Evaluation findings from genetics and family health history community-based workshops for African Americans

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Abstract The purpose of this study was to examine the implementation and effectiveness of community education workshops to change genetics and health-related knowledge, intentions, and behavior of urban African Americans. Eight workshops were held and 183 participants consented to participate in the study. A majority of the participants were African American (97%) and female (84%) and just over half were 65 years and older (60%), and had some high school or were high school graduates (52%). The community-based workshops were standardized and comprised a 45-min PowerPoint presentation that included group discussions and interactive activities. The evaluation used a pre-post design with a 2-month follow-up. The group as a whole (and the subgroups by age and education level) significantly improved their knowledge of race and genetics from pretest to posttest as measured by their scores on the “Race”, Genetics, and Health knowledge questions. Findings around intentions showed that the largest number of participants pledged to collect family health history

information from family members. Findings around behavior changes showed that, along the stages of change continuum, there were more participants at maintenance (stage 5) at the 2-month follow-up than at the pre-workshop for three health-related activities. Feedback was positive as participants indicated they appreciated the information they received and audience involvement. The article discusses local and global implications for practice and research among community health educators.

Keywords Genetics education · Family health history · Community-based workshops · African Americans · Program evaluation

Background

The mapping of the human genome has fueled the need to educate the general public about new gene-based technol-

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ogies that impact screening, risk factor management, diagnosis, prognosis, and treatment in clinical practice. Genetic knowledge has grown in the scientific community in recent years. Its application to health issues has also grown, including race-specific disparities in genetic-based disorders. However, knowledge of the importance of genetics in the development of disease and morbidity is not well understood in the broader community, especially among minority populations. If genomic application and testing are to become useful to the lay public, initiatives are needed to broaden the public's knowledge of genomics and their understanding of the appropriateness of testing. To meet this need, the field of community genetics “the art and science of the responsible and realistic application of health and disease-related genetics and genomics knowledge and technologies” emerged and is of increasing interest (Ten Kate et al. 2010).

Community genetics encompasses a service and science component that includes a number of activities for the prevention, diagnosis, and care of genetic diseases at the community level. From a global perspective, the dual and indivisible goal of community genetics is to prevent congenital disorders and genetic diseases at the population level and provide genetics services in the community for individuals and families (World Health Organization 2010). Community genetics has international significance especially in low to middle income countries with high frequencies of genetic disorders and genetic diseases. Community genetic initiatives accompany the national, community-based public health strategies that are being used to emphasize prevention and reduce health disparities at the population level.

There are many factors that contribute to racial and ethnic health disparities including socioeconomic factors, lifestyle behaviors, and access to preventive healthcare services. African Americans and other minority groups in the USA including Latinos and Native Americans bear a disproportionate burden of disease, injury, death, and disability related to common diseases such as cancer, cardiovascular disease, and diabetes. The problem is more challenging within underserved communities (particularly the African American population) that are not benefiting from the use of genomic counseling and genomic testing. Underutilization of screening practices has been attributed to knowledge-based, access-driven disparities; poor communication of family health history; inaccurate risk perception; and lack of awareness of genetic and genomic services (Hall and Olopade 2006).

There are significant differences by racial/ethnic groups in knowledge and concerns about the potential misuse of genetic testing (Suther and Kiros 2009). Mistrust and exploitation of African Americans in the biomedical arena has resulted in suspicion of the health care system (Royal et

al. 2000) and has contributed significantly to a lack of awareness about genetics and basic genetics concepts (Kessler et al. 2007). Concerns about racial discrimination are deeply rooted in past abuses of the Tuskegee Syphilis Study (Freimuth et al. 2001). Mistrust has been a significant predictor of the perceived disadvantages, negative attitudes toward screening and genetic testing, and abuse concerns (Thompson et al. 2003). A study by Catz et al. (2005) revealed that African Americans were more likely to believe that genetic testing would lead to racial discrimination such that the government would use genetic tests to label groups as inferior. Additional concerns in the African American community exist regarding insurability and ethical dilemmas posed by genetic technology (Catz et al. 2005). Equally important, African Americans may hold a number of beliefs including religious beliefs that conflict with their observed preference for genetic testing (Singer et al. 2004). The aforementioned examples of misinformation and perspectives are a reflection of the African American culture and have a significant impact on health decision making.

Still, misconceptions can be addressed with the provision of culturally specific educational and communication strategies. Cultural competency is needed to acknowledge and incorporate the unique as well as shared experiences of African Americans, other African diaspora populations, and other people of color to alleviate some of the mistrust of the scientific community (Thompson et al. 2003; Giger et al. 2007). Charles and colleagues found that women receiving culturally tailored genetic counseling materials for breast cancer genes were significantly more likely to strongly agree that their worries were lessened (Charles et al. 2006).

African Americans have limited knowledge about genetics and the availability of genetic services although they would like to have more information (Catz et al. 2005). Despite numerous concerns, members of the African American community believe that genetic testing to check for risk of getting a disease is a good idea and that research on genetics will bring cures for many diseases (Zimmerman et al. 2006). Some African American communities have a working knowledge of sickle cell disease primarily due to personal experience but have a limited understanding of the inheritance and probable risk of giving birth to a child with the disease (Long et al. 2011). Identifying such gaps in knowledge provides the opportunity to develop genetics education initiatives targeted to African Americans with a focus on increasing understanding about technical concepts related to genetics.

A promising approach has been to include community members in the development of genetics informational materials to ensure they are culturally attuned to their needs. O'Leary and colleagues found that diverse communities are receptive to family health history interventions,

and tailored health educational materials can lead to increased conversations and awareness about health issues across communities (O'Leary et al. 2011). Community genetics initiatives that utilize family health history interventions have been an effective means to provide an accurate assessment of disease risk to aid in lifestyle behavior change (Marteau and Lerman 2001; Yoon et al. 2002; Hariri et al. 2006; Murthy et al. 2011). Since family health history is the strongest known risk factor for many diseases (Vogel et al. 2007), targeted public health efforts are warranted to educate and assist individuals in collecting family health history information, and to emphasize the significance of family history as it relates to disease prevention and lifestyle modification.

Previous work in African American communities has described effective application of behavior change models to improve health regarding smoking cessation (Schorling 1995), cancer screening (Hawkins et al. 2001; Steele-Moses et al. 2009), diet (Baptiste-Roberts et al. 2007), and physical activity (Walcott-McQuigg et al. 2001; Dudley 2006). Specifically, the Transtheoretical Stages of Change model described by Prochaska and DiClemente (1983) has been used to intentionally change behaviors in action-oriented prevention programs based on an individual's readiness to change. Few studies have described the culturally specific genetic education interventions developed by and implemented in underserved African American communities.

This article outlines the process and impact of implementing a culturally and linguistically competent community-based genetics education intervention to address gaps in genetics and health knowledge, intentions, and behaviors in an urban African American community. We asked the following research questions:

1. Will the educational program increase the knowledge of race and genetics among participants?
2. Will the intentions (pledge commitment) of participants change as a result of the educational program? If so, what actions are most likely to be taken?
3. Will the behavior of participants change to reflect the impact of the educational program? If so, how extensive will this change be?
4. Will participants be satisfied with information they receive in the educational program and what are some of their recommendations for improvement?

Program description

In 2005, the U.S. Health Resources and Services Administration (HRSA) funded a 5-year cooperative agreement with the March of Dimes called the Community Genetics Education

Network (CGEN) project. The overall goal of this agreement was to increase the genetic literacy of African Americans, Asian Americans, Latinos, and Pacific Islanders to promote (a) informed health decision-making, (b) consultation with family and health care providers about genetics and health, (c) the use of genetics services among high-risk populations, and (d) lifestyle changes to reduce genetic-based health risks.

For African Americans, the Community Partnership Program/GenEthics Unit of the National Human Genome Center at Howard University was the University's conduit for the CGEN project. Goals of the project were to promote lifestyle changes to reduce genetically based health risks, and engage African Americans and other people of color in an ongoing dialogue about health and wellness. Howard University's Community Advisory Board was an integral part of the project and consisted of five community members who advised and assisted in project development and implementation and were key stakeholders in their respective communities.

The principal intervention for Howard CGEN was a community education workshop titled "Family Health History, Genetics and Your Health: Educating the African American Family," which included the use of two interactive booklets: (a) *Planning for a Healthy Future: The Importance of Family Health History* (FHH), with a family health history insert, (b) "Race", *Genetics, and Health* (RGH); and a trigger video, i.e., a 1 min video on family health history, to stimulate discussion. The FHH booklet contained several short articles that highlighted the importance of knowing your family health history. It also contained two interactive activities, a crossword puzzle and a tool to create a family health history tree. The RGH booklet consisted of several short articles on race, genetics, and health and an interactive word search activity. Both booklets contained culturally appropriate drawings and features from the African American perspective which were selected with community input. Other resources introduced at the community education workshops were the Howard CGEN Web site (www.myfamilies.org) and a toll-free information line.

The goal of the community education workshop was to empower adult community members and enable them to understand factors related to four health themes: family health history, gene–environment interactions, preconceptions about genetic differences among racial ethnic groups, and racial health disparities. The community education workshops lasted about 45-min and were conducted mainly at community centers in Washington, DC. The workshops expanded on information provided in the FHH and RGH interactive booklets. At the end of the workshop, participants were asked to complete a pledge form in which they identified one health-related activity out of three choices to which they felt they could commit to during a 2-month period.

Evaluation framework

The CGEN project as a whole applied principles of community-based participatory research (CBPR) to develop, plan, implement, evaluate, and disseminate culturally and linguistically appropriate genetics education interventions and materials for low-literacy populations of diverse cultural backgrounds. This collaborative approach to research equitably involved all partners (i.e., HRSA, March of Dimes Foundation, national evaluation team, and community advisory boards) in the research process; it recognized the diverse but complementary roles each brought in knowledge, expertise, and skills.

CBPR is described as beginning with a research topic of importance to the community that has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities (Community Health Scholars Program 2002). CBPR is further recognized as an effective means to help people focus energy and mobilize resources to solve local health, environmental, and economic problems (Wallerstein and Duran 2003). This approach relies on trust, cooperation, dialogue, community capacity building, and collaborative inquiry toward the goal of improving health and well-being (Minkler and Wallerstein 2003).

Public health initiatives have focused, in recent years, on eliminating health disparities in underserved communities while promoting broader community and social change (U.S. DHHS 2000). The renewed focus is thought to be due to many converging factors, including an increased understanding of the complex issues that affect health, the importance of both qualitative and quantitative research methods, and the need to translate the findings of basic, interventional, and applied research into changes in practice and policy (Israel et al. 1998). In public health and other related fields, CBPR has been increasingly acknowledged as the term that best captures this model. Building on the work of researchers (Green et al. 1995; Israel et al. 1998) and the W. K. Kellogg Foundation's Community Health Scholars Program (2002; cited in Minkler and Wallerstein 2003: 4), it is suggested that a combination of knowledge and action is needed for social change to improve the community. In the CGEN project as a whole, CBPR principles were incorporated in the development, planning, implementation, evaluation, and dissemination phases of all programs including the Howard program that targeted African Americans in underserved communities.

Design and methods

The implementation phase of the Howard CGEN project began on March 16, 2008 and featured a pilot project which

consisted of 178 participants in nine workshops. The pilot was conducted to evaluate the implementation of genetics education workshops using two interactive booklets and a trigger video as learning tools.

The pilot was followed by reviews and subsequent edits of program materials, the program presentation, and instruments. Edits to the materials and booklets were made by simplifying the language used to define some concepts. Changes were made to the instruments and forms to make them more user-friendly (e.g., color-coding forms for easy identification during the workshop and enlarging the print on instruments and forms to make them easier to read). Changes were made to the program presentation by distributing a card with the correct answers for the knowledge questions just before participants left the workshop.

During the pilot, the length of workshop times varied since some presentations were stand-alone events and others were part of larger meetings. After reviewing the effectiveness of the varied approaches, it was decided that the workshop length and content would be standardized to be delivered within a set 45-min-time period.

It was further decided that the Stages of Change Model (Prochaska and DiClemente 1983) would provide a framework for analyzing the study's intention and behavior data. Specifically, the analysis would assess where participants were along five stages of change (precontemplation, contemplation, preparation, action, or maintenance) for key health-related behaviors. As a result, a new instrument was introduced that addressed changes in the behavior of participants to determine their position in the continuum of change from the time they became involved in the intervention at the community education workshop to the 2-month follow-up.

In addition to revising and editing the program materials after the pilot, the Howard team also obtained IRB approval to offer several incentives to participants: (a) a Howard University hat to all workshop participants, (b) a \$20 grocery gift card to participants who correctly answered questions in a workshop knowledge recall activity, and (c) a \$10 grocery gift card for participation in the 2-month follow-up interview.

The full study commenced in February 2010 to examine the effectiveness of community education workshops in changing knowledge, intentions, and behavior of urban African Americans during the evaluation study (see Table 1). The following outcomes were assessed:

1. What impact did the community education workshop have on increasing *knowledge* among workshop participants between the time they initiated involvement in the intervention (pretest) to the time they completed it (posttest)?

Table 1 Evaluation instruments by outcomes

Intervention/approach	Number	Knowledge	Intentions	Behavior	Satisfaction
Community workshops	Pilot: 178 adults	Pre- and post-presentation knowledge questionnaires	Post workshop pledge form	Workshop 2-month follow-up pledge form	Post workshop evaluation questionnaire
	Study: 183 adults	Pre- and post-presentation knowledge questionnaires	Post workshop pledge form	Pre-workshop questionnaire Workshop 2-month follow-up pledge form (which included Stages of Change Questionnaire)	Post workshop evaluation questionnaire

2. How did intervention participants' *intentions* (pledge commitment) change as a result of the community education workshop?
3. How did intervention participants' *behavior* change from the time of their involvement in the intervention to the 2-month follow-up?
4. How did participants feel about the educational workshops and what recommendations did they have for improvements?

Data collection procedure The community education workshops targeted African American adults residing in wards in Washington, DC with the following demographic characteristics: (a) 60% African American/Black (US Census Bureau, Office of Planning 2000), and (b) high deaths rates from heart disease, cancer, hypertension, and diabetes (Cano et al. 2008). Eight community education workshops were held in the wards targeted for the study from February 2010 to May 2010 and 183 participants consented to participate in the study.

The project coordinator conducted recruitment of sites through letters, flyers, and presentations to community members. Individual sites also assisted in recruiting participants to attend the workshops with flyers received from the project coordinator.

The eight community education workshops followed a standardized format designed to last 45 min (not including evaluation procedures). Prior to the beginning of the workshop, participants were given a survey packet which included a pretest and posttest knowledge questionnaire, a workshop evaluation form, and a pledge form. During the introduction, the facilitator explained the purpose of the workshop and allowed participants to complete an informed consent form and registration form. Participants who did not want to be a part of the study were free to attend the workshop but were not required to complete the evaluation forms given in the survey packet. Following this, consenting participants were guided through the process of completing two evaluation forms: (a) the pre-workshop questionnaire, and (b) the pre-presentation knowledge questionnaire. These forms collected information on participants' level of engagement in three health-related

activities prior to the workshop and elicited participants' initial knowledge about family health history and race, genetics and health. Trained graduate student assistant volunteers from Howard University assisted participants with the completion of forms.

The facilitator then presented on topics related to family health history using a trigger video, a PowerPoint presentation, and the FHH booklet, all of which aided in the discussion. Following the session, participants completed the FHH posttest. Participants were then engaged in a dialogue around issues of race, genetics, and health where participants were encouraged to share their thoughts and insights. After several 2- to 3-min discussions, participants were referred to sections in the RGH booklet that corresponded to questions posed by the facilitator. At the close of the workshop, participants were asked to complete the RGH posttest, a pledge form, and the workshop evaluation form. The pledge form allowed workshop participants to select one of three health-related activities they planned to engage in during the next 2 months.

The workshop ended with a recall activity where participants were asked to write key words they remembered from the presentation. Winners were given gift cards and all participants were given Howard University CGEN caps for their participation. At the end of the workshop, index cards with the correct answers to the knowledge questions were distributed, and contact information for a genetic counselor who could answer any further questions was provided. Workshop participants were also reminded that they would be contacted by phone in 2 months to follow-up on their pledge.

Instruments The instruments used for data collection included a *pre-workshop questionnaire* used to collect information on participants' level of engagement in three health-related activities prior to the workshop. *Pre- and post-presentation knowledge questionnaires* completed by participants prior to and at the end of the workshop that elicited participants' knowledge about five (yes/no) questions on genetics, race, and health. Pre- to post-presentation statements found in the booklets and discussed during the presentation were the same, but rearranged in order from pre to post. A *post workshop pledge form* administered at the end

of the workshop which allowed workshop participants to select one of three health-related activities to pledge to engage in during the following 2 months. A *workshop evaluation questionnaire* gathered information from workshop participants about their experiences and feelings about the community education workshop and their understanding of the information presented. A *workshop follow-up pledge form* was completed as a telephone interview 2 months after the community education workshops. This form gleaned whether participants kept their pledge. Participants could also indicate whether they engaged in any of the other two health-related activities listed on the pledge form and their level of engagement in all three health-related activities. All instruments were developed by the local evaluator in collaboration with the project coordinator and national evaluation team. The instruments were pilot tested during the pilot and revised for the full study.

Data analysis Process evaluation data were analyzed using descriptive statistics (frequency analysis). The changes in knowledge from pretest to posttest were analyzed using a paired sample *t* test. SPSS Version 17 software was used for data analysis.

Findings/results

Eight community education workshops were held in the targeted wards for the study. Two hundred eighteen (218) individuals participated in the eight workshops of which 183 consented to participate in the evaluation for a participation rate of 84%. Of the 183 participants, a majority (or 97%) was African American, 84% were female, over half or 60% were 65 years and older, and just over half or 52% had some high school or were high school graduates. Participants came from all eight wards and the Virginia and Maryland suburbs (see Table 2).

Knowledge

Knowledge questionnaires were completed by workshop participants prior to and at the end of the community education workshops. The questionnaires consisted of ten statements (yes/no): five on family health history and five on race, genetics, and health (see Table 3). Questions were the same on both pre- and posttest but reordered from pretest to posttest.

Tables 4 and 5 show findings for paired sample *t* tests for all program participants for pre and posttest knowledge questions, followed by the same comparison for subgroups of participants by age groups (18 to 54, 55 to 64, 65 years

Table 2 Demographic characteristics of community workshop participants (*N*=183)

Characteristic	Number	Percentage, % ^a
Age (years)		
18–24	07	05
25–34	11	07
35–54	07	05
55–64	37	24
65 and above	92	60
Missing	29	
Gender		
Male	25	16
Female	129	84
Missing	29	
Race/ethnicity		
Black/African American	146	97
White, non-Hispanic/Latino	03	02
Other	01	01
Missing	33	
Highest education completed		
Some high school	24	16
High school graduate	54	36
Some college	33	22
College graduate	40	27
Missing	32	
State of residence		
DC	144	79
MD	30	16
VA	03	02
Missing	06	
Wards of residence (DC residents only— <i>n</i> =144)		
1 ^b	08	06
2	04	03
3	00	00
4 ^b	31	22
5 ^b	26	18
6	07	05
7 ^b	21	15
8 ^b	46	32
Missing	01	

^a Percentages may not add up to 100% due to rounding

^b Targeted wards

and over) and educational level (no college degree and college degree).¹

The scores on the knowledge tests could potentially range from 0 for the lowest to 5 for the highest. Of the 183

¹ Because of the small sample sizes for the following age subgroups (years): 18–24 (*n*=7), 25–34 (*n*=11), and 35–54 (*n*=7), the three groups were combined to 18–54 (*n*=25).

Table 3 Pretest/posttest knowledge questions for family health history and race, genetics, and health

Family health history		Yes	No
1	Family health history is information about your health, environment, lifestyle habits, and those of your relatives.	✓	
2	You get all of your genes from your mother and none from your father.		✓
3	Genetics is the study of heredity and how traits are passed along from parents to children.	✓	
4	Family health history information should be collected on at least three generations on your mother's and father's side.	✓	
5	Having a healthy lifestyle can reduce your risk of developing some diseases that may run in your family.	✓	
Race, genetics, and health		Yes	No
1	The genes of all people are 99.9% the same regardless of ethnic or “racial” identity.	✓	
2	Your health is determined by how your lifestyle, environment, and genes work together.	✓	
3	All people with different physical features are of different races.		✓
4	All African Americans will get diabetes.		✓
5	Your environment includes where you live, work, and play.	✓	

participants, 134 answered all five yes/no items correctly at pretest and posttest for the FHH knowledge questions and 116 answered all five yes/no items correctly at pretest and posttest for the RGH knowledge questions. *t* test results indicated that overall, scores did not differ significantly for the FHH knowledge questions from pretest ($M=4.72$, $SD\ 0.60$) to posttest ($M=4.75$, $SD=0.58$) (see Table 4). However, *t* test results for the RGH knowledge questions differed significantly from pretest ($M=3.74$, $SD\ 0.88$) to posttest ($M=4.37$, $SD=0.85$; see Table 5). Scores at pretest and posttest were very close to ceiling for the FHH knowledge questions, ranging from 4.72 to 4.86 on a scale of 0 to 5 (see Table 4). Furthermore, subgroup differences in all areas for RGH knowledge questions at pretest and at posttest were statistically significant (age groups 18 to 54, 55 to 64, 65 years and older and educational levels no college degree and college degree). Conversely, no significant subgroup differences were found for the FHH knowledge questions at pretest and at posttest (see Tables 4 and 5).

Intentions (pledge commitment)

Of the 183 consenting workshop participants, 153 participants pledged to engage in one of three health-related

activities during the following 2 months: (a) *collect family health history information with members of my family*, (b) *engage in positive lifestyle choices related to my diet*, and (c) *engage in positive lifestyle changes related to increased physical activity*. The top pledge selected by the 153 respondents who completed the pledge form was to *collect family health history information with members of family* (43%), followed by *engage in positive lifestyle choices related to diet* (34%), and *engage in positive lifestyle changes related to physical activity* (23%).

Cross-tabulation analysis was conducted to examine the relationship between what health-related activities participants stated they were currently engaged in and what health-related activity they pledged to do during the next 2 months. In completing the pre-workshop questionnaire, participants were asked to check off all activities they were presently involved in. Almost one half or 47% of the 55 respondents indicating “yes” to *currently engaging in collecting family health history information with members of your family* selected the same activity as their pledge to commit to during the next 2 months. One third (or 33%) of the 77 respondents indicating “yes” to *engaging in positive lifestyle choices related to your diet* selected the same activity as their pledge. Just over one quarter or 26% of the 71 respondents selecting “yes” to *engaging in positive*

Table 4 Group differences for family health history (FHH) pre and post knowledge questions ($N=183$)

	FHH pretest		FHH posttest		<i>df</i>	<i>t</i> test
	Mean	SD	Mean	SD		
All participants ($n=134$)	4.72	0.60	4.75	0.58	133	−0.52
Age 18–54 ($n=23$)	4.74	0.54	4.78	0.74	22	−0.27
Age 55–64 ($n=31$)	4.74	0.58	4.81	0.40	30	−0.49
Age 65 and over ($n=67$)	4.75	0.60	4.78	0.42	66	−0.41
No college degree ($n=82$)	4.78	0.52	4.74	0.51	81	0.49
College degree ($n=36$)	4.75	0.60	4.86	0.42	35	−1.28

Table 5 Group differences for race, genetics and health (RGH) pre- and post-knowledge questions

	RGH pretest		RGH posttest		df	t test
	Mean	SD	Mean	SD		
All participants (n=116)	3.74	0.87	4.37	0.85	115	−6.78*
Age 18–54 (n=22)	3.96	0.75	4.95	0.21	21	−6.21*
Age 55–64 (n=26)	3.61	0.80	4.35	0.75	25	−3.34*
Age 65 and over (n=57)	3.70	0.91	4.14	0.97	56	−3.20*
No college degree (n=70)	3.67	0.86	4.11	0.94	69	−3.46*
College degree (n=33)	3.91	0.77	4.88	0.33	32	−7.65*

* $p < 0.05$

lifestyle changes related to increased physical activity selected the same activity for their pledge.

In short, for each health-related activity, a majority of participants who indicated that they were engaged in that activity selected a different activity for their pledge.

Self-reported behavior

Two months following the workshop, participants were contacted by telephone to determine their stage of behavior change with respect to the three health-related behaviors. Data were analyzed to determine participants' stage of behavior change with regard to the three health-related behaviors, from pre workshop to the 2-month follow-up. These behaviors were self-reported.

Table 6 shows “stage of change” status findings at pre workshop and at the 2-month follow-up for matched study participants who selected a health-related activity for their pledge post workshop and provided data on the activity they selected post workshop at the 2-month follow-up. Of the 153 workshop participants who selected a health-related activity for their pledge post workshop, 111 provided data on pledge status at the 2-month follow-up, and of these: 30 who pledged to *collect family health history information with members of my family* provided both pre and follow-up

stage of change data on this behavior; 20 who pledged to *engage in positive lifestyle choices related to diet* provided both pre and follow-up stage of change data on this behavior, and 13 who pledged to *engage in positive lifestyle choice related to increased physical activity* provided both pre and follow-up stage of change data on this behavior (see Table 6).

At the beginning of each workshop, the highest percentage of participants was at preparation (stage 3) for *collect family health history with members of my family* (50%) and at maintenance (stage 5) at the 2-month follow-up (53%). It should also be noted that for the health-related activity *collect family health history with members of my family*, there was an increase in the number of participants at the precontemplation stage (6% or 20%) from pre workshop to the 2-month follow-up (11% or 37%). For *engage in positive lifestyle choice related to diet*, findings at pre workshop show the highest percentage of participants at maintenance (stage 5) both at pre workshop (65%) and at the 2-month follow-up (90%). For *engage in positive lifestyle change related to increased physical activity*, findings at pre workshop show the highest percentage of participants at maintenance (stage 5) for both pre workshop (70%) and at the 2-month follow-up (77%; see Table 6).

Findings around the extent to which intervention participants' self-reported behavior changed from the time

Table 6 Stages of change at pre workshop and 2-month follow-up, by activity pledged

Stages of change	Health-related activity selected					
	Collect family health history (n=30)		Positive lifestyle choice related to diet (n=20)		Positive lifestyle change related to increased physical activity (n=13)	
	Pre workshop n (%)	2-Month follow-up n (%)	Pre-workshop n (%)	2-Month follow-up n (%)	Pre-workshop n (%)	2-Month follow-up n (%)
1—Precontemplation	06 (20)	11 (37)	01 (05)	01 (05)	02 (15)	01 (08)
2—Contemplation	00 (00)	00 (00)	00 (00)	00 (00)	00 (00)	00 (00)
3—Preparation	15 (50)	02 (07)	01 (05)	00 (00)	02 (15)	01 (08)
4—Action	06 (20)	01 (03)	05 (25)	01 (05)	00 (00)	01 (08)
5—Maintenance	03 (10)	16 (53)	13 (65)	18 (90)	09 (70)	10 (77)

of their involvement in the intervention to the 2-month follow-up show that along the stages of change continuum, there were more participants at maintenance (stage 5) at the 2-month follow-up than at the pre workshop for all three health-related activities.

Satisfaction

At the conclusion of the workshop, participants were asked to complete a workshop evaluation form. Results showed that participants responded very positively to the educational program. The vast majority (on average over 90%) of the respondents rated various aspect of the workshop they attended on “family health history” and “race, genetics, and health” either 4 or 5 on a scale of 1 to 5 with 1 being poor and 5 being excellent. A majority of the respondents rated the purpose and location of the workshops highly (either 4 or 5). They found the information presented important and easy to understand. They rated the interactions among workshop participants and the presenter highly and found the speaker knowledgeable about the topic.

Similarly, a majority of respondents rated the two booklets used in the workshops between 4 and 5 on a scale of 1 to 5 with 1 being poor and 5 being excellent. They found both booklets useful and important to them. They liked the layout and were able to understand the contents of the booklets. A majority of respondents rated the layout and usefulness of the Family Health History insert as excellent.

Data were also collected through open-ended responses on what participants liked or felt could be improved in the community workshops. Participants indicated that they liked the (a) information they received, (b) audience involvement, and (c) knowledgeable presenter/facilitator. Improvements noted by the participants included making the presentation longer and having less evaluation paper-work during the presentation.

Discussion

Findings suggest that for all participants, there were significant knowledge increases on the RGH but not on the FHH knowledge questions from pretest to posttest for both the sample taken as a whole and its components disaggregated by age and education. The findings that the RGH knowledge questions progressed significantly from pretest to posttest for the group overall and for subgroups support the benefits of implementing the community education workshops in this area with the support of a well-designed and culturally relevant materials and booklets.

No significant changes were found in the comparison of the pretest and posttests in the FHH knowledge instrument.

This finding applied both to the full sample and to the sample when stratified by age and educational level. It was noted that scores at pretest and posttest were very close to ceiling for the Family Health History knowledge questions, reducing the possible range of change. This was observed strongly for groups of participants who were ages 18 to 54 and also for groups with college degrees. It is likely that these groups came into the workshops with a relatively high level of knowledge about issues around family health history. Nevertheless, participant feedback indicated that participants found the FHH portion interesting and that they felt they had learned something. It may be that the difficulty level of questions for FHH should be increased so that new information on FHH is garnered by participants. It is also possible that the overall educational level of the participants involved in the workshops was higher than the average level of the African American population, so that even though the FHH test may have been too easy for participants in this particular sample, it may not be too easy for the overall African American population.

Engaging in health-related activities related to physical activity, diet, and collecting family health history are important to improving health status for African Americans. Findings showed that participants indicating they were currently engaged in a particular health-related activity were not always likely to select that same activity for their pledge. They were more likely to select a different activity for their pledge except in the case of those who were currently engaged in collecting family health history. This finding shows that while some workshop participants may have been comfortable pledging to carry out an activity they were currently engaged in, a majority selected different health-related activities. Equally important, a majority selected to engage in collecting family health history. This could be due to the fact that the focus of the workshop was taking charge of their health and collecting their family health history. Additionally, for the majority, the workshop may have been a motivator to encourage them to select a new activity beyond those in which they were currently engaged. This interpretation suggests that the workshops achieved a high degree of success since participants tried new health-related activities outside of their comfort zone and previous experiences.

For study participants who pledged to *collect family health history with members of my family* and who participated in the follow-up interview, behavior change from pre workshop to 2 month follow-up showed that along the stages of change continuum, there were more participants at maintenance (stage 5) at the 2-month follow-up than at the pre workshop for the health-related activity *collect family health history with members of my family*. The increase in number of participants intending to take action at pre-workshop to taking some action at the 2-

month follow-up suggests that the workshop may have had some positive impact on this health-related activity. It could be that their involvement in the educational workshop led to their doing the family history even though they were also pledging to do something else, (i.e., diet or exercise). The workshop may have inspired them toward engaging in diet and/or exercise.

For the other two health-related activities related to diet and physical activity, the workshop may have been the impetus for participants to maintain those behaviors from pre workshop to the 2-month follow-up since findings showed positive movements at the maintenance stage for participants who pledged and did not pledge to those health-related activities. However, for the study participants who did not pledge to the health-related activities related to diet and physical exercise, there was an increase in number at the precontemplation stage from pre workshop to the 2-month follow-up.

Participants were satisfied with the standardized community workshops. Dialogue among participants and the facilitator was encouraged for all workshops and participants liked that they were involved. They found the information presented valuable and the two booklets useful. The positive feelings about the workshop held by participants suggest that the efficacy of the program to bring about greater knowledge, improved intentions, and better behaviors around race and genetics is encouraging. This information leads one to keep in mind the importance of presenting these types of topics in ways that are appealing and engaging to the audience. This further suggests that for those educating the public in genetics and related topic, materials should be culturally appropriate and technical concepts explained simply and clearly. Also, workshops should be interactive, participants should be allowed to express their views and discuss issues related to them, and forms to be completed should be few and concise.

The findings of this community education workshop provide several implications for community health educators and public health workers who are educating African American community members in the area of family health history and race, genetics, and health. The lack of awareness about genetics and basic concepts of African Americans (Kessler et al. 2007) and the importance of identifying gaps in genetics knowledge as suggested by Long et al. (2011) is critical. As findings from our study showed, the study sample appeared to have more knowledge gains in areas around race, genetics, and health as opposed to family health history. As a result, the opportunity to develop genetics education initiatives to African Americans with a focus on increasing understanding about key technical concepts related to genetics is important. O'Leary et al. (2011) found that involving the community in the development of materials to ensure that they are

culturally attuned to the needs of the community lead to individuals being more receptive to the information presented through increased conversations and awareness about health issues across the community. The importance of providing culturally specific educational materials and engaging communication strategies as acknowledged by Thompson et al. (2003) and Giger et al. (2007) are critical. Findings from our study found that participants found both booklets useful and important to them and they liked the layout and were able to understand the contents of the booklets. A majority of respondents rated the layout and usefulness of the Family Health History insert as excellent. Charles et al. (2006) had similar findings for women receiving culturally tailored genetic counseling materials for breast cancer who felt more at ease because of the materials.

Limitations

This study has some limitations. One limitation of the study is that the findings are not necessarily generalizable to other groups of African Americans, because the study population predominantly comprised African American women over age 55.

Given the relative sophistication of the target population, the knowledge instrument may also have been a limitation especially since there was a ceiling effect where participants' average scores at pretest on the Family Health History Knowledge Questionnaire was at the high end of the possible range of scores. The questions on the knowledge instruments were highlighted during the presentation and discussion and came from the two interactive booklets. Additionally, the knowledge instrument was administered once immediately after the workshop so it is not known how much of it was retained in the long-term.

Although the knowledge instruments had been tested and improved through an earlier pilot project with a sample of 178 participants, additional testing of the instruments will be needed in order to properly assess the reliability and validity of the new instrumentation. The ceiling effect was also observed during the pilot for the FHH questions and several questions were revised to measure change more effectively following the intervention.

A further limitation is that the follow-up period for the study was only 2 months. Studies of health-related interventions in the literature are often designed to measure behavior changes through the collection of data at baseline (pre intervention), immediately post intervention, and at 3, 6, and/or 12 months post-intervention, depending on the behavior to be measured.

This study relied to a large degree on self-reported behavioral data, including information collected on the pre-

workshop questionnaire, workshop evaluation questionnaire, and follow-up pledge form. The use of self-reported data carries limitations like the motivation, openness, memory, and honesty of workshop participants, which can affect the validity of information reported. Another limitation of the study is the small number of participants who responded to the pledges (self-reported behavior). A total of 63 participants responded to the pledges, a smaller number than those in the overall study.

Conclusion

The study sought to increase genetic literacy among African American populations in the Washington D.C. metropolitan area, increase access to and use of appropriate genetic educational health materials, and promote lifestyle changes to reduce genetically based health risks.

Locally, we have learned about the significance of utilizing community-based participatory research (CBPR) to develop, plan, implement, and evaluate culturally and linguistically appropriate genetics educational interventions and materials to the African American community. We have also learned how to increase the capacity to make genetics and health information accessible to underserved communities. The local impact has been positive through increased knowledge, intentions, and behaviors. From a global perspective, the findings from this study can serve to meet the goal of preventing congenital disorders and genetic diseases at the population level and providing genetic services in communities for individuals and families.

An important recommendation in the field of community genetics is the need to provide educational programming and related resources for practicing health care providers. Such resources can enhance the knowledge and skills of these professionals to interact appropriately with persons of diverse cultural backgrounds and literacy levels. Genetic education programs to increase literacy and cultural competency among health care providers are an essential complement to ongoing community-focused education efforts.

The study highlights the importance of educating the lay public about genetics and the relationship among genetics, the environment, behavior, and health. In this study, the collection of family health history emerged as a key strategy for generating interest in genetics and health, and helping community members to personalize and act on key messages concerning how they can reduce their risk of developing genetically linked diseases. The study also highlights the importance of outreach to and engagement of members in the African American community with health materials that are simple, relevant, appealing, and informative. It also emphasizes the need for more studies that examine the impact of community-based programs

designed to educate underserved groups in the areas of family health history and genetics education both locally and globally.

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Conflict of interest The authors declare that they have no conflict of interest.

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