A Community's Awareness and Perceptions of Genomic Medicine

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Abstract:

Background: Focus groups were conducted in a mid-sized community to explore community members' awareness and perceptions of genomic medicine and identify effective methods to educate the public about this topic. ***Methods:*** Thirteen focus groups were conducted with a demographically representative pool of 121 participants using a semi-structured interview guide. Transcripts were analyzed through a computer assisted approach with Atlas TI consisting of coding, categorizing, comparing, and contrasting relevant data. ***Results:*** Identified categories were organized into 6 main themes, which were similar across the groups and included: a lack of awareness, perceived benefits, concerns about genomic medicine, reasons for poor health related behavior, the potential impact of genetic information on health behavior, and the best ways to educate the community. Common concerns included lack of affordability, unanticipated physical harm, mistrust of the government and researchers, downstream effects like overpopulation, playing God/disturbing the natural order, lack of regulations, loss of privacy, genetic discrimination, and moral dilemmas posed by genetic engineering, cloning, choosing traits, and abortions resulting from genetic information. Participants also discussed ways to educate the community. ***Conclusions:*** While individuals recognized that diseases run in families, personal experience was a driving factor in participants' level of knowledge. Many expressed optimism about genomic medicine. However, the lack of depth in responses and their misconceptions reflect a deficiency of knowledge, which along with their personal, moral, and global concerns could impede acceptance and utilization of genomic medicine. Many community members are receptive to learning more about genomic medicine, and many of their concerns and misconceptions can be addressed through a well designed education strategy.

Key Words:

Attitudes, Awareness, Focus group, Health education, Health knowledge, Public health

Abstract:

Genomic medicine is the use of genetic information to improve health outcomes [1, 2]. This may include incorporating an individual's genotype, family medical history, and/or expression analysis into disease risk assessment [3]. This information could also be used to diagnose and/or tailor treatment to existing disease [3]. Despite the obvious benefits, the process by which genomic information will be incorporated into healthcare practice remains unclear [3, 4].

The Genomedical Connection™ is a demonstration project aimed at developing a model to incorporate genomic medicine into community health care. Included in this model are broad-based education programs focused on the practical, ethical, legal, and social issues related to the use of genomic medicine in target populations – the community at large, health professionals, and patients. Educational programs for each population will be grounded in a comprehensive curriculum design process that includes a thorough needs assessment. This paper addresses the first study done as part of the educational needs assessment for the community. Using focus group

methodology, we assessed the community's awareness and perception of genomic medicine and preferences regarding educational strategies and content.

Background

The success of genomic medicine relies on the public's ability to collect and use family history and genetic information, to consult with healthcare providers, and to self- monitor health-related behaviors [5, 6]. The need for active involvement of the patient poses a potential barrier to the success of genomic medicine, dictating a need for community educational programs that convey a practical and personally relevant understanding of family history, genetics, and related ethical, legal, and social issues [7– 11]. Importantly, studies suggest that educational endeavors tailored to personalized needs can promote behavior and attitude change [12, 13] . Public health education also provides a basis for facilitating realistic policy discussions when addressing barriers to the use of genomic medicine [10, 14].

Data reporting the public's knowledge of genetic topics are limited [15]. Some studies have assessed the knowledge of individuals in specific consumer groups who were at risk for, or diagnosed with, a genetic condition, which highlight gaps in the public's knowledge [16–19]. Others have revealed that the general public lacks knowledge of concepts such as DNA or chromosomes [20, 21]. Few data are available to assess knowledge and awareness of the more practical issues pertaining to the use of genetic information, though the evidence that is available suggests the public has a general perception of the association between genes, heredity, and disease and recognizes that complex diseases have a genetic component [11, 21].

Survey and focus group data have suggested that many respondents are cautiously optimistic about the application of genetic technology to medicine [21–26]. Doubts have also been raised pertaining to the use of genetic testing including anxiety about affordability and access, fear of violating the confidentiality of genetic information and the fear of discrimination, mistrust of those promoting the use of genetics in medicine, and the fear of unforeseen or unpredictable negative consequences [25–27].

Differences in people's feelings about the use of genetic information in medicine have been reported among racial and ethnic groups. African Americans tend to express higher levels of skepticism than whites [11, 28, 29], while Chinese participants have the most positive feelings regarding genetic testing [11] . Data on Latinos are variable [11, 29]. Interestingly, despite the concerns reported by African American and Latino participants in a study by Singer et al. [29], they were more likely than Caucasians to express preferences for genetic testing.

The efficacy of public health education also depends upon the distribution of relevant information through channels used and trusted by the public for health education. Focus groups have suggested that people draw on a wide range of media, including newspapers, magazines, the Internet, and television to learn about genetic advances [30], though learning preferences differ by culture [11]. As studied by Catz et al. [11], all groups acquire health information from the media. Non-Hispanic White participants primarily obtain information from doctors, television, and the Internet. Participants of minority races in this study obtained their information not only from television and physicians but also pamphlets, brochures, magazines, and friends. In this same study, regardless of background, most expressed an interest in learning more about genetics and genetic testing.

For identifying major themes within a specific community, focus groups are ideal for obtaining information in a relaxed discussion format where interaction and exploration of ideas and key points are needed [31]. Focus group research of genomic medicine topics is infrequent despite its recognized value [15]. Using focus group methodology, we aimed to assess a single target community's baseline perceived knowledge, awareness, and perception of genomic medicine, as well as to determine how members of the community would prefer the information to be delivered. The groups also were convened to identify misconceptions or concerns that may impact a community's acceptance of genomic medicine [32]. The focus group results informed a community survey and will serve as a baseline for evaluating the impact of the educational program in the future.

Table 1. Interview guide

1	What news stories have you heard about genetic information being used in medicine?
2	Has anyone here ever heard the term genomic medicine? – Where have you heard it? – What comes to mind when you hear the words 'genomic medicine' / 'genetics' / 'genetic medicine' / 'personalized medicine'? There are many different uses of the term genomic medicine. In our project, genomic medicine is very broad. We define it as using an individual's genetic information, such as from genetic testing or family history, to improve a person's healthcare.
3	What do you know about the current use of genetic information in medicine?
4	What, if any, concerns do you have about using genetic information in medicine?
5	Do you perceive any benefits of using genetic information in medicine? If yes, what?
6	It is fairly common knowledge that eating well, exercising, getting enough sleep, and things of this nature are better for our health, but many Americans don't follow these recommendations. Why do you think this is so?
7	If you could have a genetic test or family history type evaluation with a counselor or a doctor to predict whether you were personally at risk for some condition or health problem, would you want to have that?
8	Do you think genomic medicine is a topic that is important for the community to know about? How so?
9	What topics pertaining to using genetics in medicine are you interested in learning more about?
10	How do you usually access information about health/medical issues?
11	What do you think is the best way to let people like you know about genomic medicine?
12	What is the most important thing that you didn't have a chance to say in today's discussion that you'd like us to know?

Materials and Methods

To assess the community's awareness and perception of genomic medicine and preferences regarding educational strategies and content, an open-ended, semi-structured interview guide was produced based on input from genetic counselors, researchers, community health educators, and community health nurse researchers. This information was combined with reported population data to produce the script. The interview guide was pilot tested with 8 members of a community group. Modifications of the interview guide were made and the revised guide was used for all focus group sessions analyzed for this study (table 1). Interview questions were arranged from general to specific. For example, the first question was: 'Has anyone heard the term genomic medicine?' and the last question was: 'Are there specific genetic education topics you would like to learn more about?'

County Health Department and Chamber of Commerce representatives were used as key informants to identify organizations within the County that provided a representative population in terms of gender, ethnicity, religion, age, and socioeconomic status. Churches, colleges, employers, social groups, local Veteran's Administration, and Army National Guard units were contacted for inclusion. Six organizations agreed to participate, with a contact person designated to recruit participants. Subjects were recruited using flyers, advertisements in the organization's newsletter, and/or word of mouth among members. All postings and advertisements included the contact information of the project coordinator to obtain more information. Text and scripts used to recruit provided limited information to minimize bias. Potential subjects were told the focus groups were being done to

discuss 'the use of genetic information in medicine' as part of an education initiative of a genomic medicine initiative.

At the session, the facilitator provided guidance accompanied by a non-participating note taker who distributed consent forms, managed the recording equipment, and took field notes. While the participant's name is present on their consent form, no identifying information was recorded with their responses. No other personal information or demographic information was requested from participants, though the note taker documented the number of participants present, their perceived race, and their gender. Focus groups lasted approximately one hour, were conducted in settings convenient for the participants, and were audio-taped with permission of participants. Each participant was offered a gift card valued at $25 to a local store as compensation for his or her time.

Audio-tapes were transcribed verbatim and reviewed for accuracy against the field notes which were taken during all but one session. Verbatim transcripts and field notes were entered into the computer program Atlas TI for data analysis.

Data were analyzed according to principles described by Krueger and Casey [31] and focused on the meaning, context, internal consistency, frequency, extensiveness, and intensity of the comments. Atlas TI enabled the research team to code and retrieve textual data from transcripts and to organize statements into categories. Themes were then extracted from the coding categories and discussed within the research team to reach consensus. Transcripts were also analyzed manually and coded for themes by another member of the research team. Any areas of discrepancy were discussed among the research team members until 100% agreement was obtained.

Results

Thirteen focus groups were conducted between November, 2005 and February, 2006, with 121 participants in Guilford County, NC (table 2). Focus group size ranged from 6 to 16 with an average of 9 persons. Participants were 47% male and 62% non-Hispanic Whites, 35% African American, and 3% Hispanic or Asian. Individual ages were not collected, but participants ranged from undergraduates to seniors. Perceived group demographics approximated the community's demographics: 45% of residents were male, 65% were non-Hispanic Whites, 32% were African American, 5% were Hispanic, and 1% were Asian.

Themes emerging from the focus groups were organized into 6 main categories including: lack of awareness about genomic medicine, perceived benefits of genomic medicine, concerns about genomic medicine, perceived reasons for poor health related behavior in society, perceived impact of genetic testing, and the best ways to educate the community. Responses to most of the questions were similar across the focus groups. Selected passages for each theme are given.

Table 2. Focus group participants

Community organization	Number of focus groups	Total number of participants
School teachers	2	14
College students	4	48
Seniors (retired adults over the age of 55)	2	21
Veterans	1	6
Active military	4	32
Total	13	121

Lack of Awareness about Genomic Medicine

The majority of study participants had never heard the term 'genomic medicine'. A few college students reported that they heard the term on television news or in biology class. When prompted about the term's meaning, respondents from several of the focus groups replied, 'genetics', 'the genome project', 'family history', 'using genetics to heal people', and 'cloning'. The participants were generally unfamiliar with the term 'personalized medicine'. A few made comments that personalized medicine is somehow tailored to the individual ('... like your treatment, or your prescription, the way you deal with your illnesses specifically geared toward your body and genetics.'). Other comments suggested a lack of understanding or skepticism ('You'll pay for it. That is your deductible.').

Participants were asked what they had heard about genetics from the media. Many said they did not recall hearing anything or could not remember what they had heard. Among those who had heard about genetics in the media, news stories concerning controversial topics were most frequently reported, particularly those involving stem cells and cloning. Sex and trait selection were also mentioned. One participant stated: 'I heard about cloning. I think of cloning because of the sheep.' Another participant stated: 'Stem cell research. I mean, that's a big issue right now with every fundamental group known to man.' Other relevant topics heard via the media included sickle cell disease, a gene identified for disease, fetal testing, and growing of organs ('You can grow certain organs in a Petri dish that introduce certain cells.').

Perceived Benefits of Using Genetics in Medicine

After asking participants about genomic medicine, a brief explanation of genomic medicine was provided. Participants were then asked what, if any, benefits they perceived from using genetics in medicine. Only a few participants responded, and some agreed there are benefits to the use of genomic medicine. The most prevalent benefits cited were the prevention of disease and the possibility of new treatments:

'Well, it could be used to save your life, though. Because you prepare ... yourself [for] what your parents had, to make sure you change your way of life ...'

'But their knowledge of those genetics has helped them to – to do things, to help prevent it, to look for preventive medicine, and to be aware of the things that are coming in, and know what they can do to prevent it.'

A few participants specifically mentioned their own family history or that of other people they knew.

'Well, back then they didn't know. You had to almost die before they caught it, but now it's something they screen for in my whole family because we carry it.'

Another said, 'My mother died – my mother died of cancer. And so, it does concern me. And I could understand where a doctor could work from that it would give him some idea as to your problem and maybe how to treat it.'

'... It is a necessary evil to eliminate the whole guessing stuff. As someone who has had medical treatments where they had to try out a variety of drugs, many of them had undesirable side effects; switching between them was not a comfortable process, and I think eliminating that would be a powerful thing.'

'I'd say yes because if you could work it down to one gene, you have a drug specific that goes to correct that one gene, then there's your benefit.'

'Um, I think it would make a lot of problems a lot easier to diagnose.'

'Although we have the same illness, we may need different types of treatment or medicines based on our genetics.'

‘Any time you can save a life or help someone out, it’s always a good thing.’

Participants also discussed the benefits of understanding genetics for people who were planning to have a family and for their children and grandchildren. A few also mentioned that the use of genetic information in medicine might make it possible to determine the underlying cause of a child’s problem and improve the quality of life. Although unrelated to genomic medicine, participants also noted the benefit of forensic DNA testing.

Concerns about Using Genetics in Medicine

Many categories emerged in this theme. Common categories include the cost of genomic medicine to the individual and affordability to all (‘It’s really not fair to people who can’t afford to do that because of a money thing.’), unanticipated physical harm from the use of technology (‘Is it going to hurt me in the future ... Well, sometimes sickness that I would have never had if I had never took that medicine.’), mistrust in the government, doctors, and/or scientists along with the need for regulations (‘Well, I’m concerned is do the doctors really tell you what they know about you? And if they are really telling you the truth of everything they know.’), downstream effects such as overpopulation from healthier people (‘That would cause our tax money to go up. If you are living longer, you are going to need more nursing homes, more stuff like that. We’ve got to pay for that.’), playing God/ disturbing the natural order (‘You know, basically it’s, you know, cancer and stuff like that are here for a reason.’), privacy, and genetic discrimination (‘But I have also heard that if insurance companies find this out they will drop you, although they are not legally supposed to do that.’). Concerns about issues such as genetic engineering (e.g., cloning and stem cells), choosing traits, and abortions resulting from genetic information were also raised in almost all of the focus groups. When discussing cloning and stem cell research, one participant indicated that he, ‘... do not believe in cloning. Emphatically do not believe in cloning. I think that’s against God’s law, absolutely.’

Perceived Causes of Poor Health Related Behavior

Participants were also asked to express opinions about the cause of poor health related behaviors in society. Laziness was the most cited reason to explain poor health behavior (‘Um, simply put because we’re lazy. I know that’s why I’m not doing it.’) The prevalence of fast food, fast-paced life-styles, expectation of immediate results, prevalence of sedentary activities such as watching TV, and the lack of cultural support to lead a healthy lifestyle were also noted frequently:

‘I think people who are constantly working don’t have time to prepare quality food and, so, they just eat out more frequently.’

‘Everybody wants convenience. Just run to McDonalds to get something to eat.’

‘TV gobbles up the American public’s time.’

‘It’s not encouraged.’

‘You know, it’s a – there’s a culture that’s been developed over the years is that most Americans want immediate results.’

Perceptions about Genetic Testing and the Impact of Genetic Information on Health Behavior

Participants were asked: ‘If you could have a genetic test or family history type evaluation with a counselor or a doctor to predict whether you were personally at risk for some condition or health problem, would you want to have that?’ Responses were mixed in almost every focus group, although many said they would choose testing. Those who favored using genetic information cited the potential for improving health or preventing disease.

‘If you could take preventative medicine to maybe turn it back and not get the disease.’

‘Like he said risk for my health, I would say yes. But like I say I don’t know almost nothing about it. Medicine and tests. But even if I don’t know enough information about the test, if you tell me, OK, it doesn’t have any risks for your health, I would say yes.’

‘You know, you grow up, you hear your family ... family members, and you never know well, heart disease runs in this side of the family. I think I would actually like to know what actually does, what I’m looking at for the future. If I can help it now ... if I can help it now, maybe it won’t be so bad later ...’

Among those who were opposed to obtaining genetic information, a variety of reasons were given. Many viewed the test result as deterministic. Some were scared about obtaining test results or thought that others would be scared, some didn’t feel they needed the information, and others were simply uncomfortable with the information:

‘Not me. I don’t know, I’m one of those persons that’s like, you know, if it is going to happen, let it happen. I don’t really need to know because then if I know then something I’m susceptible to, maybe terminal, that’s coming up pretty soon, then I’d go out here honestly I’d act a fool. I wouldn’t care.’

‘I think there’s other people here too, who would be scared to find out any results that may come. I mean, I know there are things that can change. If there is something in my genes if I find out now that I can prevent something later. It’s the finding out part that I don’t think that – I would rather just let it happen later.’

‘I know that my family has diabetes, heart trouble, cataracts. I know I’m susceptible to it. Now, if there is a test that will tell me that I’m going to get this, I’m going to be blind in, you know, 15 years from now. No, I don’t want to know that. Let me enjoy my time. I got other things I need to worry about. That’s not worth it.’

‘No, ’cause I feel the same way, ’cause if I find out that, okay, you’re gonna die when you’re 50, ’cause you’ve got this heart disease. Okay, why bother doing anything? I’ll just sit here and wait for it. If I don’t know anything about it, I’m just gonna live like I wanna live, when it happens it happens.’

Facilitator probes: ‘If there was something you could do about it, would that make any difference?’ Participant responds: ‘No.’

‘I feel like I kind of already know some of the things that I may be at risk for because of my family members. And, so, I know that. To me that’s enough information and enough motivation to have a healthy lifestyle. Or at least try that.’

There were also some participants who said they would need to know more information before they could say whether they’d have such testing or not. The type of information they cited needing include the cost, how invasive the test is, the reason for the test, their risk of discrimination, and whether there was something they could do based on the test result.

‘I don’t think I could afford it if it had to come out of my pocket, you know, depending on what the cost would be.’

‘I would think it would depend on what the test is ... Like a stress test is like running on a machine or exercise test, and that has nothing to do with your genes whereas a genomic test may be like dissecting, you know, part of your body or something. You know a lot of people don’t know what the test actually is. And that might have an effect. Until I knew what the test was or what it would entail.’

‘If something like a simple blood test, I would say yes, and if it is something like cutting up, like he said, I would say uh-uh (negative response).’

‘Pretty much the same reason, just to live life to the fullest ... Yeah, it would take that away ... You would become scared ...’

Facilitator probes: ‘What about like a prevention?’ Participant responds: ‘Yeah, okay, I would do it for that.’

In discussions, some participants suggested that genetic information may motivate improvements in health behavior, but others were skeptical this would help.

‘I do think some people would still turn their heads.’

‘... he had 3 uncles that passed away of cancer, too, from drinking. I mean it’s just something he says he knew that he was going to die from. But my thing is, OK, why don’t you stop? If you see this pattern happening, and it is happening to other people, then why can’t you stop? And he said it is just something that he’s been doing for so long that he’s just used to it. He is just, you know, it’s just part of his life, you know, the drinking ...’

Most Effective Ways to Educate the Community

Participants were asked if genomic education was an important topic for the public, what topics were most important, and the best ways to educate the public. Overwhelmingly, the participants felt genomic education was an important topic for which the public needed more information. Topics identified as important covered a broad range of areas including specific diseases such as autism, cancers, and high blood pressure, diseases that run in their family, details of current genomic research, information on insurance coverage, and information on stem cell research and other controversial issues (cloning, genetic engineering).

When asked how they usually obtain health information, members from all the groups reported that they use the Internet, their health care providers, and media sources. Specific web sites mentioned included WebMD and the National Institutes of Health sites. Participants also obtained health information from the television, the newspaper, magazines (including Time, Self, and Fitness), and from mass mailing advertisements. When questioned, few of the participants indicated the use of a public library as a regular source of healthcare information.

The participants were also asked how they would like to learn more about genomic medicine. Responses were consistent across all groups. Preferred sources of information included their physician, the Internet, magazine and newspaper articles, radio announcements, television commercials, billboard advertisements, pamphlets, especially in a doctor’s office, posters in public places, and newsletters from the local healthcare system or their employee health department. When specifically asked, several persons mentioned that they would attend formal programs on the topic if held in their community.

The participants offered advice on effective ways to present genomic education such as timing the presentation of information with doctors’ visits. As one participant noted, ‘You usually don’t think about your health until your health is in crisis or something’s going wrong.’ Other participants also recommended targeting doctors’ offices, when people are focusing on their health and the source of the information is credible. As one said ‘... if it is not coming from their family doctors or close family members that are in the medical profession, they won’t believe it.’

Several participants emphasized the need for easy to understand information (‘Don’t get too complicated with the explanations. You’ve got to realize that you’re dealing ... with a group of people [with a] wide variety of educational levels.’) On topics that are personally applicable to the individual (‘... making it personal and related to [the person] because if it’s not about them they’re not going to care.’).

Other advice included ‘... a news broadcast or something on the Internet. Something that pops in your face.’ and ‘... commercials are very important ... commercials will come on about healthy images’. In addition, ‘Bright colors. People are automatically drawn to it, if you do colors. [When] I see ... a bright yellow billboard ... I [do

a] double look.' Another cautioned that 'People don't want to work for their information. It's like watching a popcorn commercial, and all of a sudden you're like 'oooh some popcorn.' Not really hungry but hey, tastes pretty good!'

Discussion

Our study demonstrates that while community members are not familiar with the terms 'genomic medicine' or 'personalized medicine', most are aware of the expanding amount of human genetic information. We found that the public's knowledge of genetics and genetics in medicine is influenced by their own personal experiences, their general perception that diseases run in families, and media reports, especially reports on controversial topics such as stem cells, cloning, 'designer babies', and the potential for genetic discrimination, which is consistent with previous studies [11, 20, 30, 32] . The focus group discussions described here suggest the media has had less impact on the lay public's knowledge of genetics to aid in disease prevention and treatment. Further, the prevalence of controversial topics that focus group participants associated with genomic medicine and medical genetics such as cloning and stem cell research suggests strongly that it may be necessary to acknowledge and address these topics in the education plan to allay misconceptions about genomic medicine and facilitate its acceptance into a community health system.

Community members participating in the focus groups shared many concerns about the use of genetics in medicine, many of which have been previously reported by others [25–27] . Some respondents mentioned concerns because of little or no understanding about how genomic medicine works, what is involved in obtaining a genetic test, or what could be done as a result of a genetic test. Some had misconceptions about the technologies that are used in genomic medicine. Concerns fell into 3 groups: (1)Concerns that do not apply to genomic medicine, such as cloning, and unrealistic concerns or misconceptions of genomic medicine, such as unanticipated physical harms; (2)Moral and global concerns that impact health policy such as the availability of testing, use of genetic information for unethical or immoral purposes, need for regulations, playing God and disturbing the natural order, affordability for all, and downstream effects such as overpopulation resulting from improved healthcare; and (3) Personal concerns that may impact utilization of genomic medicine, such as fear of genetic discrimination by insurers and employers and affordability. Educational information can directly counter misconceptions about genomic medicine. For global and personal concerns, educational information can facilitate the decision making process and policy considerations by the public.

A mistrust of government, physicians, and scientists conducting research was a prevailing concern that emerged from the focus groups, which is likely impossible to remedy via an education program. However, this distrust about motives and concerns regarding availability and cost of genomic medicine, which appeared throughout the transcripts of most focus groups, makes it imperative that genomic medicine initiatives provide the community they serve with clear information about intent and the outcomes and implications of genomic medicine for the individual.

Despite the concerns noted earlier, a sense of possibility about genomic medicine was expressed by many participants. This is consistent with the optimism related to the application of genetic advances reported by others [22, 23, 25, 26].

Participants also conveyed a strong interest in learning more about genomic medicine for themselves and the community, further offering suggestions about topics of interest, distribution channels, and teaching strategies for the education plan of this initiative [Potter-Powell et al., 2008, unpublished data]. Because participants for most focus groups were self-selected, it is impossible to determine whether the same level of interest exists in the general population, though the responses were similar across all groups.

Study Limitations

The study participants were recruited from a single urbanized community in the Southeastern United States whose collective perceptions cannot be projected onto other communities. Also, the sample was limited to English-speaking participants who were self-selected. No effort was made to divide participants by age, race, or

gender, although they were separated by rank at the Army Reserve Unit. Finally, news events at the time of the focus group interviews may have affected participant responses. At the time of the interviews several news reports were being aired about a South Korean scientist who falsified his reports on cloning. During the time period of the focus groups, news shows presented coverage of the 'Genographic Project' which utilizes personal DNA information to reconstruct human migration patterns. Debate about stem cell research was receiving wide coverage during the time frame of the focus groups.

Conclusion

The public remains mostly unaware of the term genomic medicine and sometimes confuses it with other medical technologies. Participants seem aware of and interested in the connection between genetics and family history. Many expressed optimism about genomic medicine by voicing perceived benefits for healthcare, and a number of concerns were raised as well, including a general distrust of the healthcare system, which poses a potentially difficult obstacle. However, the lack of depth in responses and the misconceptions reflect a deficiency of knowledge pertaining to the uses of genetic information in healthcare and associated issues that could impede acceptance and informed choices. Community education programs must be properly planned, developed, implemented, and evaluated in response to the concerns emerging from focus group discussions.

This study represented the initial phase of a needs assessment to determine the knowledge, attitudes, and awareness of genomic medicine within a community prior to a community wide, random digit dialing survey. Data from these 2 assessments and a literature review will be used in the ongoing curriculum development for the community as part of this genomic medicine initiative.

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