

Feasibility and Acceptability of a Culturally Sensitive Intervention To Promote Genetic Counseling

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Abstract

Background

Despite the benefits of genetic counseling (GC) and testing, uptake of cancer genetic services is generally low and African American (AA) women are substantially less likely to receive genetic services than non-Hispanic White women. Our team developed a culturally sensitive, narrative decision aid video to promote uptake of GC among AA women at risk for a hereditary breast cancer syndrome. We report here a pilot study to demonstrate feasibility and acceptability of incorporating this intervention in conjunction with population-based cancer risk assessment in a clinical setting with medically underserved AA women.

Methods

AA women recommended for GC based on cancer genetic risk assessment performed in a mammography center were recruited at the time of the mammogram. A prospective, pre-post survey study design, guided by theoretical constructs, was used to evaluate baseline and immediate post-intervention psychosocial factors, including intention to participate in GC and intervention satisfaction.

Results

Pilot recruitment goals were met (n=30). Pre-intervention, 50% of participants indicated that they were extremely likely to make a GC appointment, compared with 70% post-intervention (p=0.0001). After watching the intervention, 50% of participants indicated that the video changed their mind regarding GC.

Conclusions

This study demonstrated cultural acceptability of a decision aid intervention designed to motivate AA women with hereditary breast cancer risk to attend a GC appointment. Our study showed that intention may be a specific and key construct to target in interventions designed to support decision-making about genetic services. Study results informed the design of a subsequent large scale, randomized implementation study.

Introduction

Carriers of germline mutations in cancer susceptibility genes have up to an 85% lifetime risk of developing breast cancer compared with 12% for the general population.(1-3) Cancer genetic risk assessment (CGRA) and genetic counseling (GC) allow those with hereditary breast cancer risk to make informed choices about genetic testing and cancer prevention options.(4) Genetic counselors determine whether genetic testing should be performed based on pedigree analysis, provide education and pretest counseling on genetic testing risks and benefits, interpret results of genetic testing in the context of cancer risk counseling, and facilitate cascade testing of at-risk family members.(5) Although genetic counseling and testing are a critical component of personalized cancer risk management, over 90% (~10.7 million) of those with hereditary

susceptibility to breast and ovarian cancer in the U.S. have yet to be identified and tested.(1, 6) Underutilization is especially problematic for African American (AA) women, who are 40% more likely to die from breast cancer than non-Hispanic white (NHW) women. Breast cancers arising in AA women frequently share features that are common among *BRCA1*-associated cancers, such as younger age of onset, high tumor grade, and negative hormone receptor status, which all contribute to disparate breast cancer mortality rates.(3, 7-10) The U.S. Preventive Services Task Force (USPSTF) guidelines recommend incorporating assessment of family history into routine primary healthcare in order to identify women at risk for hereditary breast and ovarian cancer so that genetic counseling and testing can be provided for women at risk for hereditary breast cancer syndromes.(11, 12)

Despite the benefits of genetic counseling and testing, uptake of cancer genetic services is generally low. This is particularly problematic among AA women, who are approximately 50% less likely to receive genetic services than NHW women due to multi-level barriers, including bias in provider referrals, lack of perceived benefit, barriers to access and lack of awareness of genetic services, and cost.(1, 6, 13-26) Increasing utilization of genetic services for AA women may reduce breast cancer mortality disparities by improving early detection and disease prevention among those at greatest risk. Moreover, it will help curtail the problem of underrepresentation of racially and socioeconomically diverse populations in genetic and genomic research.(1, 13, 17, 27) Our prior work demonstrated that it is feasible to implement a population-based approach to identify candidates for genetic counseling for hereditary breast cancer risk in community health centers located in underserved minority communities. This strategy addresses systemic barriers and improves the rate of provider referrals and access to genetic counseling.(28) However, only 16% of referred women attended a genetic counseling appointment even after receiving a recommendation from their physician, prompting the need for interventions that support informed decision-making about genetic counseling services for underserved minority women.

Decision aids promote positive health behavior change, improve health outcomes and mitigate health literacy barriers. Relatively little work has been conducted to understand the decision-making process among racial/ethnic minority women recommended for genetic counseling for breast cancer risk, or to develop culturally-tailored decision aids to promote uptake of genetic services.(27, 29-33) The tools developed to date are primarily to supplement information provided in genetic counseling sessions, are largely print or telephone-based, are not developed with input from end-users, do not support familial communication, and for the most part are not targeted to specific cultural groups.(27, 30, 34, 35) To address this need, we developed a culturally sensitive narrative intervention to facilitate decisions about genetic counseling among AA women at risk for hereditary breast cancer syndromes. The decision aid was grounded in a robust theoretical model of health behavior (the Integrative Model of Behavioral Prediction, IMBP), and development of the intervention was informed by AA women with a family history of breast cancer who were recommended for genetic counseling, by breast cancer advocates, and by primary healthcare providers.(36) Here we report findings from a pilot study with the narrative intervention to demonstrate the feasibility and acceptability of incorporating the decision aid in conjunction with population-based cancer risk assessment in a clinical setting with medically underserved, AA women. We tested the effect of the intervention on measures of knowledge, self-efficacy, normative beliefs, and intentions to engage in genetic counseling.

Methods

Study Design

A prospective, pre-post survey study design was used to evaluate baseline and immediate post-intervention intentions, knowledge, and beliefs regarding genetic counseling, as well as to assess satisfaction with the video intervention. The study was registered at Clinicaltrials.gov (NCT04082117) and was approved by the Institutional Review Board at the University of Illinois at Chicago (#2016-1219). All study participants provided written informed consent.

Study Population

The study was conducted in a mammography center at a safety net academic medical center in Chicago, IL, between August, 2019 and October, 2019. Eligibility criteria included: 1) AA women between the ages of 25 to 69 years old presenting for a screening or diagnostic mammogram; 2) no personal history of breast cancer; 3) never attended an appointment with a genetic counselor; 4) underwent breast cancer risk assessment at the time of the mammogram; and 4) were recommended for genetic counseling based on family history of breast and/or ovarian cancer. Formal power calculations are difficult to perform for pilot studies. A sample size of n=30 is commonly recommended for pilot studies.³⁷ We followed that practice and enrolled 30 participants.

Breast Cancer Risk Assessment

The participating mammography center conducted family history screening for hereditary cancer risk as a routine component of the evaluation for all women undergoing screening or diagnostic breast imaging beginning in 2018. Risk assessment was conducted at the time women checked-in for the mammogram using a software application (CancerIQ®) on tablet computers and patient-reported information on family cancer history. Women who met national guideline criteria for genetic counseling referral(37) due to hereditary breast cancer risk were advised by mammography center staff to obtain a referral from their primary care physician (PCP) to the Hereditary Cancer Clinic at our institution. PCPs were notified of the recommendation for genetic counseling referral. Participants for this study were recruited from the group of women who received a recommendation for genetic counseling as a result of the risk assessment performed at the time of their mammogram.

Study Recruitment and Participation

Radiology technicians gave a study recruitment flyer to all women who were recommended for genetic counseling and briefly described the study to eligible women using a recruitment script. Women who expressed interest in participating in the study were directed to a privacy-protected area in the mammography center where research personnel completed eligibility screening and informed consent. Research personnel then administered a pre-viewing survey, played the six-minute narrative decision aid on a laptop computer for the participant to view, and then administered a post-viewing survey. Women completing all study activities received a stipend for research participation.

Data Collection

The pre-viewing survey and post-viewing survey were administered by research personnel using an electronic data capture and management system (REDCap) with an encrypted laptop computer. The initial study protocol included review of the electronic health record 6 months after completion of study recruitment to determine rates of attendance at a genetic counseling session. However, due to clinic restrictions that were initiated in 2020 due to the COVID-19 pandemic, all elective outpatient appointments were cancelled, so the 6-month medical record review was not completed.

Culturally Sensitive Decision Aid to Promote Genetic Counseling

A culturally sensitive, narrative decision aid was developed by the study team to promote uptake of genetic counseling among AA women at risk for a hereditary breast cancer syndrome.³⁶ Development of the intervention was guided by the IMBP theoretical framework, which asserts that the primary driver of engaging in a health behavior is forming an intention to do so. The process of forming an intention is determined by three cognitive domains (expected outcomes of engaging in the behavior, cultural norms, and self-efficacy beliefs). The IMBP further proposes that the relationship between intention to engage in a health behavior and carrying through on the intention may be impacted by contextual factors.⁽³⁸⁾ In order to ensure that the intervention is culturally sensitive for AA women, we employed Kreuter's framework for achieving cultural appropriateness in health promotion programs.⁽³⁹⁾ Details about intervention design methodology were previously published.⁽³⁶⁾ Briefly, phase 1 consisted of in-depth, semi-structured interviews and story circles with AA women recommended for genetic counseling by their PCP based on their family history of breast/ovarian cancer.^(28, 36) Importantly, the majority of study participants did not attend a genetic counseling session even though it was recommended by their PCP. One-on-one interviews garnered information about motivating and facilitating factors and barriers to genetic counseling attendance. Story circles sought to understand women's personal and familial experiences related to breast cancer. A script was developed for the narrative intervention based on themes that emerged from in-depth interviews and story circles. Phase 2 consisted of a series of focus groups conducted with three cohorts: an independent group of AA women with a family history of breast cancer who had not undergone genetic counseling and did not participate in one-on-one interviews, primary care providers at a federally qualified health center, and representatives from breast cancer advocacy organizations. Focus groups provided feedback on the script and the final video production. The decision aid that was produced is a six-minute narrative video that tells the story of an AA women recommended for genetic counseling due to the presence of breast cancer in her family. A link to the narrative intervention is provided at the end of this manuscript.

Survey Instrument

Pre- and post- survey questions, guided by the IMBP theoretical constructs, assessed participants' intentions, knowledge, perceived normative beliefs, barriers, self-efficacy beliefs, attitudes, and environmental constraints. Intentions regarding GC attendance were measured with six items. Responses for four of these items were measured on a 5-point likert scale ranging from 1 (extremely likely) to 5 (extremely unlikely), and 1 item was open-ended. Knowledge about genetic counseling was measured by 6 true/false items.⁽⁴⁰⁾ Perceived normative beliefs were measured with two yes/no items.⁽⁴¹⁾ Barriers to GC were captured by three

items (yes/no). Self-efficacy beliefs were also measured with 3 items with responses captured by a 5-point likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). (42, 43) Attitudes about the importance of GC were measured with 1-item using a 10-point likert scale ranging from 0 (not at all important) to 10 (very important). Environmental constraints were only measured at pre-test since the intervention was not designed to impact these factors, and were measured with 6 true/false items. Nine questions assessed satisfaction with the video, with responses captured as a 5-point Likert scale ranging from 1 (either strongly agree or extremely likely) to 5 (strongly disagree or extremely or unlikely) (44) or as yes/no response for three questions, and one open-ended response.

Statistical Analysis

Demographic characteristics of participants were summarized with descriptive statistics. Survey responses were summarized as frequencies and percentages. Responses of “no” and “not sure” were combined into the same response group. Pre- and post-intervention responses were compared using McNemar’s test for paired data. Fisher’s exact test was used in instances where the number of responses were less than five. A two-sided p-value less than 0.05 was considered statistically significant.

Results

Thirty AA women enrolled in this study and completed all study activities. The median age among participants was 53 years (interquartile range 48-60); ages ranged from 30 to 69.

Intentions regarding genetic counseling. Before viewing the intervention, 50% of participants indicated that they were extremely likely to make a genetic counseling appointment, compared with 70% of participants after the viewing ($p=0.0001$) (Table 1). After watching the intervention, 50% of study participants indicated that the video changed their mind regarding genetic counseling (Table 3).

Normative beliefs and barriers. At baseline, 76.7% of participants believed their family would be interested in learning more about genetic counseling because of cancer in their family (Table 2). This increased to 93.3% ($p=0.02$) following the intervention. Eleven women (36.7%) indicated that they anticipated experiencing barriers or would have difficulties attending a genetic counseling session before the intervention. There was a non-significant numeric decrease in this proportion following the intervention (20.0%, $p=0.06$).

Self-efficacy. Before the intervention only 16.7% of participants were confident that they could pay for genetic counseling services (Table 2). This increased significantly to 40.0% ($p=0.02$) following the intervention. The proportion of women indicating that they were confident that they knew who to call to make an appointment to attend a genetic counseling session increased from nine (30.0%) to twenty women (66.7%, $p=0.001$) following the intervention.

Environmental Constraints. When asked about health care in general, 50% of women indicated they often worry about the cost of medical care and 63.3% ($n=19$) indicated they did not know how much their medical expenses will cost when seeing a doctor. Despite this, 83.3% ($n=25$) indicated they could easily get needed medical care when needed, and over 90% felt comfortable asking their doctor questions and making and getting to and from medical appointments.

Video Satisfaction. The majority of participants enjoyed watching the video and felt they could relate to the actors (Table 3). All but one participant indicated they would share the video with family and friends, and 90% (n=27) of participants thought the video would motivate their loved ones to engage with their doctors about genetic counseling. Four participants indicated they would make changes to the video. Women who did specify suggested changes recommended giving more details about the personal benefit a woman gains from genetic counseling in addition to limitations of genetic counseling.

Knowledge. The intervention was designed to motivate attendance at a genetic counseling session. As expected, knowledge about genetic counseling did not change significantly after viewing the intervention (Table 4).

Discussion

This study demonstrated the acceptability of a decision aid intervention designed to motivate AA women with hereditary breast cancer risk to attend a genetic counseling appointment. The intervention has now been thoroughly evaluated for cultural appropriateness using qualitative research with focus groups in earlier work,³⁶ and now with a quantitative analysis. Moreover, the intervention significantly increased participants' intentions to attend a genetic counseling session, which was the primary objective of the intervention. The results of this pilot study underscore the value of multiple qualitative methods (i.e., one-on-one interviews, story circles, and focus groups) and a narrative approach when designing interventions to promote uptake of genomically-informed cancer care in underrepresented racial/ethnic minority groups.

Evidence-based decision aid interventions increase patient knowledge, supplement clinical consultations, improve congruence with patient values, reduce decisional conflicts, and help patients make informed decisions.(29, 30, 45, 46) A recent systematic review that aimed to identify published resources to support decision-making related to *BRCA1* and *BRCA2* genetic testing in women with breast cancer found that all studies examined (n=9) described gains in knowledge about hereditary breast cancer, but lacked a theoretical justification for why or how interventions impacted outcomes.(30) Additionally, the majority of studies that examined the effectiveness of decision support interventions for women with family histories of breast or ovarian cancer were conducted with primarily non-Hispanic white study participants.(30, 33, 46) Guided by the IMBP theoretical framework of health behavior, our study showed that intention may be a specific and key construct to target in interventions designed to support decision-making about genetic services. Importantly, few studies have assessed factors that influence decision-making regarding genetic counseling utilization among high-risk AA women. The results presented here confirm the relevance of the cognitive domains in the IMBP for racial/ethnic minority women, and the effectiveness of health behavior interventions that are designed to address beliefs mapping to constructs of that theoretical model. Our study also expands understanding of psychosocial factors that may be salient to this group of focus.

This pilot study has limitations. It was intended to inform the design of a subsequent large scale implementation study, and therefore the sample size was relatively small by design. The sample size resulted in zero cells for some survey responses, which precluded us from presenting p-values for each pre/post comparison. The intervention was designed for urban AA women with a family history of breast cancer. It is

unclear whether this intervention would have the same effect with women from other racial/ethnic groups or in other geographic settings, or with different family cancer histories. Additionally, we were unable to complete planned analysis of genetic counseling uptake at 6 months post-intervention since clinic restrictions resulting from the COVID-19 pandemic prevented women from scheduling a non-urgent appointment. However, it is likely that a multilevel approach that also addresses barriers to scheduling and attending the consultation will be necessary in order to maximize uptake of cancer genetic services among underserved, high-risk AA women. We are testing this hypothesis in a randomized trial (NCT 04378751) that will couple additional evidence-based strategies (patient navigation and transportation assistance) with the decision aid in order to increase utilization of genetic counseling in this patient population. An additional limitation of this study is that we did not test the effect of the decision aid on diffusion of knowledge about genetic risk and counseling among the social networks of AA women recommended for genetic counseling. This is an important aspect of a population health approach to cancer genetics and risk assessment, since the benefits of population screening for genetic risk can be amplified by identifying and testing at-risk family members of patients found to carry a pathogenic variant (cascade testing). We are addressing this issue in the ongoing randomized trial.

Conclusion

We developed a culturally tailored narrative decision aid that meets the need for cost-effective interventions to facilitate informed decisions on genetic counseling and testing and communication about heritable cancer risks among medically underserved, AA women. Acceptability of the intervention among the target audience was very high. The intervention increased self-efficacy and intentions to attend genetic counseling among high risk AA women, and it may facilitate cascade testing among at-risk family members. This intervention warrants further investigation as a component of population-based strategies to identify racial/ethnic minority women with hereditary breast cancer risk in an effort to curtail health disparities that may be perpetuated with advances in precision medicine.(27, 36, 47)

URL link to the intervention: https://youtu.be/_bR81v_nCaM

List Of Abbreviations

AA – African American

CGRA – Cancer Genetic Risk Assessment

GC – Genetic Counseling

IMBP – Integrative Model of Behavioral Prediction

NHW – non-Hispanic White

PCP – Primary Care Provider

USPSTF - U.S. Preventive Services Task Force

Declarations

Ethics approval and consent to participate: Approval to conduct this human subjects research was obtained by the University of Illinois at Chicago institutional review board. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

Consent for publication: Not applicable

Availability of data and materials: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: VH, KH: intervention development, study design, instrumentation, interpretation of data, writing, editing; JM: data analysis, interpretation; writing, editing; LK, PP: acquisition of data, study implementation; JN, IC, VC, GG, DC, SS, CR, RK, LB, TM, ZR, CB, RW, KW, AO: intervention development, study design. All authors read and approved the final manuscript.

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Tables

Table 1. Intentions Regarding Genetic Counseling (n=30)

Intention Questions		Pre-intervention (Extremely or Somewhat Likely)	Post-intervention (Extremely or Somewhat Likely)	p-value
		n (%)	n (%)	
How likely are you to discuss genetic counseling with your family?	Extremely likely	25 (83.3)	25 (83.3)	1.0
	Somewhat likely	5 (16.7)	5 (16.7)	
How likely are you to speak with your doctor about genetic counseling?	Extremely likely	18 (60.0)	23 (76.7)	0.10
	Somewhat likely	12 (40.0)	7 (23.3)	
How likely are you to share information about genetic counseling with others, aside from your family?*	Extremely likely	18 (60.0)	20 (66.7)	0.57
	Somewhat likely	9 (30.0)	8 (26.7)	
	Neither likely nor unlikely	3 (10.0)	2 (6.7)*	
How likely are you to make an appointment with a genetic counselor?	Extremely likely	15 (50.0)	21 (70.0)	0.0001**
	Somewhat likely	14 (46.7)	9 (30.0)	
	Neither likely nor unlikely	1 (3.3)	0	

p-values computed using McNemar's test

*percentages do not add up to 100% due to rounding

**p-value from Fisher's exact test

Table 2. Normative Beliefs, Barriers and Self-efficacy (n=30)

	Pre-intervention		Post-intervention		p-value
		n (%)		n (%)	
Normative Beliefs					
Do you think your family would be interested in learning more about genetic counseling because of cancer in your family?	Yes	23 (76.6)	Yes	28 (93.3)	0.02
	No/Not sure	7 (23.3)	No/Not sure	2 (6.7)	
Do you believe your family would get genetic counseling if their doctor recommended it to them?	Yes	27 (90.0)	Yes	28 (93.3)	0.32
	No/Not sure	3 (10.0)	No/Not sure	2 (6.7)	
Barriers					
Difficulties to make an appointment with a genetic counselor	Yes	9 (30.0)	Yes	6 (20.0)	0.26
	No/Not sure	21 (70.0)	No/Not sure	24 (80.0)	
Difficulties to make an appointment with a genetic counselor	Yes	11 (36.7)	Yes	6 (20.0)	0.06
	No/Not sure	19 (63.3)	No/Not sure	24 (80.0)	
Difficulties to speak with a doctor about genetic counseling	Yes	3 (10.0)	Yes	3 (10.0)	1.0
	No/Not sure	27 (90.0)	No/Not sure	27 (90.0)	
Self-efficacy (<i>How much you agree or disagree with the following statements regarding genetic counseling?</i>)					
I am confident that I can pay for genetic counseling services.	Strongly agree or agree	5 (16.7)	Strongly agree or agree	12 (40.0)	0.02
I am confident that I can act on information learned as a result from genetic counseling.	Strongly agree or agree	30 (100.0)	Strongly agree or agree	30 (100.0)	-
I know who to call to make an appointment for genetic counseling.	Strongly agree or agree	9 (30.0)	Strongly agree or agree	20 (66.7)	0.001
I feel comfortable talking with my doctor about genetic counseling.	Strongly agree or agree	29 (96.7)	Strongly agree or agree	30 (100.0)	-

p-values computed using McNemar's test

Table 3. Post-Intervention Satisfaction with the Video Intervention (n=30)

Items	Responses	Overall n (%)
The video was enjoyable to watch.	Strongly agree or agree	29 (96.7)
	Neither agree or disagree	1 (3.3)
	Disagree or Strongly disagree	0
My attention was held throughout the entire video.	Strongly agree or agree	29 (96.7)
	Neither agree or disagree	1 (3.3)
	Disagree or Strongly disagree	0
I felt I could relate to what the actors were saying	Strongly agree or agree	27 (90.0)
	Neither agree or disagree	2 (6.7)
	Disagree or Strongly disagree	1 (3.3)
I enjoyed the mix of real actors and animations	Strongly agree or agree	28 (93.3)
	Neither agree or disagree	1 (3.3)
	Did not respond	1 (3.3)*
How likely are you to share this video with your family or friends?	Extremely or somewhat likely	29 (96.7)
	Neither likely or unlikely	0
	Somewhat or extremely unlikely	1 (3.3)
Do you think this video would motivate your loved ones to speak with their doctors about genetic counseling?	Yes	27 (90.0)
	No/Not sure	3 (10.0)
Did this video change your mind about genetic counseling?	Yes	15 (50.0)
	No/Not sure	15 (50.0)

*percentages do not add up to 100% due to rounding

Table 4. Knowledge of Genetic Counseling

Knowledge Question (correct answer)	Correctly Answered Pre-intervention n (%)	Correctly Answered Post-intervention n (%)	p-value
A purpose of genetic counseling is to help people understand their ancestry. (false)	4 (13.3)	7 (23.3)	0.08
A purpose of genetic counseling is to provide information about how genetics contributes to health problems. (true)	30 (100.0)	30 (100.0)	-
A purpose of genetic counseling is to provide an explanation of treatments for breast cancer. (false)	6 (20.0)	5 (16.7)	0.74
A purpose of genetic counseling is to provide information about the chances of you or your family developing breast cancer in the future. (true)	30 (100.0)	29 (96.7)	-
A purpose of genetic counseling is to help people understand their options for genetic testing. (true)	27 (90.0)	30 (100.0)	-
A purpose of genetic counseling is to provide information and support to individuals with breast cancer in their family. (true)	27 (90.0)	28 (93.3)	0.32

N=30

p-values computed using McNemar's test