seemed interested. Some said that their family members were in denial about kidney failure and did not want to discuss it. Some had provided information about kidney disease to their family members when they were first diagnosed but now mainly provided updates on their health. Some patients served as volunteers at their dialysis clinic and spoke regularly to other patients or within the community.

Most said they were interested in providing information to others and were comfortable doing so. As one said, “If I could prevent one person. It doesn’t have to be a family member. I don’t care who it is. If I could prevent one person to not have to go through what I’ve gone through, that’s a blessing.” When asked if they would pick up materials at the dialysis unit and give them to their family members, several said they would.

Sources of Kidney Disease Information

Doctors, nurses, the Internet, other patients, seminars, and national and local organizations were sources of information on kidney disease for patients. Most patients mentioned getting information from a doctor or nurse but not all were satisfied with the information they received from their doctor. Some felt that doctors did not provide complete information or presented things from only a clinical/medical perspective. Others felt that doctors were only interested in activities that generated income. As one noted, “I’m kind of shy from doctors because I believe there is money in treatment, but it’s not money in care.” Kidney-specific organizations such as the National Kidney Foundation, Georgia Kidney Foundation or Renal Network Association were preferred associations.

The best sources of information were other patients, support groups, and the National Kidney Foundation. Most patients felt that other patients were the best sources of information and several felt they were the most motivating. They stressed that this should be someone who has been on dialysis for some time, is very knowledgeable, and is compliant with their treatment regimen (“does the right thing”). Some patients stressed that there was no best source of information and preferred to gather information from as many different sources as possible.

Familiarity with government agencies providing kidney disease or health information was low. Few patients were familiar with NIDDK or NIH by name or acronym. Few patients were familiar with AAKP.
