

Attitudes of African American premedical students toward genetic testing and screening

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Purpose: Genetic research is progressing at a rapid rate. While most view genetic advances favorably, concerns regarding eugenics and discrimination based on genetic test results have been raised. These concerns have been found among all groups studied; however, they have particular relevance for members of the African American community. Studies have shown that because of a long history of negative experiences, African Americans have a general mistrust of the medical establishment. It is unclear whether these negative attitudes encompass genetic advances. Because there is little empiric data in the literature, it is not known whether African Americans have a positive view of genetic advances or whether they have the same level of mistrust as is seen in their attitudes toward other forms of biomedical research. **Methods:** This study was conducted as an initial effort to examine the attitudes of African Americans toward recent genetic advances and, specifically, genetic testing. A cohort of 97 college-age minority students, including 78 African Americans, participating in the Health Career Enhancement for Minorities Program (HCEM) at Case Western Reserve University were surveyed. Surveys were made available before and after the summer long course, which included five lectures on basic genetic principles and medical genetics. **Results:** Both African American students and other minority students initially (questionnaire prior to HCEM course) had an overall positive view of genetic testing. The vast majority supported genetic testing for preventive care (95%) and presymptomatic detection of disease (88%) and agreed that it should be easily available (83%). However, several concerns were expressed as well, including fears about discrimination (68%), privacy (68%), that abortions will become more common (51%), and eugenics (37%). It is interesting that in the postcourse questionnaire, the percentages of positive views remained similar to those of the precourse survey, but the number of respondents expressing concerns increased. **Discussion:** These results suggest that the minority students surveyed view many aspects of genetic testing and other advances favorably. However, these students expressed concerns about discrimination, privacy, and eugenics. These concerns were increased, not lessened, by exposure to genetics education. One possible explanation for this observation is that the students had a greater understanding of the issues regarding genetic testing after the HCEM lectures and discussion. Of note, there was a greater negative response toward genetic screening programs among the African American students compared with the non-African American minority students. This suggests that the negative attitudes of African Americans toward biomedical research do extend to some aspects of genetics and that educational programs must be designed and implemented if this community is going to receive the maximum benefits of this advancing technology. *Genet Med* 2003;5(1):49–54.

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Medicine is in the midst of a genetic revolution, as new disease-related genes are being identified at a rapid rate. These

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discoveries are providing new insights into the basis of many diseases, and they offer the promise of new more accurate tests, improved treatments, and even cures for some disorders.¹ However, the rapid pace of advancing genetic knowledge has also raised concerns in both the medical community and the public.² Major areas of concern range from more global societal issues that genetic research will lead to eugenics, to very personal issues faced by individuals such as the fear of discrimination or of losing health insurance based on genetic test results.^{3–5} While these concerns have been identified in all groups that have been surveyed, they may have particular relevance for

the African American community.^{6,7} African Americans have been found to generally hold negative opinions toward the American medical establishment as well as biomedical research.^{6,8–10} Perhaps as a consequence of this distrust, African Americans have been underrepresented in medical research, and this has led to fewer medical advances that directly impact the African American community.^{6,10}

Scholars have attributed this societal distrust by African Americans toward medical research to a number of factors.¹⁰ Events stemming from several hundred years ago, with the use of slaves for medical experimentation, to examples from our recent past, such as the Tuskegee syphilis study from 1932 to 1972,^{9,10} have continued to make African Americans wary of the medical establishment. Several examples from the 1970s are also cited, including the sickle cell screening program and the involuntary sterilization of minorities in government-supported family planning clinics.¹⁰

The sickle cell screening program was established to lessen the burden of sickle cell disease in the African American community. The goal was to identify sickle cell carriers and thereby change their reproductive behavior. However, the program created a great deal of misunderstanding about sickle cell disease, as healthy carriers became stigmatized and discriminated against.¹⁰ Furthermore, many in the African American community perceived the program as nothing more than an effort to decrease the African American population.¹¹ This fear is echoed today in the belief held by many in the African American community that the AIDS epidemic was intentionally created by the CIA to reduce the inner-city African American population.⁸

It is clear that fear and anxiety toward biomedical research remains. A conference on “Genetic Factors in Crime” was protested by African American leaders who claimed it legitimized the belief that African American males are genetically predisposed to violence.¹⁰ It is not surprising then that given such attitudes, African Americans are unlikely to participate in biomedical research.^{6,8,12} Reasons included a general distrust of the investigators, which in at least some instances was based on incorrect information regarding the consent process, and the fear of being used as “guinea pigs” without any clear benefits for themselves or their families.⁸ Many individuals expressed a belief that the medical community values African American lives less, citing Tuskegee and other examples of medical “abuse” of African Americans.^{6,8} Furthermore, there is the fear that identifying genetic differences or an increased carrier rate of a genetic mutation among African Americans may lead to further discrimination or stigmatization, as it did in the sickle cell screening program.¹³ There is also the concern that African Americans, being overrepresented among the economically disadvantaged, are even more vulnerable now to being victimized by a new eugenics movement.¹³

While these issues have been discussed in editorials and opinion papers, there is little empiric data available regarding the attitudes of African Americans toward genetic advances. Do African Americans have a positive view of genetics similar to those noted in a study by the American Medical Association

surveying the general public?¹⁴ Or has the African American historical experience with the medical establishment created the same level of mistrust of genetic advances as is seen in their attitudes toward other forms of biomedical research?^{6,8} In an initial effort to address this question, we undertook a study that surveyed a cohort of African American college-age premedical students on their attitudes toward genetic testing and genetic research.

METHODS

Subject selection

We surveyed undergraduate premedical majors who participated in the Case Western Reserve University School of Medicine’s Health Career Enhancement for Minorities Program (HCEM). HCEM is an 8-week summer program designed to prepare underrepresented minority and disadvantaged students for medical school (for more information on HCEM, please contact Joseph Williams at jxs26@po.cwru.edu). The students are recent college graduates or entering their junior or senior year of university from across the United States.

The HCEM program focuses on medical school preparation. A major objective is to provide an academic enrichment program in the basic sciences including a 1-week block of five lectures on basic genetic principles and medical genetics. Genetic topics include Mendelian inheritance, clinical/prenatal genetics, genetic testing, and ethical issues in clinical genetics.

We chose to study this group for several reasons. These students represent a subset of African Americans whose attitudes toward genetic testing and research have not been studied. Furthermore, they are young, highly educated, and planning a medical career. They may represent the future leaders on medical issues in their communities, and thus their attitudes may influence how entire communities accept genetic testing and genetic research. We hypothesized that because of their advanced education and favorable view of medicine, this group might have fewer concerns about genetic testing and research than has been found among the African American community in general. Therefore, if this group did indeed have a similar level of concern as has been alluded to in the literature,^{6,8–10} it would suggest that these concerns are deeply imbedded and may be more difficult to dispel regardless of the educational level or socioeconomic status of the African American community.

Questionnaire

The written survey was made available to the 97 HCEM students at their orientation session in June 2001. Of the 97 HCEM students, 72 were African American. Seven were Hispanic, and 18 indicated “other,” which included Filipino, Asian, and Eastern Indian. The questionnaire consisted of 11 demographic questions regarding gender, race, religious preference and level of participation, educational background, and history of genetics education. The questionnaire is available from the corresponding author. The main body of the survey was 21 questions regarding genetic testing in general, popula-

tion screening, prenatal testing, discrimination, confidentiality issues, abortion, and uses of genetic test results. All answers were on a 5-point Likert scale, ranging from strongly agree to strongly disagree.

A modified version of the questionnaire was distributed at the end of the 8-week HCEM session. The survey was identical with the initial survey, with the addition of two sections. The first asked if respondents' opinions regarding specific issues had changed, i.e., if they were more or less concerned about a specific issue. The issues included prenatal testing, desire to know own genetic makeup, discrimination, abortion, confidentiality, screening of targeted or high-risk groups, and genetic counseling. The second section asked respondents to list their major concerns regarding genetic testing as well as what they thought would be the greatest benefits of such testing.

Participation was voluntary and anonymous. Students were assured that all responses would remain confidential. The study was conducted with approval of the University Hospitals of Cleveland Institutional Review Board.

Statistical methods

Demographic data were described overall and by ethnic division (previously described) for pre- and postcourse participants separately. Study questions were tabulated on the original Likert scale in the same fashion for initial examination. Because sample sizes were small, the scale was collapsed to a 3-point scale for analysis: positive (agree or feel favorably), neutral, and negative (disagree or feel unfavorably). Comparisons were made between ethnic divisions for pre- and post-time periods separately. The study was presented to the students as anonymous, and no unique identifier was assigned to course participants for use in the surveys. Therefore, direct statistical comparisons between the two time periods could not be made, as each time period had some participants who responded in that time period solely, and some who participated in both, and assumptions of neither independence nor correlation could be made. Change in feeling from pre- to post-responses was self-assessed with questions specifically addressing these issues. The Fisher exact test was used to compare frequencies, and the level of significance was set at 0.05 for all comparisons.

RESULTS

Sixty-six participants responded to the survey distributed prior to the start of the HCEM course (S1) for a response rate of 68%. Of these, 71% (47/66) were African American and 29% (18/66) non-African American minority students. One student did not identify race on the initial survey. The male-female ratio was 14/52 (21% and 79%). The response rate for the postcourse survey (S2) was 84% (81/97), with a racial composition of 69% (56/81) African American and 29% (25/81) non-African American minorities. The male-female ratio was 18/63 (22% and 78%). See Table 1 for additional demographic data. In S1, almost half reported having taken a course in genetics prior to HCEM; 28% self-rated their understanding of genetics

Table 1

Demographics pre- and post-HCEM course

	Pre-HCEM questionnaire (S1) (n = 66)	Post-HCEM questionnaire (S2) (n = 81)
Total respondents	68% (66/97)	84% (81/97)
Respondents by race		
African American	71% (47/66)	69% (56/81)
Hispanic	11% (7/66)	12% (10/81)
Other	18% (11/66)	19% (15/81)
No response	0.02% (1/66)	
Male/female	21/79% (14/52)	22/78% (18/63)
Level of participation in organized religion		
High	56% (37/66)	57% (47/81)
Moderate	29% (19/66)	27% (22/81)
Low	3% (1/66)	11% (9/81)
Previous genetics course (yes/no)	41/52% (27/34) ^a	43/56% (35/45) ^a
Understanding of genetics (self-rated)		
Excellent/good	27% (18/66)	37% (30/81)
Fair	45% (30/66)	44% (36/81)
Poor	27% (18/66)	7% (6/81)

^aIndicates some respondents did not answer this question.

as "excellent/good," and 45% as "fair" (Table 1). In S2, there was a small increase in the number of respondents who rated their understanding of genetics as "excellent/good" (37%), with approximately the same number (44%) responding "fair."

In S1, the vast majority of students were in favor of genetic testing for preventive measures. The majority of students strongly agreed that genetic testing should be used for preventive care (95%, 63/66), that it should be used for presymptomatic detection of disease (88%, 58/66), that it should be widely available to patients (83%, 55/66), and that it should be used to influence one's health (74%, 49/66) (Table 2). These percentages were similar in both the African American and non-African American groups and not statistically significantly different from each other. This appeared to change very little in S2, after the completion of the HCEM program.

While the first series of questions showed that these minority students appreciated the potential benefits of genetic testing, they also demonstrated concerns about the potential use of such testing. In S1, 68% (45/66) expressed concern that genetic testing would lead to discrimination as well as make abortions more common (51%, 34/66). Again, these concerns were not different among the African American and non-African American minority students (Table 2). It is interesting that the number of respondents concerned that discrimination would be more common rose from 68% to 80% (65/81), abortion

Table 2
Attitudes toward genetic testing and screening

	Pre-HCEM course (S1)				Post-HCEM course (S2)			
	All (n = 66)	AA ^a (n = 47)	Other ^b (n = 19)	P value	All (n = 81)	AA ^a (n = 56)	Other ^b (n = 25)	P value
Strongly agree with								
Genetic testing for preventive care	95 (63)	96 (45)	95 (18)	0.65	87 (70)	85 (48)	92 (23)	0.85
Genetic testing for presymptomatic identification of disease	88 (58)	85 (40)	95 (18)	0.42	91 (74)	89 (50)	96 (24)	0.76
Widespread availability of genetic testing	83 (55)	81 (38)	89 (17)	1.00	80 (65)	80 (45)	80 (20)	0.85
Use genetic testing to influence one's health	74 (49)	74 (35)	74 (14)	1.00	80 (65)	80 (45)	84 (21)	0.77
Genetic testing may lead to discrimination	68 (45)	64 (30)	79 (15)	0.44	80 (65)	79 (44)	84 (21)	1.00
Genetic testing may lead to eugenics	37 (24)	34 (16)	42 (8)	0.83	67 (54)	64 (36)	72 (18)	0.40
Genetic testing may make abortions more common	51 (34)	53 (25)	42 (8)	0.72	68 (55)	64 (36)	76 (19)	0.62
Confidentiality of genetic test results will be a problem	68 (45)	68 (32)	72 (13)	1.00	65 (53)	66 (37)	60 (15)	0.83
Genetic screening of high-risk groups for carrier status	35 (23)	33 (15)	42 (8)	0.74	32 (26)	29 (16)	40 (10)	0.26
Genetic screening of children if proven treatment exists	35 (23)	37 (17)	32 (6)	0.13	54 (44)	46 (26)	72 (18)	0.11
Desire to know your own genetic makeup	61 (40)	49 (23)	89 (17)	0.01	64 (52)	55 (31)	84 (21)	0.04

Values represent % (n).

^aAfrican American students.

^bNon-African American minority students.

concerns increased from 51% to 68% (55/81), and concerns regarding eugenics increased from 37% to 67% (54/81). (Direct statistical comparisons among participants in each group could not be made as participants responded anonymously.) As in S1, the percentages were similar among the African American and non-African American respondents.

Questions regarding genetic screening of high-risk groups for carrier status and screening of children for a disease with a proven treatment were both viewed relatively unfavorably (35%, 23/66) in S1. The numbers were similar among both African American and non-African American minority students (Table 2). In S2, the overall percentage of those expressing a favorable view of genetic screening for carrier status was similar (32%, 26/81), but there was a somewhat higher favorable response to screening of children for a disease with a proven treatment, with 54% (44/81) responding favorably. For both of these questions in S2, non-African American students demonstrated a trend toward a higher positive response rate. For the question on carrier screening of high-risk groups, 40% (10/25) were in favor of such screening compared with 29% (16/56) of the African American students ($P = 0.26$). For the question on screening of children for a disease with a proven treatment, 72% (18/25) of non-African American students responded favorably after the HCEM course, a considerable increase from the S1 percentage of 32% (6/19). In comparison, 46% (26/56) of African American students in the follow-up questionnaire responded favorably ($P = 0.11$) (Table 2).

Finally, when compared with the African American HCEM students, a statistically significantly higher percentage of non-

African American students desired to know their own genetic makeup in both S1 and S2: 89% (17/19) versus 49% (23/47) in S1 ($P = 0.01$) and 84% (21/25) versus 55% (31/56) in S2 ($P = 0.04$) (Table 2).

DISCUSSION

This study was a first attempt to examine the attitudes of African American and other minority premedical students toward genetic advances—in particular, genetic testing. While previous studies have looked at attitudes toward biomedical research of patients in urban medical centers and clinics,^{6,8} this study focused on genetic issues specifically and surveyed college-age premedical students. The majority of students demonstrated a positive view of genetic testing, both for themselves and for their potential patients; they had a positive view of the utilization of testing for prevention of disease and for presymptomatic detection, and they held the view that such testing should be widely available. However, these students also demonstrated concerns about potential misuse of genetic testing, including that it may lead to discrimination and an increase in the number of abortions and that it might lead to eugenics. It is interesting that the number of students expressing these concerns increased after they attended the genetics lectures, with the most dramatic increase in the question on genetics leading to eugenics (37% to 67%).

While the number of responses expressing positive attitudes toward genetic testing remained fairly consistent in the surveys before (S1) and after (S2) the genetics lectures and the HCEM

course, the number of students expressing concerns increased (Table 2). We had anticipated that after attending lectures regarding principles of human genetics and their application to real-life medical genetics cases, the students would recognize the actual benefits as well as the limitations of genetic technology, medical genetics, and the ethical principles that guide medical genetics clinical practice. Instead, the opposite was observed. For example, those who strongly agreed with the statement that "genetic testing may lead to eugenics" almost doubled in number after the course (34% and 64%, respectively). Furthermore, there were increases in the number of those expressing concern about discrimination and abortion. In S1, 53% (25/47) of African American respondents and 42% (8/19) of non-African American minority respondents stated that they were concerned that genetic testing would make abortion more common; in S2, these numbers increased to 64% (36/56) and 76% (19/25), respectively (Table 2).

There are several possible explanations for this observation. It may be that the students did not fully understand many of the concepts that were asked about initially in the S1, such as eugenics, discrimination, and genetic privacy. The genetics lectures may have provided a better understanding of these issues, and thereby a greater appreciation of the potential issues and concerns, as reflected in the S2 responses.

A second, complementary explanation is that the genetics information presented to the HCEM students was not intended to address in depth the ethical, legal, and social issues regarding genetic testing. The genetics lectures were intended to prepare the students for premedical examinations and, only as a secondary goal, to provide a brief exposure to this dynamic specialty. In this regard, the material presented could be deemed successful if it raised the students' awareness of these important ethical and social issues.

Regardless of the reason why these concerns were heightened as noted in S2, it is clear that the week of genetics lectures did not, as we had hoped, lessen concerns around genetic testing. This finding is actually consistent with previous studies that have shown that education alone, while an important part of any genetic screening program, does not lead to an immediate acceptance of genetic testing.^{3,15} To have any success, educational programs must emphasize the practical benefits of genetic testing for a given community.¹⁶ As discussed above, this would be especially relevant when targeting the African American community. However, this was not the intent nor would it have been possible in the allotted timeframe of the HCEM lecture series.

There were some notable differences between the responses of the African American students and the non-African American minority students. Unfortunately, the small number of non-African American HCEM students prevents most comparisons from reaching statistical significance. The non-African American students were more interested in knowing their own genetic makeup both before (89% vs. 49% in S1; $P = 0.01$) and after (84% vs. 55% in S2; $P = 0.04$) the genetic classes and HCEM course than the African American students. This was an unexpected finding. Unfortunately, the literature provides

no guidance as to why there would be attitudinal differences between African Americans and other minority groups regarding these issues. Perhaps the African American students were able to separate out their personal beliefs which reflected a continuing mistrust of biomedical research from their views as future health care providers wanting to provide the best care for their patients. Perhaps other minorities do not identify themselves with such deep-rooted misgivings as has been reported in previous studies regarding the African American community's mistrust of researchers.^{6,8} Another example of this is reflected by the heightened concern at S2 among the African American students compared with the other minority students on such issues as eugenics and discrimination (Table 2). Obviously, these findings warrant additional research.

Non-African American students were somewhat more accepting of genetic screening of high-risk groups for carrier status both before and after the genetics lectures (42% vs. 32% in S1, 40% vs. 29% in S2). However, after attending the lectures they were considerably more in favor of testing of children if a proven treatment existed (32% vs. 36% in S1, but 72% vs. 46% in S2). The African American students' relative reluctance toward viewing genetic carrier screening favorably again may have its origin in the after-effects of the poorly conceived and executed sickle cell screening program of the 1970s.^{7,10,17} While certainly understandable, such reluctance has the unfortunate effect of limiting the potential benefits that genetic testing and counseling offers.¹⁴

There were limitations to this study. The group surveyed was a relatively small and homogeneous group of highly educated African American and other minority respondents. The small sample size limited statistical analysis from being able to detect significance on most parameters. Moreover, these findings only provide us with trends and cannot be generalized to the larger African American community. Furthermore, because the questionnaire was anonymous, we were unable to track individual responses. This would have been especially useful in trying to understand how the students' attitudes changed from before to after the HCEM course. Further complicating this issue is that we had a greater number of respondents to S2. Therefore, it may be that the changes we observed between S1 and S2 reflect only the attitudes of these additional 15 respondents, not changes in the attitudes of those who responded to both S1 and S2. It may be that the students who responded only to S2 disproportionately had increased concerns. Finally, the wording of some questions may have reflected more of reality than attitudes such as the question, "genetic testing may make abortions more common."

Given these limitations, however, the study results are interesting for several reasons. This is an initial attempt to learn about the attitudes of African Americans and other minorities toward genetic testing. The group chosen does not represent the community at large, but rather may have special relevance to illuminating issues and concerns held by African Americans. As stated previously, these well-educated and motivated students will be providing medical expertise to their patients and families and thus may be asked to provide guidance and rec-

ommendations regarding medical issues including genetic testing and genetic research in the African American community. Furthermore, because of their strong scientific backgrounds, it is reasonable to assume that the concerns that these students expressed would be tempered by a greater understanding of the underlying scientific issues compared with the African American lay public. For these reasons, we would expect that any concerns expressed by the students in this study would be magnified in the general African American community.

It was the intention of this study not to definitively answer questions concerning how African Americans and other minorities view the recent advances in genetics, but rather to further define what questions need to be explored regarding these issues. If African Americans and other minorities are to enjoy the benefits that genetic research promises, the issues that have caused these groups to have a negative view of the medical establishment need to be addressed. As was shown by this study and others,¹⁶ limited and general educational efforts do not succeed. Rather, educational programs will need to be developed that specifically target the fears and issues most evident in the African American and minority communities. Toward that goal, additional studies should be carried out on a more widespread cohort of African Americans and other minorities to determine whether the results of this study begin to reflect the opinions seen in the community at large.

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