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.
prevalence, 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 genomics 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-Whynot et al., 2016; Wolfe et al., 2015, 2016; Wolfe et al., 2015). BRCA-Gist was initially designed to complement genetic counseling, which is ideal when available (Cedillos-Whynot 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-Whynot 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 Stirmat and colleagues FRAME (Stirmat 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 sociodemographic 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-generality 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, arguments (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 sociodemographic 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.

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 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

| Sociodemographic and Clinical 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 – <$80,000 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.
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 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).

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(100) |
| 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 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) |

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.
| Contextual Modifications | At-risk women Suggestions | Genetic Counselors Suggestions |
|--------------------------|---------------------------|--------------------------------|
| Format                   | Internet access challenges | Internet access challenges/no computer at home (e.g., print out, tablet, social media) |
|                         | Other formats: (e.g., print out, tablet, social media) | Other formats: (e.g., smart phone, tablet) |
| Setting                  | Doctor’s office             | Doctor’s office/clinic (e.g., PCP visit, gynecologist, surgeons) |
|                         | Others: recreation centers, libraries, schools, community centers, churches, colleges, home | Genetic counseling: group counseling, supplement to counseling 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                | Doctors referring patients to BRCA- Gist | Doctors referring patients to BRCA-Gist (including PCPs and gynecologists) |
|                         |                             | At-risk individuals including affected and unaffected, relatives of individuals who test positive |
| Population               |                             |                             |

| Content Modifications    | At-risk women Suggestions | Genetic Counselors Suggestions |
|--------------------------|---------------------------|--------------------------------|
| Tailoring/ tweaking/ refining | Health literacy (e.g. simplify language, bullet points, include topics previews) | Health literacy (e.g. simplify language and numbers) |
|                         | Usability (e.g. improve layout, bigger font, replace avatars with human voice, more interactivity) | 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) | Cultural adaptations (e.g. targeted HBOC information, appeal to cultural values like familismo, 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) | 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. statistical approach, breast cancer background-stages, types) | Clarify and refine certain concepts |
Table 5

| Contextual Modifications | At-risk women, direct quotes | Genetic counselors, direct quotes |
|--------------------------|------------------------------|----------------------------------|
| **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) | “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) |
| **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**           | “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) | “Adding elements (intervention modules of activities) “Well, the only thing my question is about how it affect the insurance.” (1 1 1) |
| **Content Modifications**| “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 ” | “Like I said, that ovarian link – I think maybe people should be more aware of that” (1 0 5) |

Table 5 (continued) At-risk women, direct quotes | Genetic counselors, direct quotes |
| **Adding elements (intervention modules of activities) | way, they can see that it’s not just other races and stuff” (1 0 6) |
| | “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) |
| | “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) |
| | “I think 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) |
| | | “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 metastasis 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 |
|------------------------------|----------------------------------|
| **Shortening/condensing**    | 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) |
| **(pacing/timing)**          | “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) |
| **Loosening structure**      | “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) |
| **Acceptability and satisfaction** | “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) |
| **Positive feedback**        | “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) |
| **Suggestions for improvement** | “So what did I like about it? So I guess the fact that it was interactive I thought could be useful.” (1 0 8) |

| At-risk women, direct quotes | Genetic counselors, direct quotes |
|------------------------------|----------------------------------|
| **Lengthening/extendng**    | “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) |
| **(pacing/timing)**          | “I would kinda like other than that, it was only critique about it but I know, so that was my weirdness with me finding her kind of bossy. I just my weirdness with me thinking that writing those 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) |
| **Making it more simpler**   | “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) |
| **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) | “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) |

| At-risk women, direct quotes | Genetic counselors, direct quotes |
|------------------------------|----------------------------------|
| **Re-ordering elements**    | “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) |
| **(pacing/timing)**          | “One thing I noticed was that the intervention bounce back and forth about talking about the hereditary cancer risk and going over what is breast cancer and then switching back to hereditary cancer.” |
| **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) | “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) |
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 (recognising 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 providing a context to interpret the meaning of risk information (e.g., can talk vs. type). Another consideration highlights cognitive engagement to derive gist. Another adaptations to include culturally targeted messages can increase the acceptance of BRCA-Gist for at-risk Black and Latina women.

### 4. Discussion

Advances in precision medicine have not benefited all populations equally (Armstrong, 2017). Black and Latina 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 & Yadi, 2017; Jooja 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 & Yadi, 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, 2006a; 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 target 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 patient 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 especially 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 (Vadaparampil 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 telegenetics, 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-prefering 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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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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