



Adapting a Theoretically-Based intervention for underserved clinical populations at increased risk for hereditary Cancer: Lessons learned from the *BRCA-Gist* experience

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ABSTRACT

Background: Minorities at increased risk for Hereditary Breast and Ovarian Cancer (HBOC) frequently have low awareness and use of genetic counseling and testing (GCT). Making sure that evidence-based interventions (EBIs) reach minorities is key to reduce disparities. *BRCA-Gist* is a theory-informed EBI that has been proven to be efficacious in mostly non-Hispanic White non-clinical populations. We conducted formative work to inform adaptations of *BRCA-Gist* for use in clinical settings with at-risk diverse women.

Methods: Genetic counselors (n = 20) were recruited nationally; at-risk Latinas and Blacks (n = 21) were recruited in Washington DC and Virginia. They completed the *BRCA-Gist* EBI between April 2018 – September 2019. Participants completed an acceptability scale and an interview to provide suggestions about implementation adaptations. T-tests for independent samples compared acceptability between at-risk women and genetic counselors. The Consensual Qualitative Research Framework was used to code adaptation suggestions. Suggested adaptations were discussed by a multidisciplinary team to integrate fidelity and adaptation considerations.

Results: At-risk women had a significantly higher acceptability ($M = 4.17, SD = 0.47$ vs. $M = 3.24, SD = 0.64; p = 0.000$; scale 1–5) and satisfaction scores ($M = 8.3, SD = 1.3$ vs. $M = 4.2, SD = 2.0; p = 0.000$; scale 1–10) than genetic counselors. Genetic counselors and at-risk women suggested contextual (e.g. format) and content (e.g. shortening) adaptations to enhance the fit of *BRCA-Gist* for diverse clinical populations.

Conclusions: Findings illustrate the process of integrating fidelity and adaptation considerations to ensure that EBIs retain their core components while enhancing the fit to minoritized clinical populations. Future studies will test the efficacy of the adapted *BRCA-Gist* in a Randomized Controlled Trial.

1. Introduction

BRCA1/2 mutation carriers have an increased lifetime risk of developing breast (up to 64.6%) and ovarian cancers (up to 48.3%) compared to non-carriers (Chen et al., 2020). National guidelines recommend referral for individuals at increased risk for Hereditary Breast and Ovarian Cancers (HBOC) (i.e., “at-risk individuals”) to genetic counseling and consideration of genetic testing (GCT) based on their personal or family history of cancer (National Comprehensive

Cancer Network, 2018; U.S. Preventive Services, 2013). Obtaining a positive test can inform treatment decisions, screening, and risk reduction strategies in both survivors and unaffected women. (Kauff et al., 2002). Risk-reducing prophylactic surgeries can reduce breast cancer risk by >90%, ovarian cancer risk by 85–90% (Rebeck et al., 2002; Schwartz et al., 2012), and increase life expectancy among mutation carriers (Salhab et al., 2010).

Unfortunately, GCT participation is lower among minorities compared to non-Hispanic Whites (NHW) due to healthcare (e.g.

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insurance, cost, suboptimal referrals) and psychosocial barriers (e.g. awareness) (Williams et al., 2019). African Americans and Latinx have lower GCT awareness (Hann et al., 2017) and lower breast cancer genetics knowledge than NHW, which is associated with decreased GCT uptake (Donovan & Tucker, 2000; Gammon et al., 2011; Hughes et al., 1997; Hurtado-de-Mendoza et al., 2017; Kinney, 2006; Thompson et al., 2002). Differences also exist in health literacy/numeracy, which are key to understanding risk information (Kutner et al., 2006; National Center for Education Statistics., 2006). Removing barriers to GCT access and ensuring that information about HBOC risk is understandable and culturally appropriate is critical to reducing persistent disparities.

Theoretically guided interventions that support increased understanding of HBOC in underserved populations are needed. Theory-based interventions are essential for generalizable knowledge to determine the interventions' active ingredients and for whom they are effective (Reyna & Mills, 2014; Rothman & Sheeran, 2020). *BRCA-Gist* (Breast Cancer Genetics Intelligent Semantic Tutoring) (Wolfe et al., 2015) is an evidence based intervention (EBI) informed by Fuzzy Trace Theory (FTT), a theory of medical decision-making which posits that people encode information in a continuum of verbatim (i.e., facts and numbers) to fuzzy gist representations (i.e., essential bottom-line meaning). Gist representations are more likely to inform decision-making (Blalock & Reyna, 2016). *BRCA-Gist* (Reyna, 2008a) was developed as an Intelligent Tutoring System that uses avatars to emulate tailored one-to-one human tutoring and includes the gist of risk messages (Cedillos-Whynott et al., 2016; Wolfe et al., 2015; 2016). *BRCA-Gist* was initially designed to complement genetic counseling, which is ideal when available (Cedillos-Whynott et al., 2016; Wolfe et al., 2015). It can be used as an added resource in the clinical setting (before or after the clinical encounter), and self-administered by the patient because terms are defined and modules build on one another. The efficacy of *BRCA-Gist* in improving psychosocial outcomes (e.g., knowledge) was previously established in different settings (Cedillos-Whynott et al., 2016; Wolfe et al., 2015; Wolfe et al., 2016). Evidence suggests that *BRCA-Gist* had greater effectiveness for women with less formal education (Widmer et al., 2015). Yet, *BRCA-Gist* was tested in mostly NHW samples who were not at-risk of HBOC (Wolfe et al., 2015). Thus, adapting *BRCA-Gist* for diverse clinical populations is needed. Adaptations that retain the interventions' core components and enhance the fit to contextual and cultural factors have the potential to increase the reach of EBIs to diverse populations (Castro & Yasui, 2017). This is an essential step to ensuring that advances in genomics medicine equally benefit diverse populations to address disparities in knowledge, access, and utilization of life saving services.

Implementation science, the scientific study of strategies to integrate EBIs into clinical practice (Eccles & Mittman, 2006), provides an excellent framework to conceptualize the adaptations of *BRCA-Gist* for clinical practice with diverse populations. However, Implementation Science has not been robustly applied in the field of translational genomics (Roberts et al., 2017) nor in the field of disparities (Chinman et al., 2017). This study uses Stirman and colleagues FRAME (Stirman et al., 2019) to inform the adaptation of *BRCA-Gist*. The goal of this adaptation is to maintain the core components (effect drivers) while making adaptations to enhance the fit of *BRCA-Gist* for use in clinical settings with at-risk minorities. We present an overview of the decision-making process informed by feedback from the target population (Black and Latina women at risk for HBOC, N = 21), genetic counselors (N = 20), and a multidisciplinary research team.

2. Methods

2.1. Procedures

This report focuses on the adaptation phase (Phase 1) of a larger multi-phase study. Phase 1 aims to conduct formative work to inform adaptations of *BRCA-Gist*. Data were collected from April 2018 –

September 2019. Phase 2 focuses on testing the adapted *BRCA-Gist* in a Randomized Controlled Trial. Data for Phase 2 will be presented in another manuscript. The study conforms to recognized international ethical standards. The Institutional Review Board from Georgetown University, Virginia Commonwealth University, and Cornell University approved all study procedures.

Women At-risk of HBOC: Participants were eligible if they 1) self-identified as African American/Black or Latina women, 2) were fluent in English, 3) were at-risk for HBOC based on NCCN guidelines (2018) for referral to genetic cancer risk assessment for HBOC.

To recruit, we collaborated with two community organizations that provide patient navigation and conducted community outreach. Patient navigators at the community organizations identified potentially eligible women and asked for permission to be contacted by Research Assistants (RAs). RAs called interested women, performed a detailed screener, provided more information, and scheduled an in-person visit to conduct informed consent and present *BRCA-Gist* on a laptop. Upon completion, participants responded to a survey that included socio-demographic and clinical information and an acceptability scale. After, the RA conducted a semi-structured interview (~30 min) to assess feedback and suggestions for adapting *BRCA-Gist* for the target population.

Genetic counselors: were recruited as content experts and key stakeholders for implementation. We recruited nationally through listservs and snowballing from April-September 2018. RAs emailed genetic counselors to inform them about the study. Then, RAs scheduled a call to review the consent. After, the RA emailed the link to the intervention and followed up in two weeks to schedule a call to conduct an acceptability scale and a semi-structured interview (40 min average) to gather feedback about potential adaptations.

BRCA-Gist: To increase the platform-generalizability and technological robustness, we transformed *BRCA-Gist* from the original Artificial Intelligence (AI) platform AutoTutor Lite (Wolfe et al., 2013) to Qualtrics. Qualtrics is an online secure platform that provides didactic and interactive content, and can be easily shared via links. *BRCA-Gist* in Qualtrics involves pre-recorded videos of the original intervention and survey questions where participants can write answers in their own words. However, while the content remains the same, the platform relocation eliminated automated individualized feedback that was based on the AI component of the original intervention. Through videos, three ethnically/racially diverse avatars (agents) provide education on four modules ("Breast Cancer and Metastasis," "Risk Factors," "Genetic Mutation Testing," and "Consequences of Testing"). The information is presented by the avatar verbally in speech bubbles and using graphs, pictures, and videos. *BRCA-Gist* includes strategies to engage individuals including multiple choice questions, argumentations (e.g., provide the pros and cons of genetic testing), and soliciting gist explanations (e.g., type 6–8 sentence answers in their own words summarizing and interpreting the content as a substitute for the tutorial dialogues in the original *BRCA-Gist*). Completion of *BRCA-Gist* lasted approximately 1.5 h.

2.2. Measures

2.2.1. Quantitative measures

Socio-demographic factors: included age, ethnicity, race, and education. Additionally, at-risk women's surveys included other socio-demographic and clinical factors. Genetic counselors answered specific questions about their training and experience.

Acceptability: We used an adapted 18-item 5-point Likert scale that assessed components included in validated acceptability measures: comprehensibility, length, amount of information, and ease of use (O'Connor & Cranney, 2002; Tariman et al., 2011) ($\alpha = 0.89$ at-risk women; $\alpha = 0.90$ counselors). Higher scores indicate higher acceptability. Items were summed to create an acceptability score. Additionally, participants rated their overall satisfaction with one item ranging from 1 (not at all satisfied) to 10 (highly satisfied).

2.2.2. Qualitative methods

The interview had a funnel structure starting with general questions (e.g. perceptions of *BRCA-Gist*, experiences completing *BRCA-Gist*), followed by specific aspects (display and presentation, comprehension, clarity of the information, cultural acceptability), and suggestions for adaptations to implement in clinical settings for the target population. Genetic counselors also provided suggestions on information to update to provide up-to-date scientific knowledge and clinical practices.

2.3. Analysis

2.3.1. Quantitative analyses

Descriptive statistics summarized sociodemographic, clinical data, and acceptability scales. T-tests for independent samples compared acceptability and satisfaction in the target population and genetic counselors.

2.3.2. Qualitative analyses

Interviews were recorded and transcribed verbatim. We used a deductive approach to develop a codebook using Stirman and colleagues' framework for reporting adaptations to evidence-based interventions (FRAME) (Stirman et al., 2013). FRAME categorizes each change to the intervention as adaptations conducted at either the contextual (i.e., changes in the format, channel, setting, personnel, and target) or content level (i.e., changes in the intervention procedures, materials, and delivery) (Stirman et al., 2013).

Two authors trained in qualitative data analysis independently coded each interview in Dedoose guided by FRAME's contextual/content categories (Dedoose, n.d.), and later met to reconcile any differences in their applied codes, following guidelines from the Consensual Qualitative Research Framework (Hill et al., 1997). A third author helped to resolve disagreements. Following Stirman et al.'s expanded framework (Stirman et al., 2019), which considers fidelity to core components in its own category, the research team also discussed (1) whether each suggested adaptation could compromise fidelity to the core components of *BRCA-Gist* based on FTT (e.g., (Blalock & Reyna, 2016; Reyna, 2020)) and prior research on its active ingredients (Cedillos-Whynott et al., 2016; Widmer et al., 2015; Wolfe et al., 2013; 2015) and (2) how to balance fidelity and adaptation considerations.

3. Results

3.1. Participants

At-risk Women: 21 women consented to participate. One participant did not complete *BRCA-Gist* due to the length. She did not complete the sociodemographic nor the acceptability survey but she completed the interview and was included for the qualitative analysis only. Participants were 50.4 years old ($SD = 16.5$), 70% self-identified as Black, 85% had completed some college or above (Table 1).

Genetic counselors: Genetic counselors ($N = 20$) were on average 40.4 years old ($SD = 9.2$). Most (95%) were women and self-identified as White (90%) (Table 2). Most (60%) had worked with women at-risk of HBOC for over 5 years.

3.2. Acceptability

At-risk women had a significantly higher acceptability score ($M = 4.09$, $SD = 0.55$; scale 1–5) compared to genetic counselors ($M = 3.24$, $SD = 0.64$; scale 1–5) ($p = 0.000$). Fifteen of the 18 acceptability items showed significant differences. Likewise, at-risk women reported higher satisfaction ($M = 8.3$, $SD = 1.3$; scale 1–10) than genetic counselors ($M = 4.2$, $SD = 2.0$; scale 1–10) ($p = 0.000$) (Table 3).

Table 1

At-risk women Sociodemographic and Clinical Characteristics.

Sociodemographic and Clinic Characteristics (n = 20*)	
Ethnicity- N (%)	
Hispanic or Latino	5 (25)
Not Hispanic or Latino	12 (60)
No ethnicity	3 (15)
Racial Background – N (%)	
Black	14 (70)
White	1 (5)
Unknown	1 (5)
Other	4 (20)
Born in the US	
Yes	16 (80)
No	4 (20)
English as first language	
Yes	17 (85)
No	3 (15)
Marital Status- N(%)	
Married/Living as Married/engaged	3 (15)
Never Married/divorced/single/separated/widowed	17 (85)
Highest Education-N(%)	
High school or below	2 (10)
Some college	8 (40)
2-year college degree	2 (10)
4-year college degree	6 (30)
Graduate degree	1 (5)
Missing	1 (5)
Annual Income	
<\$40,000	7 (35)
≥ \$40,000	6 (30)
Not answered	7 (35)
Health Insurance Status	
Yes	19 (95)
No	1 (5)
Breast or Ovarian Cancer Diagnosis	
Yes	9 (45)
No	11 (55)
Confidence filling medical forms	
A little bit	1 (5)
Somewhat	4 (20)
Quite a bit	5 (25)
Extremely	10 (50)

*Note: One participant did not complete *BRCA-Gist* due to the length. She did not complete the sociodemographic survey nor the acceptability survey but she completed the interview.

3.3. Suggestions for adaptations

Table 4 describes the contextual and content adaptations according to FRAME categories and Table 5 includes selected quotes. To illustrate the decision-making process, we focus on examples of suggested adaptations that relate to fidelity to *BRCA-Gist* core components. We discuss fidelity considerations (core components), suggested adaptations (feedback from at-risk women and genetic counselors), implementation considerations (whether adaptations could potentially impact implementation outcomes), and potential solutions to balance fidelity and adaptation considerations.

3.4. Fidelity and adaptation considerations

3.4.1. Knowledge: Background information

Fidelity Considerations. FTT posits that individuals rely on background information to form gist representations (i.e., bottom-line interpretations of information). That is, learning depends on prior knowledge, which helps people understand and remember new information by building on old information to contextualize it. New information is encoded in gist (and in parallel, verbatim) mental representations that cue emotions and values (Reyna & Rivers, 2008). Because “getting the gist” builds on background knowledge, the original intervention includes comprehensive background knowledge about breast cancer and is ~ 1.5 h.

Table 2
Genetic Counselors' Sociodemographic Characteristics.

Demographic Characteristics (n = 20)	
Ethnicity- N(%)	
Hispanic or Latino	2(10)
Not Hispanic or Latino	13(65)
No ethnicity	4(20)
Missing	1(5)
Racial Background – N(%)	
White	18 (90)
Asian	1(5)
Other	1(5)
Marital Status- N(%)	
Married/Living as Married	16(80)
Never Married	3(15)
Other	1(5)
Highest Education-N(%)	
Graduate degree(e.g.,MS.,PhD)	20(1 0 0)
Years worked with women at-risk HBOC-N(%)	
Less than a year	1(5)
1–5 years	7(35)
5–10 years	3(15)
More than ten years	9(45)
Role- N(%)	
Medical Oncologist	1(5)
Genetic Counselor	17(85)
Nurse	1 (5)
Other	1(5)
Number of women at-risk of HBOC seen per week- N(%)	
0–5	5(25)
5–10	12(60)
10–20	3(15)
Percentage of at-risk Latina women seen-N(%)	
Less than 5%	8(40)
5–10%	7(35)
11–30%	3(15)
31–50%	1 (5)
More than 70%	1(5)
Percentage of at-risk Black women seen-N(%)	
Less than 5%	3(15)
5–10%	7(35)
11–30%	7(35)
31–50%	3(15)

Suggested Adaptations. Several women suggested shortening the intervention, reporting that the current length and amount of information were overwhelming. However, most valued obtaining background information about breast cancer. Women, including cancer survivors, mentioned that it was their first time learning about breast cancer in detail.

Genetic counselors reported concerns about the length and complexity of the information included, especially when targeting a population with low health literacy. They suggested a maximum of 20–30 min to implement in clinical practice and recommended removing content about general breast cancer to focus on HBOC.

Implementation Considerations. Retaining the original length can impact several implementation outcomes. *Patient-facing considerations:* On the one hand, for patients completing *BRCA-Gist* outside of a study, maintaining the length could result in low dose fidelity. On the other hand, maintaining breast cancer background information can increase acceptability and efficacy, given that women welcomed the inclusion of general information and that background knowledge is key to build new knowledge. *Provider-facing considerations:* Maintaining the original scope and length may reduce providers' perceived feasibility of implementing *BRCA-Gist*, which can reduce its likelihood of adoption in clinical practice.

Potential Solutions, Adaptations, and Future Research. Providing background information to form gist knowledge is a core element of *BRCA-Gist* as posited by FTT. However, it is at odds with the content adaptations suggested by genetic counselors in terms of removing background knowledge. Research has shown a dose–response effect for behavioral interventions, indicating that length is positively associated

Table 3
At-risk Women and Genetic counselors' Acceptability of BRCA-Gist.

	At-risk women M (SD)	Genetic Counselors M (SD)	P value
Overall satisfaction (1–10)	8.3 (1.3)	4.2 (2.0)	0.000***
Acceptability score (1–5)	4.09 (0.55)	3.24 (0.64)	0.000***
Adequate length (1–5)	3.6 (1.2)	2.05 (1.0)	0.000***
Easy to navigate (1–5)	3.7 (1.0)	3.8 (0.9)	0.870
Information easy to understand (1–5)	3.6 (1.1)	3.2 (0.9)	0.170
Helpful information (1–5)	4.2 (1.0)	3.6 (0.8)	0.046**
Breast cancer and metastasis module helpful (1–5)	4.35 (0.8)	3.2 (1.0)	0.000***
HBOC risk factors helpful (1–5)	4.5 (0.5)	4.0 (0.8)	0.045*
GT information helpful (1–5)	4.3 (0.7)	3.4 (1.1)	0.006**
Consequences of testing helpful (1–5)	4.4 (0.6)	3.7 (1.0)	0.019*
Intimidated web-based intervention (1–5)	2.0 (1.2)	1.2 (0.4)	0.009*
Use of graphs and figures useful (1–5)	4.3 (0.9)	3.0 (1.1)	0.000***
Use of avatars helpful (1–5)	3.8 (1.2)	2.9 (1.2)	0.016**
System worked well (1–5)	3.8 (1.2)	3.5 (1.0)	0.280
Quantity and detail of information adequate (1–5)	3.9 (1.0)	2.5 (1.1)	0.000***
Answering in own words useful (1–5)	3.9 (0.9)	2.8 (1.2)	0.003**
Learned a lot about HBOC (1–5)	4.50 (0.6)	3.2 (1.0)	0.000***
Information useful to understand own risk (1–5)	4.45 (0.6)	3.4 (0.9)	0.000***
Had trouble understanding the information (1–5)	2.70 (1.1)	3.5 (1.1)	0.029*
Would recommend to at-risk women (1–5)	4.45 (0.9)	2.5 (1.1)	0.000***

*p ≤ 0.05, ** p ≤ 0.01, *** p ≤ 0.001.

with effectiveness (Pot et al., 2020; Smith & Liu, 2020). Potential solutions that could maximize implementation outcomes while considering fidelity includes (1) reordering content to avoid repetition, while ensuring sequential mastery of background information; (2) shortening (vs. removing) the background modules, and (3) tailor to prior knowledge by loosening the structure (i.e., allow participants to choose levels or modules).

3.4.2. Mental Representations: Encoding the meaning of key medical facts

Fidelity Considerations: Engagement and active learning are core components of *BRCA-Gist* (Widmer et al., 2015). Forming gist representations is key to making informed health decisions (Blalock & Reyna, 2016). Prior studies suggest that gist dialogues (participants write in their own words 6–8 sentences about what they learned) are active ingredients of *BRCA-Gist* (Wolfe et al., 2018). These findings are also supported by cognitive psychology research showing that active learning and testing are important for learning (Reyna & Titcomb, 1997).

Suggested Adaptations: Both genetic counselors and at-risk women suggested that writing 6–8 sentences could be overwhelming, especially for low literacy populations. Participants who were not technologically savvy or had low literacy were unable to complete this task by themselves. Suggestions for adaptations included removing the open-ended questions, reducing the number of sentences to write, and only retaining multiple-choice questions.

Implementation Considerations: The original intervention had an AI component in which avatars provided feedback about participants' 6–8 sentences responses to the gist prompts (e.g., correcting or eliciting more information). Maintaining the interactivity may result in reduced reach, dissemination, and adaptability since participants would need to access AutoTutor Lite and to have fast broadband Internet connection for a smooth functionality. Therefore, the reach and capacity to disseminate *BRCA-Gist* would be diminished with the original software.

Table 4
At-Risk Women and Genetic Counselors' Suggested Adaptations Based on Stirman and Colleagues' (2013) Framework.

	At-risk women Suggestions	Genetic Counselors Suggestions
Contextual Modifications		
Format	Internet access challenges Other formats: (e.g., print out, tablet, social media)	Internet access challenges/ no computer at home. Other formats: (e.g., smart phone, tablet)
Setting	<ul style="list-style-type: none"> Doctors' office Others: recreation centers, libraries, schools, community centers, churches, colleges, home 	<ul style="list-style-type: none"> Doctor's office/ clinic (e.g., PCP visit, gynecologist, surgeons) Genetic counseling: group counseling, supplement to counseling pre or post, useful if pre-test counseling is not conducted due to limited access or shortage of counselors Other: community health centers, church, home, rural practices
Personnel	<ul style="list-style-type: none"> Doctors referring patients to BRCA-Gist 	<ul style="list-style-type: none"> Doctors referring patients to BRCA-Gist (including PCPCs and gynecologists) At-risk individuals including affected and unaffected, relatives of individuals who test positive
Population		
	At-risk women	Genetic Counselors
Content Modifications		
Tailoring/ tweaking/ refining	<ul style="list-style-type: none"> Health literacy (e.g. simplify language, bullet points, include topics previews) Usability (e.g. improve layout, bigger font, replace avatars with human voice, more interactivity) Cultural adaptations (e.g. translate into Spanish, use Ebonics, add targeted HBOC information, use actress vs. avatars) 	<ul style="list-style-type: none"> Health literacy (e.g. simplify language and numbers) Usability: (e.g. improve layout, bigger font, replace avatars with human voice, more interactivity) Cultural adaptations (e.g. targeted HBOC information, appeal to cultural values like <i>familismo</i>, avatars more culturally appropriate, using actresses vs. avatars) Update information (e.g. panel testing, costs of testing, other cancer risks, GINA laws, NCCN guidelines, medical records) Clarify and refine certain concepts (e.g.

Table 4 (continued)

	At-risk women Suggestions	Genetic Counselors Suggestions
Adding elements (intervention modules of activities)	<ul style="list-style-type: none"> Add content (e.g. ovarian cancer, male breast cancer, environmental causes of cancer) Add glossary Add additional resources (e.g. how to obtain GCT, insurance coverage) 	<ul style="list-style-type: none"> Variant of Uncertain Significance) Add content (e.g. genetic counseling process, process of testing) Add additional resources (e.g. how to find a counselor)
Removing elements (removing/ skipping intervention modules or components)	Remove some content (e.g. statistical approach, T-cells)	Remove some content (e.g. T-cell, statistical approach, breast cancer background-stages, types)
Shortening/ condensing (pacing/timing)	Shorten: simplify, narrow-it down, compile, reduce repetition, and the amount of information presented. Highlight key points Gist prompts: 6–8 sentences too long	<ul style="list-style-type: none"> Shorten: simplify, narrow-it down, compile, reduce repetition, and the amount of information presented. Highlight key points Ideal duration between 10 and 45 min (most suggest 20–30 min) Gist prompts: 6–8 sentences too long, make it 3–4 or use multiple choice instead
Lengthening/ extending (pacing/timing)	<ul style="list-style-type: none"> Pacing: Slow it down: Make it slower but shorter Timing: Have two sessions 	
Re-ordering elements		<ul style="list-style-type: none"> Reorder the modules to avoid jumping back and forth between the topics Condensing information in one module vs. mentioning concepts in multiple modules Mentioning genetic counseling and the hereditary component earlier in the intervention
Loosening structure	<ul style="list-style-type: none"> Free navigation: Break down the intervention into multiple shorter modules that can be selected separately Tailor: Include more detailed information for women who are already familiar with the topic 	<ul style="list-style-type: none"> Free navigating power: Be able to go back and forth, pick a different order Tailor: Include some modules just for individuals who want more information about certain topic, tailor for unaffected vs. affected women Break in two modules: breast cancer and HBOC

Table 5
Direct quotes from at-risk women and genetic counselors.

	At-risk women, direct quotes	Genetic counselors, direct quotes
Contextual Modifications		
Format	“Because I know my mom (...) or sometimes they don’t have access to the Internet. So maybe if it was like printed out or something” (1 0 9)	“Most of my patients do have cell phones and many of them have smart phones, but many of them do not have computer access. It would need to be smart phone doable. If it had to be done on a computer, that would limit it probably to me handing a patient an iPad in the clinic (1 0 4)
Setting	“And perhaps could be used in a community center or churches, something like that. ‘Cause real informative.” (V105)	“I think you really have to kind of go where the patients are (...) I think that more talking to community health centers and neighborhood clinics and things like that where people are maybe a little more likely to go, especially if they’re uninsured.” (1 1 3)
Personnel	“To recommend for them to watch it (...)I feel probably their doctor” (1 0 6)	“I think it would be useful as pre-counseling. I think it would be great if it nudges people to wanting to get more information but not necessarily to reach a decision.” (1 1 6)
Population		“This is one scenario: the primary care identifies the patient and they say, “You know, I think you’re a good candidate for genetic testing. I think you should watch this video, whether you wanna watch it at home on your own time, and if you’re interested in genetic testing and genetic counseling, I can send a referral.” (1 0 3)
		“I think how it is right now is that the best population is women who have been diagnosed with breast cancer given the amount of information and details it goes into about breast cancer and the specifics. But, I can see if that part is shortened a little bit, the information is still relevant to women who have a family history and not just those who have been diagnosed” (1 0 7)
Content Modifications		
Tailoring/tweaking/refining	“The video talked something about...I think it was a certain type of Jewish people. So, maybe talk about how it’s affecting Latino people and more research on the number of Latino people that are affected by this. That	“I’m not saying that it’s only Hispanic or Black women who are concerned about their children, but I think that is something that could be included. When I think of culturally just how close people are with their families, you know, geographically or just in

Table 5 (continued)

	At-risk women, direct quotes	Genetic counselors, direct quotes
	way, they can see that it’s not just other races and stuff” (1 0 6)	relationship-wise if their families are living in other parts of the world, it’s important for them to know that this information impacts them.” (1 1 7)
	“Well, I’d say for information-wise it was good information-wise, but it just has – the information has to be torn down to a ninth grade education.” (V107)	“In general for any patient of any race or ethnicity, would find this to be too long, too dense, and have unnecessary information (...), if the patient was low literacy or low education background, then it would – I would pare it down even more” (1 0 4)
	“They (avatars) looked like cartoonish. Like when you have someone real it does something. It just – it does something when you see the person” (1 1 3)	“The literacy level seems very, very high. It was just too much information.” (1 1 8)
Adding elements (intervention modules of activities)	“Well, the only thing my question is about how it affect the insurance.” (1 1 1)	“ I guess a couple of the benefits of genetic testing, you might also include treatment decision-making. I don’t know if that was in there. And that could be surgical decision, that could be immunotherapy, that could be clinical trial eligibility. A lot of times those are the reasons people are coming to see us.” (1 1 6)
	“Like I said, that ovarian link – I think maybe people should be more aware of that” (1 0 5)	“Maybe addressing some of the misconceptions about what a genetic counseling session is and what – a little education about what will happen during a session could be helpful.” (1 0 4)
Removing elements (removing/skipping intervention modules or components)	“Some of the statistics I don’t think were necessary.” (1 0 4)	“I guess my main thing is that I felt like it was way too much information. (...) the whole part on like the stages of breast cancer and what metastasize is and things like that and how breast cancer can metastasize. I mean, I guess I could see some of that being helpful to patients who were really recently diagnosed and their doctors didn’t take any time to go through that. But if the main goal is to (...) educate people about genetic testing for hereditary breast cancer and encourage them to pursue those services when appropriate or when they’re interested, I feel like that really doesn’t have anything to do with it” (1 0 8)
		“There was this whole conversation about the killer T cell (...) it felt like extra information and I wasn’t sure why that was there. The two by two table,

(continued on next page)

Table 5 (continued)

	At-risk women, direct quotes	Genetic counselors, direct quotes
		<p>while it was well presented – so it was a really good way to illustrate that concept to people (...) I felt like it was too much information and didn't really bring anything to the conversation." (1 0 4)</p> <p>"The other kind of potentially unnecessary thing in going over the Gail Model. I'm not sure you need to – at one point I think it talked about the Gail Model statistically weighting each of the factors. And I'm not sure people need to know that. And again, it might cause test anxiety to say statistical weight." (1 1 6)</p>
Shortening/condensing (pacing/timing)	<p>"It was very long and you know, very fast. You know, so that was my only critique about it but other than that, it was helpful." (1 0 8)</p> <p>"I would kinda like narrow it down and not have the questions, even though it was true or false, agree/disagree – not to be so repetitious (...) you want to narrow it down that it's not so long and drawn out." (V103)</p>	<p>"It just felt too information dense again (...) I would rather see the quizzes as maybe something multiple choice rather than – I know that having people write sentences is a better education process as you process and formulate things into sentences, but (...) I think for lower – patients who have lower education and lower exposure to those types of – that would be off putting. I think that writing those sentences would be a little daunting. Anyways – or it's just my weirdness with me finding her kind of bossy. I don't know." (1 0 4)</p>
Lengthening/extending (pacing/timing)	<p>"Making it more simpler I guess, and more I understand, like it's a lot of things were moving so fast, I mean well maybe just for me I guess and for my pace" (1 0 8)</p>	
Re-ordering elements		<p>"I didn't quite understand why you started with alcohol and then module three, you're talking about pros and cons of genetic testing. Haven't even told them what it is and may not be covered by insurance. It was so out of context and that's why I wondered if you separated breast cancer and then do genetic testing." (1 1 9)</p> <p>"One thing I noticed was that the intervention bounces back and forth about talking about the hereditary cancer risk and going over what is breast cancer and then switching back to hereditary cancer.</p>

Table 5 (continued)

	At-risk women, direct quotes	Genetic counselors, direct quotes
		<p>So, reorganizing better a lot of the bits so that it goes... I'm not sure what order is better, like going over what is breast cancer first and then talking about hereditary cancer but just so it's not bouncing back and forth so that it is easy to follow." (1 0 7)</p>
Loosening structure	<p>"I feel like the better strategy for that is to do it in small modules that you can pick up and put down. Because then the motivator would be: "Okay, I've mastered that piece in 15 min." Doesn't seem like that long. But I couldn't in my regular everyday life sit down for an hour and a half and learn something like that. But I could do it in ten-minute intervals between stuff." (1 1 0)</p>	<p>"I would again approach it from two different perspectives: individuals who've had a breast cancer diagnosis and individuals who have not. And I would tailor the information for those two situations." (1 0 4)</p>
Acceptability and satisfaction		
Positive feedback	<p>"I liked the information. The information that it gave was really, really helpful because, like I said, I didn't know any of this." (1 0 5)</p> <p>[what she liked the most] "That it provided a lot of information, and it wasn't specific to the certain race, or stuff like that. So, it gave different scenarios of different stuff. So, I really liked that."</p> <p>(1 0 6)</p>	<p>"I thought that overall the information was accurate. And it was comprehensive. There was a lot of information that we like to make sure we cover during a genetic counseling session. So those are pros." (1 1 0)</p> <p>"So what did I like about it? So I guess the fact that it was interactive I thought could be useful." (1 0 8)</p>
Suggestions for improvement	<p>"Speak in their own language. Got to get to the heart of things. If you're going to get to the heart of people, you've got to speak in their language." (V07)</p> <p>"Yes. Like I said before, it needs to be in a better format where people in general could understand. If you have to use big words, break down the meaning so they know what you're talking about. In video form. No avatars. In video form. And that's about it." (V07)</p>	<p>"if it was divided into smaller pieces I think it could be implemented both pre- and post-genetic counselling. As a genetic counselor, I think it is more productive when patients have some previous knowledge of the topic. Though I can also see it working post-counselling as a way for patients to consolidate their knowledge." (1 1 1)</p>

Additionally, conducting adaptations and updates in the AutoTutor Lite platform is burdensome. Updating capacity is crucial because knowledge in genomics is rapidly advancing. Given that *BRCA-Gist* was originally developed to be interactive, the AI component would need to be re-trained with any new information and the potential answers to accurately categorize participants' written responses. In a fast-paced field, where guidelines change often, the adaptability of the original *BRCA-Gist*—if used with the original software—can be limited. These same challenges would be faced if *BRCA-Gist* were to be translated into other languages. In contrast, the adapted version, hosted in Qualtrics, is easily edited to integrate emerging data.

Patient-Facing Considerations: Keeping the 6–8 sentence gist prompts may reduce the acceptability of the intervention for at-risk women, since they considered this requirement burdensome. Fidelity may be reduced if women do not adhere to the 6–8 sentence guidelines. However, any level of cognitively active response (e.g., writing one-two sentences) is better than passive reading/listening.

Potential Solutions/Future Research: Relocating *BRCA-Gist* to Qualtrics can facilitate delivery/accessibility of the intervention for our target population as well as the process of making adaptations. However, this change in platform eliminated the interactive AI component. Given that the need to engage respondents in active cognition is likely to be necessary for any successful intervention (e.g., (Blalock & Reyna, 2016; Reyna & Mills, 2014)), more research is needed about strategies to increase engagement without the interactive AI component.

While removing 6–8 sentences gist prompts and retaining only multiple-choice questions may reduce participant burden, theoretical considerations highlight cognitive engagement to derive gist. Another option would be to incorporate speech recognition software so that users can talk vs. type.

3.4.3. Retrieval of values (recognizing the relevance of key values).

Cultural Adaptations.

Theoretical Considerations: FTT accounts for the role of culture in providing a context to interpret the meaning of risk information (e.g., (Reyna & Adam, 2003)). FTT emphasizes the importance of values applied to mental representations of information in decision-making (Reyna, 2012). Culturally targeted interventions are more effective than interventions that are not culturally targeted (Barrera et al., 2013; Griner & Smith, 2006). Thus, the adaptations suggested align with the theory.

Suggested Adaptations: Genetic counselors and at-risk women recommended translating the intervention into Spanish and including more directly relevant information for the target population. For instance, genetic counselors suggested that the intervention explicitly address the higher rates of Variants of Uncertain Significance (VUS) in these populations. A VUS test result means that genetic mutations have been found, but the impact of those genetic mutations in health it is not yet known (Mersch et al., 2018). Higher rates of VUS in Black and Latinx communities stem from the limited opportunity that they have had historically to participate in genomics research, which hinders the characterization of the mutation spectrum in these populations (Hall et al., 2009). Additionally, several genetic counselors recommended making the avatars more culturally appropriate, and addressing cultural values such as *familismo* to highlight the importance of GCT in informing family risk in a culturally appropriate way.

Implementation Considerations: *Patient-facing considerations.* Making adaptations to include culturally targeted messages can increase the acceptability of *BRCA-Gist* for at-risk Black and Latina women.

Adaptations Conducted/Planned. Including the addition of culturally targeted information about HBOC and highlighting the implications of testing for family members.

4. Discussion

Advances in precision medicine have not benefited all populations

equally (Armstrong, 2017). Black and Latinx populations have been severely underrepresented in genomics research (Roberts et al., 2017). Enhancing representation of diverse populations in genomics research and making sure that EBIs reach these populations is key to reduce disparities (Castro & Yasui, 2017; Jooma et al., 2019). Systematic approaches to adapt EBIs are needed to make sure that EBIs retain their core components while enhancing the fit when implemented in clinical practice with historically underrepresented populations (Castro & Yasui, 2017). This study illustrates the process of integrating fidelity and adaptation considerations to maintain theoretical congruence of *BRCA-Gist* while addressing potential barriers for implementation. There is extensive research on the theoretical foundations of *BRCA-Gist* and its core components (Reyna, 2008a; Widmer et al., 2015), which have been tested across cultures and countries (Fraenkel et al., 2016; Liberali et al., 2012). Some of the suggested adaptations to enhance acceptability raised fidelity concerns (e.g., removing gist dialogues). Other adaptations could maximize its reach (use of Qualtrics vs. AutoTutor Lite), while compromising the AI and interactive components, potentially affecting engagement. However, some of the suggested adaptations to enhance the fit with the population did align with core intervention components (e.g. cultural adaptations).

Engaging multidisciplinary teams with basic and applied researchers, implementation science experts, and key stakeholders (e.g., diverse patients, providers) is key to inform the early stages of research. This allows identifying potential challenges in implementation from the beginning. More research is needed to assess the effectiveness of the adapted *BRCA-Gist* as well as its effect drivers. Future studies should also explore alternative ways of increasing engagement and the minimal doses needed to promote engagement without adding to participant burden (e.g., 2–4 sentences gist prompts vs. 6–8 sentences).

We found differences between at-risk women and genetic counselors' perceptions of *BRCA-Gist*. At-risk women had significantly higher ratings of satisfaction and acceptability of *BRCA-Gist* compared to genetic counselors. During the interviews, women at-risk highlighted that they specifically liked the level of information shared because they had never received it before. In contrast, counselors suggested that some general information may not be necessary for all at-risk women (see Table 5). Prior studies have also shown converging and diverging perceptions between patients and providers (Evans et al., 2016; Joseph et al., 2017; Lu et al., 2016). Further exploration of these differences is warranted. For instance, at-risk women and genetic counselors made similar suggestions in the semi-structured interviews (e.g., reducing length). However, at-risk women valued more the inclusion of background information while genetic counselors suggested focusing more on HBOC. Genetic counselors may overestimate patients' background knowledge or they may have different perceptions about burden for participants. In contrast, genetic counselors are content experts and their suggestions on content accuracy and how to integrate *BRCA-Gist* within clinical practice are crucial for implementation. Identifying the different perspectives from at-risk women and genetic counselors is important to inform patient-facing and provider-facing implementation strategies.

Previous studies suggest that using a psychosocial counseling approach (vs. information/education approach) may be specially beneficial with low health literacy populations (Joseph et al., 2019). This mode of counseling may improve patient satisfaction and shared decision making (Biesecker et al., 2017). Using *BRCA-Gist* as a complement to pre-test genetic counseling could support this goal, by reducing the amount of time that counselors spend providing biomedical education and increase the time they spend counseling on psychosocial factors, such that patients would still receive the all the information that they want/need to make decisions aligned with their values (Ellington et al., 2006; Joseph et al., 2019). Importantly, rather than just listing medical facts, *BRCA-Gist* provides the bottom line meaning (gist information), which can enhance knowledge, understanding, and decision-making (Reyna, 2008b). In this regard, we build on both psychosocial and information approaches, integrating them with gist.

Some genetic counselors envisioned an adapted *BRCA-Gist* being used as a supplement to counseling. Others suggested using it as an additional resource either pre-counseling, to obtain background information, or post-counseling, to solidify the knowledge patients learn during the appointment. Several genetic counselors also agreed that *BRCA-Gist* could be particularly helpful in situations where patients receive genetic testing without seeing a genetic counselor. While not ideal, this practice has become more common due to the increasing demand for genetic testing with limited availability of genetic counselors (Hoskovec et al., 2018) and the challenges for covering the costs of genetic counseling for underinsured individuals (Hurtado-de-Mendoza et al., 2018). Unfortunately, the lack of access to adequate genetic counseling results in patients missing important information (Vadapampil et al., 2015) and higher chances of tests being ordered incorrectly as well as errors interpreting test results (Farmer et al., 2019). The shortage of genetic counselors and raising demand has sparked the development of different service delivery methods including tele-genetics, group counseling, use of trained genetic counselors assistants, and use of patient education tools (Raspa et al., 2021). *BRCA-Gist* is an easily disseminatable web-based tool that can be integrated into different delivery methods to increase understanding in a culturally appropriate way and to streamline the efficiency of the genetic counseling process.

This study has some limitations. We recruited a small convenience sample of women from the Mid-Atlantic region. Thus, findings may not generalize to women from other regions. The Latina women sample were mostly second-generation. Findings may not generalize to first-generation Latinas or Spanish-preferring Latinas. Despite these limitations, the study has several strengths. First, the use of Implementation Science concepts. Less than 2% of genomics studies have used Implementation Science frameworks (Roberts et al., 2017). Second, this study was targeted to populations severely underrepresented in research (Roberts et al., 2017). Last, the consideration of perspectives from diverse stakeholders including the intervention developers, disparities researchers, at-risk women, and genetic counselors. Future studies will assess the efficacy of the adapted *BRCA-Gist* in a RCT.

5. Availability of data and materials

The authors welcome inquiries from investigators interested in possible collaboration and use of de-identified data from this study. The data has not been placed into a public repository.

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Alejandra Hurtado-de-Mendoza: Conceptualization, Formal analysis, Funding acquisition, Investigation, Supervision, Writing – original draft. **Valerie F. Reyna:** Conceptualization, Funding acquisition, Supervision, Writing – original draft. **Christopher R. Wolfe:** Conceptualization, Supervision, Writing – original draft. **Sara Gómez-Trillos:** Formal analysis, Investigation, Project administration, Writing – original draft. **Arnethea L. Sutton:** Investigation, Project administration, Writing – original draft. **Ashleigh Brennan:** Formal analysis, Investigation, Writing – review & editing. **Vanessa B. Sheppard:** Conceptualization, Funding acquisition, Supervision, Writing – original draft.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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