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Evaluation of a Story-telling Approach to Educate Minority Populations About Inherited Cancer

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Evaluation of a Story-telling Approach to Educate Minority Populations About Inherited Cancer

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science
with a concentration in genetic counseling
College of Public Health
University of South Florida

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ABSTRACT

Utilization of hereditary cancer genetic counseling and testing services is substantially lower among minority populations compared to white populations due, in part, to lower levels of awareness and knowledge. To help improve awareness, we designed a 7-minute video that uses storytelling to translate knowledge of genetic testing and hereditary cancer to individuals who have a personal history or family history of cancer. Consented participants were asked baseline questions about hereditary cancer and genetic testing, reviewed the video, and provided feedback on its content, understandability, and visual appeal during semi-structured interviews. Data were coded and analyzed to identify themes and determine whether the educational materials addressed some of the perceived obstacles to genetic testing that were raised by participants. Analysis of 13 coded interview transcripts suggest the video may improve self-efficacy to access genetic testing because it addressed some barriers related to cost of genetic testing and the information was easy to understand. After viewing the video, a majority of participants indicated that pursuing genetic testing would be useful. Multiple participants appreciated the logical, concise flow of the video, stated that it increased their knowledge on genetic testing for hereditary cancer, and asked for more information on possible next steps. Most participants reported needing more information about whether their personal insurance plans would cover genetic testing and about the logistics of obtaining the DNA sample before they would take action to pursue genetic counseling or testing. Based on constructive feedback, we added links to more information and listed possible next steps people could take to learn more or to obtain genetic counseling and testing.

CHAPTER 1: INTRODUCTION

Rates of genetic counseling and testing services uptake for hereditary cancer are significantly lower in minority populations in comparison to white populations (Khan et al., 2022, Swami et al., 2022). Previous studies have shown that most minority patients are referred for genetic testing based on a cancer diagnosis and less likely due to a family history or hereditary cancer risk factors (Chapman-Davis et al., 2021, Delikurt et al., 2015) Further studies support this by showing lower physician referral rates for minority populations compared to White populations in genetic testing for breast cancer, colorectal cancer, prostate cancer, and other hereditary cancer syndromes (Chapman-David et al., 2021, Cragun et al., 2019, Muller et al., 2018, Peterson et al., 2020, Weise et al., 2022). Additionally, awareness about genetic services and understanding of hereditary cancer risks among minority populations was lower when compared to White populations (Allford et al., 2014, Canedo et al., 2019). More research is needed to determine what strategies can be used to increase awareness and interest in genetic testing among minority populations.

Stories have been used to communicate information in education, policy development, research, anthropology, and many other disciplines due to their ability to evoke emotion and spur us into thinking or behaving differently (Brooks et al., 2022). Stories have also been utilized in healthcare to translate knowledge (Brooks et al., 2022, Fix et al., 2012, Greenhalgh et al., 1999, Rose et al., 2015) and on social media to raise awareness about genetic testing for asymptomatic conditions of direct-to-consumer products such as 23andMe (Harris et al., 2014). Narratives have been effective in translating knowledge of general cancer information and cancer screening

(Cueva et al., 2013, Borrayo et al. 2017; Kreuter et al. 2007; Larkey and Gonzalez 2007; Murphy et al. 2015). An 18-minute Spanish-language film used storytelling to convey risks factors and ways to overcome barriers to pursue genetic counseling for hereditary breast and ovarian cancer (HBOC). Among the 31 individuals who viewed the video, most were highly satisfied with the provided information and believed the information would be beneficial for the Latina community and other women who were at-risk for HBOC (Hurtado-de-Mendoza et al., 2020). Nevertheless, other research has shown that engagement with video educational materials is highest when the length of the video was less than 6 minutes, and engagement continuously decreased as the length of the video increased beyond 9 minutes (Brame, 2016, Guo et. al., 2014). Although prior materials on hereditary cancer has been targeted for specific minority groups (Kinney et al., 2010), there is a need for additional patient resources that can actively engage multiple minority groups on the benefits of genetic testing to ensure that at-risk individuals, especially minorities, are aware of the genetic services available and its benefits.

In addition to lower awareness of genetic services, negative attitudes and perceptions have been observed when discussing cancer diagnoses and genetic testing among minority populations (Meilleur & Littleton-Kearney, 2009, Kinney et al., 2010). Some of the attitudes found in African American, Hispanic, and other minority populations were secrecy, stigma, and fear around cancer, which may result in not discussing a diagnosis within their family or even with their provider (Meilleur & Littleton-Kearney, 2009, Kinney et al., 2010). Additionally, medical mistrust as well as mishandling of genetic information are considered important barriers in Black cancer patients from continuous systemic disadvantage and inequities within the US healthcare system (Hoadley et. al, 2022, McDonald et al., 2014, Sutherland & Kiros, 2009).

To help overcome some of the fear, stigma, negative attitudes, and concerns we designed a short English-language video that uses storytelling to educate minority populations about genetic testing benefits, including possible changes in cancer screening and prevention. The goal of our evaluation was to determine whether this type of media and process of disseminating information through storytelling was acceptable, addressed perceived barriers to testing, conveyed benefits of testing and increased interest in testing among the target population, which consisted of racial/ethnic minority groups.

CHAPTER 2: METHODS

Story and Video Development

We first created a story board using the Story-based Knowledge Translation Framework proposed by Brooks et. al. and applying it to the topic of cancer genetic testing (Figure 1).

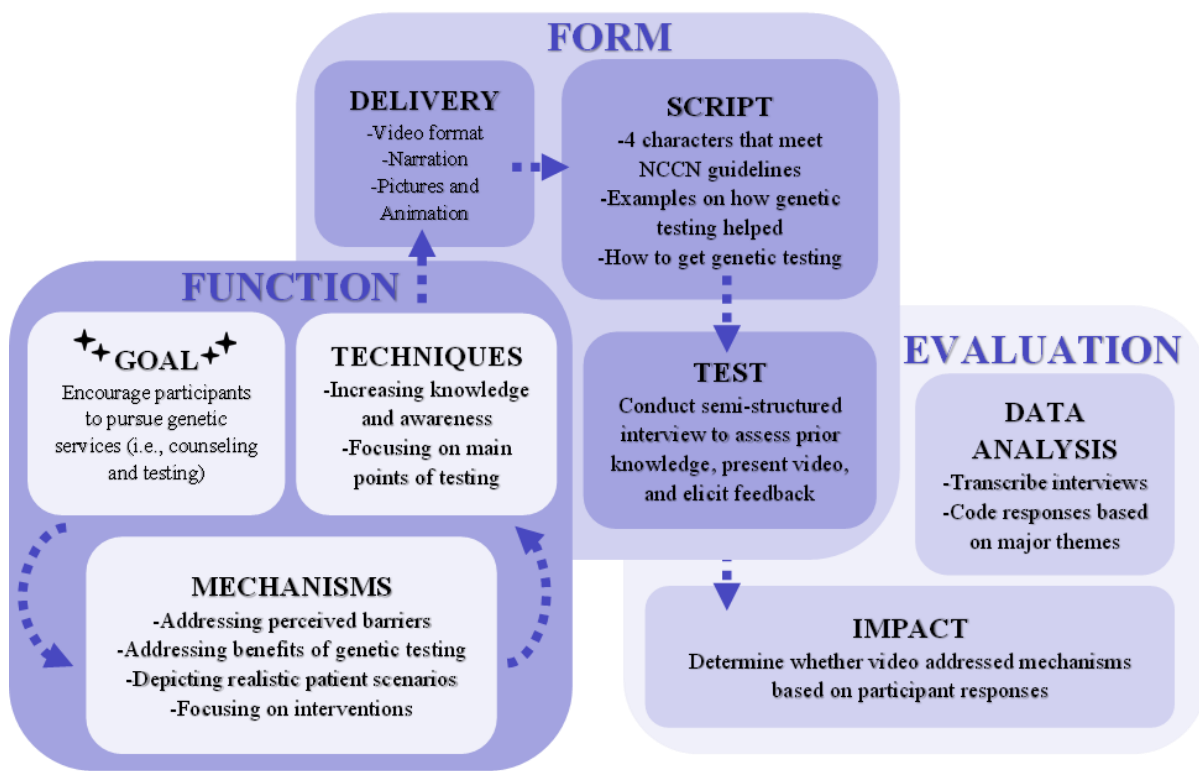


Figure 1. Story-based Knowledge Translation Framework for Video

The four, distinct characters in the video depict realistic scenarios of a broad array of individuals from different minority groups. Each individual qualified for genetic testing by meeting the National Comprehensive Cancer Network Guidelines (NCCN) for either genetic high-risk assessment of breast, ovarian, and pancreatic cancer, or high-risk assessment of colorectal

cancer. The main character, Serena, has a 1st-degree relative who tested positive for a pathogenic variant in a high-penetrance breast cancer gene; the second character, Veronica, has a diagnosis of ovarian cancer; the 3rd character, Seymour, has a diagnosis of metastatic prostate cancer; and finally, Oscar, has a diagnosis of colorectal cancer at <50 years of age. All characters are considered ideal candidates for genetic testing (Rahner & Steinke, 2008). The storyboard and video design were made using resources available with a licensed subscription to CANVA and supplemented with additional hand-drawn digital media by Celestyn Angot using the Sketch App. This story board was developed into an approximately 7 minute, and 36 second video. The contents of the educational video explained the importance of genetic testing and featured the following commonly asked questions of individuals who qualify for genetic testing: “What is genetic testing?”, “How does my family member’s diagnosis affect me?”, “Why would I want to know if I have hereditary cancer?”, “Who has access to my genetic testing results?”, “How much does genetic testing cost?”, and “How do I start the genetic testing process?”.

Several messages in the video were guided by constructs from the Extended Parallel Process Model (EPPM), which is hypothesized to increase the likelihood that the message will be both attended to and acted upon. The EPPM states that there are four “cognitions” that need to be at high levels: susceptibility, severity, self-efficacy, and response efficacy for people to take actions to deal with a health threat (Popova, 2012). Susceptibility refers to whether an individual perceives they are at risk (i.e., individuals who feel they might have a genetic predisposition for developing cancer) (Termeh Zonouzy et al., 2018). We addressed susceptibility by “depicting realistic patient scenarios” with different characteristics that increases their chances for hereditary cancer, including the main character who did not have cancer but was at high risk due to her family history. Severity refers to how serious the consequences would be if they did not

get genetic testing (e.g, a diagnosis of a cancer that might have been prevented or treated earlier, etc.) (Termeh Zonouzy et al., 2018). Severity was addressed through “focusing on interventions” by showing examples of prophylactic prevention options such as surgical removal of both breasts and female reproductive organs in addition to cancer screening starting in young adulthood. We also wanted to ensure messages that would impact other key EPPM constructs (i.e., response efficacy and self-efficacy) because it is important that individuals feel they can take action to reduce the threat of hereditary cancer. Self-efficacy refers to the ability of the targeted individuals to overcome barriers to pursue recommended actions that could help mitigate the threat (e.g., pursuing genetic testing, speaking to their provider/physician about genetic testing, etc.) (Popova, 2012). This was done by having characters in the story illustrate possible ways to overcome commonly discussed barriers that prevent individuals from pursuing genetic (e.g., genetic information protections, how to find a genetic counselor, etc.), this may help our target audience realize that genetic testing is attainable for them. Finally, response-efficacy in the context of hereditary cancer refers to perceptions that getting genetic testing can lead to changes in medical care that could effectively reduce the risks for cancer or find it early when it is easier to treat (Popova, 2012). This was illustrated in the video by the three different characters explaining how genetic testing helped provide information for their family members (i.e., colonoscopy screening for Oscar’s son, removal of reproductive organs for Veronica’s daughter, etc.) as well as helped one character with treatment options for his metastatic prostate cancer.

Procedures

After the evaluation plan and interview guide were reviewed by the IRB it was determined to be an evaluation of the video content, rather than human subjects research. However, all procedures were followed in accordance with ethical guidelines of the University of

South Florida IRB. All applicable international, national, and/or institutional guidelines were followed. This evaluation was approved by the IRB after expedited review and was granted an informed consent waiver. Only individuals who voluntarily agreed to participate completed the interviews. Participants were recruited through a convenience sampling using various social media outlets (e.i., Facebook, Instagram, Discord, etc.). Eligible individuals were purposively selected for being English-speaking adults with a personal and/or family history of cancer that. Individuals who met eligibility criteria and expressed interest in the project were messaged a recruitment flier with the contact information of the Principal Investigator (PI) and details about the interview process by which feedback on the video would be elicited as part of the evaluation. Recruitment of participants was stopped once theoretical saturation was reached, meaning that no new themes or suggestions for improving the video were raised.

Prior to the interviews, verbal consent and permission to record and transcribe the interviews was obtained. Semi-structured interviews were conducted by the student investigator using Microsoft Teams or Zoom in a private setting. Questions were asked both before and after individuals reviewed the video. After initial feedback was collected and analyzed from 7 participants, action steps were added to empower individuals to find more information, speak with their healthcare providers about genetic testing, and access a genetic counselor.

Instrumentation

Individuals were asked to provide basic demographic/clinical information (i.e., age, gender, race, type of cancer in their personal and family history). To determine the impact of the video, we developed a semi-structured interview guide (Appendix A) to assess whether individuals from the target population were already aware of hereditary cancer or potential benefits of genetic testing for hereditary cancer and to identify barriers they may have to getting genetic testing if

they wanted. Other questions were included to elicit what they learned from the video. For example, after viewing the video, they were asked: “How hard or easy was [the information/storyline] it to understand?” and “What information did you feel was most important?”. To assess for message rejection, whereby individuals do not understand how the message components would benefit them (Hong, 2011), we asked questions such as, “What about the video stood out to you the most?”, “How did this video change your view(s) [if at all] on genetic testing?”, etc. Message acceptance refers to understanding the benefits of genetic testing for hereditary cancer, and intention to speak with their provider about genetic testing (Hong, 2011) and was assessed with questions such as, “Overall, what did you think about this a resource?”. We sought out feedback on information preferences by asking: “What information may not be needed?”, “What information may be missing?” as well as what changes could be made. EPPM has been utilized in other studies to evaluate the effectiveness of health messages (Hong, 2011, Termeh et al., 2018). Figure 2 shows how the EPPM constructs and questions from the interview guide were used to help assess for message acceptance, rejection, and ways to amend (or alter) the messaging.

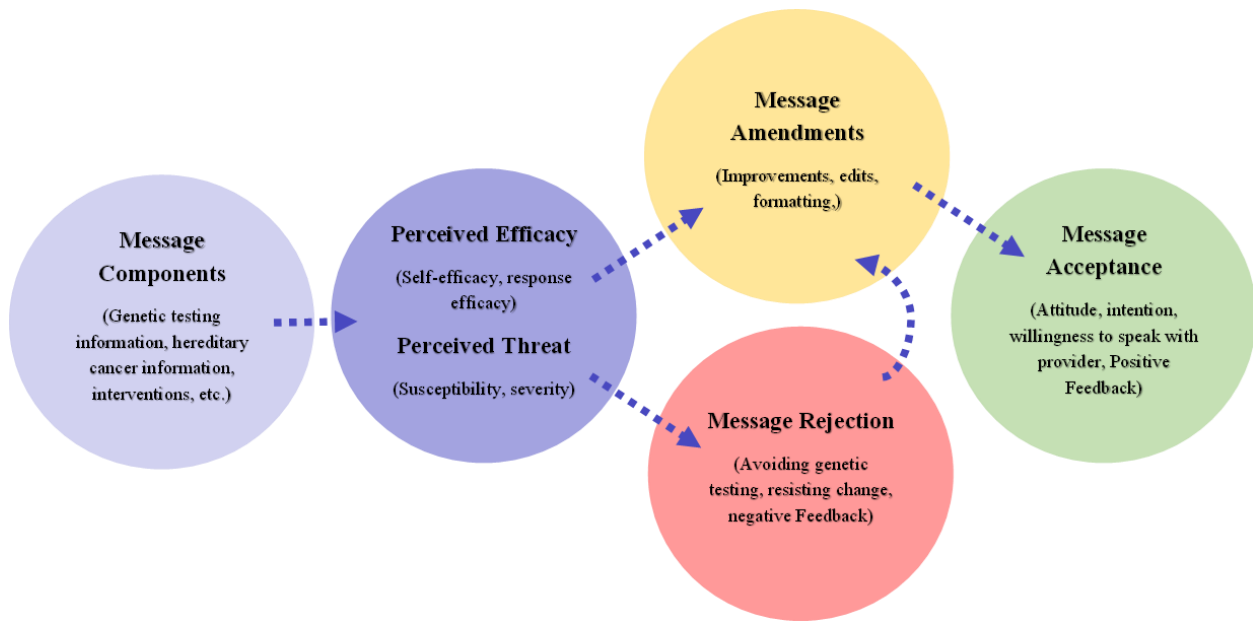


Figure 2. Diagram of the Extended Parallel Process Model and How it Relates to the type of Feedback Elicited about the Video During Interviews

Data Analysis

Interviews were transcribed using the Sonix.ai software. Transcripts were then coded line-by-line to describe each participant’s level of baseline awareness/knowledge and to identify and describe both positive and negative feedback. Interview content was initially categorized into “Positive Feedback”, “Negative Feedback”, and “Improvements”. Within each of the three primary categories, more focused themes emerged, and data were assigned a secondary theme that captured the essence of what individuals were saying. Additionally, we determined whether the video was successful in addressing perceived barriers by comparing their responses to the preliminary questions in the interview-guide that assessed barriers to subsequent responses after viewing the video.

CHAPTER 3: RESULTS

Participant Characteristics

A total of 14 participants with a personal or family history of cancer expressed interest in participating in the semi-structure interviews. One individual was lost to follow-up before being interviewed. Interviews lasted between 40 to 50 minutes long (including time viewing the video). The last 7 participants cited no novel improvements to be made to the visuals or content of the video, yet this data is insufficient to determine saturation. Participant characteristics are shown in Table 1. The mean age of participants was 37.77 years. All participants self-identified as a part of a minority group, with nearly half identifying as Hispanic and 23% identifying as Black. Most (85%) participants reported a family history of cancer, with the most common being breast cancer followed by pancreatic cancer.

Table 1. List of Participant Demographic Information and Type of Cancer History

| | N | Percent* | Mean | SD |
|-----------------------|----------|-----------------|-------------|-----------|
| Age | | | 37.77 | 15.84 |
| Gender | | | | |
| Male | 4 | 30.77 | | |
| Female | 8 | 61.54 | | |
| Transgender | 1 | 7.69 | | |
| Total | 13 | | | |
| Race/Ethnicity | | | | |
| Black | 3 | 23.1 | | |
| Asian | 1 | 7.69 | | |
| Hispanic | 6 | 46.15 | | |
| Multi-racial/Black | 1 | 7.69 | | |
| Multi-racial/Hispanic | 2 | 15.38 | | |

Table 1. (Continued)

| | N | Percent* |
|--|----------|-----------------|
| History of Cancer | | |
| Family History | 11 | 84.62 |
| Personal History | 1 | 7.69 |
| Both | 1 | 7.69 |
| Type of Cancer(s) in Family and Personal History** | | |
| Colon | 3 | 7.5 |
| Breast | 17 | 42.5 |
| Uterine | 2 | 5.0 |
| Prostate | 1 | 2.5 |
| Pancreatic | 4 | 10.0 |
| Ovarian | 3 | 7.5 |
| Other | 10 | 25.0 |

*Percent out of 100 that represents the respective groups.

**Some individuals had more than one type of cancer in the family.

Baseline Cancer Awareness and Understanding

Most participants reported having some basic understanding of cancer, but limited information about genetic testing for hereditary cancer. Three reported hearing about genetic testing and hereditary cancer on the internet or social media. One of these three participants mentioned they had “read about Angelina Jolie in Vogue magazine” -263697C, while another participant stated that they “learn a lot of stuff through TikTok” -720249D.

One of the main concerns all participants reported was the cost of genetic testing, with many listing cost as one of the main barriers preventing them from pursuing or seeking out genetic testing. Other barriers included negative experiences with healthcare navigation. One participant stated, “the way [my medical navigation] was handled had such a negative impact in my life at a time I was going through a lot” -112798L. Other participants expressed a lack of understanding related to how genetic testing would be useful or whether it would change: “...one of the doctors was like, ‘so what are you going to do if you find this?’...Let’s say I’m more prone to colorectal cancer, but will it tell me to do the colonoscopy yearly rather than every five years?” -274036H. Concerns about privacy were also brought up: “while it’s helpful to know on

a personal level...and also share with any immediate family members...I certainly wouldn't want that information to be accessible in the way that like how HIV information is shared." - 92416I. Finally, the last perceived barrier was uncertainty and fear around the subject matter: "[The only concern] is probably just the unknown and not knowing the risk factors and family history, just being nervous maybe about getting the results." -825850G. Most participants reported being "old school" and preferred written materials when presented with information about hereditary cancer and genetic testing. Only six individuals preferred a video format stating that they were "visual learners". Additional quotes showing baseline understanding are included in Table 2.

Table 2. Baseline Cancer Information

| Prior Knowledge | Quotes |
|---------------------------------|---|
| Uncertainty with Susceptibility | <p data-bbox="646 972 1414 1188">“So. So you know, it's good to have genetic testing available so you "can kind of be proactive and see what you would need to do... I just know that my mom got hers done, and I was like, cool. But I didn't really know what happens with it. I assume it's just like, I think of, like, those science we learned, like biology.” -263697C</p> <p data-bbox="646 1230 1414 1446">“I know it's for my benefit. But being that I had ovarian cancer and I only have one son, I, I know that ovarian cancer and breast cancer are closely related and may get breast cancer... But I think if I had had a daughter instead because her chances were much greater, I would have gone through it.” -112798L</p> <p data-bbox="646 1488 1414 1661">“So that is a familial tendency is like around that because whatever I mean, what I kind of learned from before my doctor in particular, when my sister was diagnosed with pancreatic, he said it is not hereditary, although it's like there is a familial tendency.” -274036H</p> |

Table 2. (Continued)

| Prior Knowledge | Quotes |
|----------------------------|--|
| Uncertainty about Severity | <p data-bbox="646 270 1409 485">“Yeah, I've only heard about it in the sense of if there is a extremely rare disease in your family that you want to see, if it if it'll pass down to your children, but not in the sense of these every day diseases that people have that are can be hereditary, that we should probably be doing genetic testing for.” -297423J</p> <p data-bbox="646 527 1409 705">“I'm just I've known based off of demographic that I've heard that certain races and certain people are I've heard are like, you know, more susceptible to certain cancers and then just some that are hidden for a certain period of time come out a certain age.” -721641F</p> |
| Barriers | <p data-bbox="646 783 1409 890">“I think for me, I am more worrisome at the point like I haven't gotten to the point where I'm looking to take action...I was like, do I have to get tested?” -720249D</p> <p data-bbox="646 932 1409 1220">“Well. I'm going to be very honest with you. When I went to [redacted], some people did reach out and they wanted to do [genetic testing], and I was willing to do it.... I asked them if it was possible to coordinate [the blood draw] at the time that I had my infusion so that they could get extra whatever they wanted. But it was not possible. I had to go a separate time and have it done now. Throughout all of this, I was working at a school.” -112798L</p> <p data-bbox="646 1262 1409 1329">“Obviously, readily being readily available is a big thing. So any time conflicts can really get in the way.” -935041M</p> <p data-bbox="646 1371 1409 1581">“The only barrier would be and I think for most people it's just like, how much is this going to cost? Will my insurance cover it? I work for a good company and I have a good I have a good insurance plan. But my the currently for my situation, the insurance I have is a high deductible.” -433649K</p> |

After the video review, participants provided feedback that showed several perceived barriers had been addressed in the video. A majority of participants (10) expressed that the reason why genetic testing was important, and the possible preventative measures were what was

most important to them or stood out to them the most. All participants were able to understand the benefits of genetic testing which was one of the observed barriers. One participant stated: “I like seeing the different scenarios of the different characters and their ages and their how it affects their children.”- 92416I. Another participant stated: “The reasoning behind why different people would get the testing like that helps people relate, you know, depending on where their what situation they're in.”-297423J. Additionally, the same participant who had indicated concerns about privacy prior to viewing the video stated that these concerns had been addressed: “I really like that you included the privacy aspect of it because that's important to me...the GINA, so this one was protects people from workplace discrimination and health insurance discrimination. Yeah. Like, I didn't even think about that.” -92416I. The participant who discussed feeling uncertainty about not knowing about risk factors or how family history is helpful before viewing the video mentioned that this video had changed their view on genetic testing. This participant stated: “...it sounds like I may be [a candidate for genetic testing] ...I think just being aware of your family history is super important. So, it kind of opened my eyes to that for sure.” -825850G.

Main Themes Related to the Video

Emergent themes for the positive feedback category included: “Diversity”, “Good Pacing & Length”, “Good Format, Visuals & Graphics”, “Relatable”, “Benefits of Learning Risks”, and “Empowering”. Themes related to negative feedback included: “Slow Introduction”, “Formatting”; and the following themes were identified as improvements: “Need for Action Steps” and “Accessibility”. These categories and themes are described below along with illustrative quotes. Additional quotes supporting each theme can be found in Table 3.

Table 3. Main Themes Coded Based on Feedback with Representative Quotes

| Themes | Quotes |
|-------------------------|---|
| Diversity | <p data-bbox="521 310 1419 485">“I like that you gave like the examples regarding, like how like, it doesn't matter what age you are that's still informative and it helps to better understand your risk whether you have certain mutations or not. So it doesn't really matter what age you are, it's still beneficial.” - 193508A</p> <p data-bbox="521 527 1419 667">“But I did like the aspect that you're saying, like... different people, different backgrounds, what do they have in common? Like kind of get to it. So it gave that perspective, which I don't think you'll get in a pamphlet, you know,.” -92416I</p> |
| Good Pacing and Length | <p data-bbox="521 747 1406 888">“I think the length was right because in order to cover what you need to cover in a way for people to understand it, it needed to be that length. But when you show this video, you show it to people who are considering or you're using it.” -112798L</p> <p data-bbox="521 930 1406 1073">“I think that's a really good way that it's not too short. Like, it's not like a tiktok video or anything. It went just enough in depth and gave those offering to put the different perspectives of like the three different people.” -720249D</p> |
| Good Visuals & Graphics | <p data-bbox="521 1152 1406 1360">“I thought, like the artwork... the animation made it very helpful and interactive to follow as you were narrating. So I felt it was like I was able to feel like I followed it really well and understood it. And like I said, just how it was formatted and animations, the artwork really made it easy to follow. I liked how when you made the video.” - 433649K</p> <p data-bbox="521 1402 1406 1583">“Oh, I feel like it all is supposed to be there. I feel like it's all supposed to be there to explain how genetic testing actually works in, like, a simple beginning form. And then, I mean, some people might not like having the three different storylines, but for me, I thought it was really awesome.” -720249D</p> |
| Relatable/ Feels Real | <p data-bbox="521 1663 1406 1730">“...because, you know, the situation we're in is our mother has had breast cancer at a young age. Why should we care.” -433649K</p> <p data-bbox="521 1772 1406 1839">“Oh, no. Based on my own personal knowledge of, you know, of the medical field. It's very real.” -422277N</p> |

Table 3. (Continued)

| Themes | Quotes |
|--------------------------------------|---|
| Relatable/ Feels Real (Continued) | “I know the patients in this video were made up, but they're they're very real and relatable because when you said, oh, blah, blah, So 65-year-olds has ovarian cancer, I'm like, geez, my mom was like 66 when she got ovarian cancer. So very relatable for me.” -92416I |
| Benefits of Learning Risks | “... I also liked how when you're going through the family... the specific gene and you would show how they would get a 50% inheritance if they did get the gene or if they didn't get the gene. So I thought that was good... if you get the the genetic testing early enough based on that, you could really be more proactive and have access to therapies that can really improve the quality of life.” -263697C |
| | “I understood the risk factors and knowing and then preventative what you need to do... Like when you say you're more risk of those cancers and they do preventative for hysterectomy and getting all the breasts and everything...I know I have a cousin who did that. She was never diagnosed with cancer... when she learned that so she had these breakout tests and it was positive for whatever, she then she upped for taking out the whole ovary and the whole breast and everything...Yeah, it's a very good, very informative and very good information. And ideally what you're supposed to do at an early age and all. Yeah, I understand.” -274036 |
| | “...She has A, she has A, B, C, she has like a 50% chance, right. She can get tested to see if she has that mutation or not, Right...And I liked how you were going through the process. Like, Oh, if you have it now, you can get more screenings at younger age.” -433649K |
| | “And understanding it definitely was a learning experience for me... oh, it's like I even think about like colon cancer and ovarian cancer... I didn't think of those as being genetic, now I do...I feel like that's such a powerful thing to be able to know [family history], because then you're able to tell your providers... I mean to say push the doctors that maybe this should be looked into a little harder rather than just taking at face value because, I mean, that's I was like that. I was like, oh, I was like, now I think now I think about cancer.” -720249D |
| | “For me, that's kind of like the whole point of regular screening is to catch these things and they're going to start happening. And my understanding of cancer treatment is that when you catch something early. That there is almost no chance of you really succumbing to it.” -639828B |

Table 3. (Continued)

| Themes | Quotes |
|-------------------------------------|--|
| Empowering/ Overcoming Fears | <p>“But if there's something I can do to prevent it or, you know, then I want to know what I can do so they don't have to go through it.” - 112798L</p> <p>“I mean to say to push the doctors that maybe this should be looked into a little harder rather than just taking at face value...I was like, Wow, I feel like I have more of a way of being like, okay, looking at my family history coming from here and also the view on genetic counseling, I'm like, Okay, I hadn't thought about it for this. I've thought about it for like just for breast cancer or for other diseases, but never really truly for cancer other than breast cancer.” -720249D</p> |
| Negative Feedback & Improvements | <p>Slow Introduction “The only part that could have been sped up a little was like the beginning.”</p> <p>Formatting “I guess if I had to nitpick, it would be just the volume. Or I guess because some words weren't as clear, I felt as they could have been in the recording.”</p> <p>Need for Action Steps “I guess just the procedure of the genetic testing would be the only thing [to add]. Like just knowing what would you actually go into the office to do.”</p> <p>Accessibility “I would put. captions, so it could be more accessible.”</p> |

Positive feedback

Positive feedback consisted of five major themes. First, several individuals described how they appreciated the diversity of individuals within the story in terms of age, race/ethnicity and circumstances. For example, one participant stated, “Well, I like the way the information was presented in the different phases and that you selected men, women with different types of cancer. And how. It affected each one of them in a different way, but it helped them.” -112798L

Next, several individuals described that the pacing and length of 7 minutes and 36 seconds was sufficient in providing the intended information, but not too long. One participant said: “I

thought it was a good length. I didn't think about cutting anything out. I thought everything had good flow because I'm in. I'm also like, just because I may know it doesn't mean the other person may know it.” -443649K. All participants, even those who initially stated they preferred written educational materials over a video or narrative formative, shared views that this was the best format to present this type of information. Additionally, all participants enjoyed the visuals and graphics of the video. One participant noted: “I like the presentation of it. It was nice and bubbly, so it didn't make me feel about, like, droll and dark things in the health industry. So that was good.” -721641F. Several participants stated that the overall storyline was very real. Two participants were able to directly relate to the characters. For example, one participant stated: “I'm kind of like Selena or what was her name, you know? Yeah, yeah. It helped, like, relate to it where maybe someone is older and has cancer and they want to pass on the knowledge for their kids or whatever it may be.” -92416I. Several participants noted the benefits of testing and reported how it helped in overcoming fears of genetic testing: “Yeah, because I came in not really informed and then now, I'm, I'm more so comfortable with the idea of it, and I don't think that's something that should be afraid of. If you have necessarily had anybody that had cancer is more so just getting over the mental barrier of the trauma of what happened, you know?” -721641F. One participant commented on how the video addresses health disparity and may be beneficial for minorities as a group: “I'm glad that you're bringing awareness to it so that black people, minorities, but black people especially, they really need to do this because I know because of racism and all this other stuff, we have like a really complicated relationship with medicine, but, you know, you want to really have the best quality of life.” -263697C.

Negative Feedback and Improvements

Although overall patient commentary was overwhelmingly positive, negative comments were raised. For example, all three participants who reported having prior knowledge of genetic testing did not like the introduction of each individual in the story because they felt like that slowed things down. The overwhelming majority of participants expressed the need for action steps after watching the educational video. Participants verbalized wanting to learn more about personalized questions which included health insurance testing coverage (“I wonder how this is fit under the Affordable Care Act and how if like if there's something under it that health insurance has to cover for certain reasons.” -720249D), logistics of obtaining DNA (“How do you actually take like, what is genetic testing in the sense of like what is the test actually? Is it like a blood test?” – 297423J), and the type of information they would receive if they pursue genetic testing (“Yeah. Like if you have this BRCA 2, did you go from like a 1% chance of getting cancer to like a 1.5, or is it just. Or is it a lot more than that?”-639828B).

After the three additional “next step” slides were included to the video, all the participants (7) who had evaluated these additional slides stated that these were appropriate additions to the video. One participant agreed that the action steps are “Very important information to dish out to people, including me.” -274036H. Another participant stated, “I think that’s fine, it’s really going to be dependent on the person that’s watching the video.”- 935041M.

In addition to wanting more information, one participant provided feedback they felt would improve accessibility for the video: “I would put. Like captions, so it could be more accessible. Like at the bottom” -263697C. Three participants recommended shorter story segments that focus on each individual character to make it more “social-media friendly”. For example, one participant asked: “Is there a way that you can make it like a real on Instagram, like

on Instagram and just let it go?” -263697C. Formatting issues were also identified which included a few grammatical errors, unclear quality of the audio, and small issues with pictures overlapping the written text, though these were fixed as they were identified.

CHAPTER 4: DISCUSSION

We developed and evaluated an educational video to help increase levels of awareness and interest in genetic testing for hereditary cancer among minority populations. We were able to recruit a diverse group of participants with a personal or family history of cancer who are part of our target audience to gather feedback on our educational video and determined the video successfully addressed several perceived barriers to pursuing genetic services among minority populations such as such as cost, preventative screenings, and privacy concerns but did not address enough of their specific questions related to their own personal insurance and costs. This project was one of the first to utilize the storytelling framework proposed by Brooks et. al., to create a storytelling knowledge translation format for healthcare services regarding genetic testing for hereditary cancer. Other studies on educational narratives have focused on specific cancer types and were targeted to a single demographic. To our knowledge, this is the first type of educational, narrative story about genetic testing for multiple types of hereditary cancer that targets a diverse audience.

Feedback from the interviews showed that participants were often unaware of genetic testing initially but were able to explain key concepts about the possible benefits of genetic testing for hereditary cancer. This suggests that utilizing the story-telling format may help individuals understand key information. This aligns with previous studies that show use of storytelling as knowledge translation can help improve awareness and knowledge among patients (Park et. al., 2021, Brooks et. al., 2022). Surprisingly, participants mentioned that the length of the educational video, which was 7 minutes and 36 seconds long, was acceptable and may be a

necessary amount of time to cover everything they thought was important to learn, which included: the reason why people would get genetic testing what genetic testing is, what hereditary cancer is, how genetic testing helps individuals with cancer predisposition, the costs, protections, and process of pursuing genetic testing. The three participants who felt the length of the video seemed too long, already had an above average knowledge about genetic testing for hereditary cancer and one had interacted with a genetic counselor to discuss and decide about whether to have genetic testing. This finding suggests that participants who have already had a basic understanding of genetic testing for hereditary cancer wanted to get to the main points of the educational video quicker and were less positive about the storytelling narrative even though they indicated this type of animated video was the best format for presenting this information.

Overall, the present video messaging, appeal, and engagement through the use of video story-telling shows promise in conveying the benefits of genetic testing for hereditary cancer and reducing the fears of starting the genetic testing process. Some of the strengths of this evaluation include the participant population of diverse individuals that provided far more positive than constructive feedback. Another strength of this project is the clear and deliberate method used to develop the educational material, evaluation questions to assess feedback, and data supporting benefits to the individuals. This video addresses some of the missing elements of other narrative story videos including a straightforward title involving genetics and hereditary cancer as well as a focus on preventative treatment options (Hurtado-de-Mendoza et al., 2020). Despite the positive feedback and achievement of theoretical saturation, such a small study does not allow us to determine whether the educational video would be acceptable to all minority populations. Furthermore, the video has not been translated to other languages at this point. Additionally, although it shows promise, evidence for the effectiveness of this video is insufficient because we

did not assess whether it was enough to motivate participants to take any actions such as talking to their healthcare provider or pursuing genetic counseling or testing. Participants did show improvement in knowledge about benefits of learning about hereditary cancer risks as well as decrease in overall fears about genetic testing, yet these improvements alone may be insufficient in motivating participants to take action. However, the additional material about next steps people can take to learn more about or get genetic testing was well received by the 7 participants who saw this addition, and this may improve the likelihood that they will take action because they had fewer unanswered questions. However, questions that are specific for each individual's health insurance or circumstances cannot all be addressed in this type of video, though the hope is that they will talk to their provider or a genetic counselor. Future directions include a larger evaluation, inclusive of additional minority groups to ensure that this resource is broadly effective. Ideally a longitudinal study would follow-up to assess whether viewing the story led to increased genetic counseling or testing access. Future interventions may benefit from implementing a combination of storytelling as knowledge translation in addition to providing concrete "next steps" for participants.

In conclusion, results from this evaluation show that our story-telling approach is highly acceptable and shows promise for increasing awareness and knowledge about genetic testing benefits. After additional efficacy testing this could easily be shared on social media and hopefully would be able to reach individuals who may not be aware of the potential benefits of genetic testing for hereditary cancer.

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APPENDIX A:

INTERVIEW GUIDE QUESTIONS BY EXTENDED PARALLEL PROCESS MODEL

Introductory Questions:

- Are you ok with me recording our discussion so I can go back later and make sure that I didn't miss anything in our conversation?
- What questions do you have before we begin?

Baseline Cancer Information Questions

- What, if anything, have you heard or read about hereditary cancer(s) in general or genetic testing for hereditary cancer(s)?
- What is your interest level in this topic?

Will ask those who have heard of hereditary cancer:

- What else do you know about genetic testing for hereditary cancer?
- What did you think of the information you found (or were given)?
 - Were there specific types of information that you were looking for?
 - Would you have preferred to have the information given to you in a different way?
 - Do you feel you have enough information about hereditary cancer and genetic testing?
 - i. What kinds of questions do you still have – if any?
- How did you find out about genetic testing?
 - Who have you talked to about hereditary cancer or genetic testing?
 - Do you know of anyone who got genetic testing?
 - Would you want genetic testing? Why or why not?
 - i. Can you tell me a little bit more about what has or might stop you from getting genetic testing?

If they do not have any information about hereditary cancer:

- What comes to your mind when I say genetic testing for hereditary cancer?
- How interested are you in learning more about it?
- How would you like to be given information about hereditary cancer and genetic testing? (Examples: website, brochure, etc.)
 - What would you like to know?

- Who would you trust to give you the information?
- Do you have any concerns about genetic testing for hereditary cancer?

Material Feedback Questions

- Overall, what did you think about this resource?
 - Were there specific things you liked?
 - Were there specific things you disliked?
 - What about the video stood out to you the most?

(will probe about: storyline, information, graphics etc.)

- How hard or easy was it to understand?
 - What made it hard or easy?
- What information did you feel was most important?
- What information may not be needed?
- What information may be missing?
- How did this video change your view(s) [if at all] on genetic testing?
- Did it feel realistic?

Check in Would you prefer what I presented with more animation or is it fine as it is?

- Would you prefer a simple, informational fact sheet?
- What else would you like to share about the video?
- Did your interest level go up or down as the information kept going?

Thank you so much for your feedback and participation, your contribution to this evaluation will really help us give some insight on how we can people to learn more about genetic testing for hereditary cancer.

APPENDIX B:

EVALUATION INFORMATION SHEET

Evaluation of Educational Materials on Inherited Cancer Information Sheet

Title: Evaluation of Educational Materials on Inherited Cancer

Overview: You are being asked to share your opinions about a cancer educational video. The information in this document should help you to decide if you would like to participate.

Participation: You are being asked to share your opinions about a 7-minute audio-visual tool about genetic testing for hereditary cancer because you have either a personal or family history of cancer and have not previously had genetic testing for inherited cancer risk.

Staff: This evaluation is being led by Celestyn Angot, a Genetic Counseling Graduate Program student at the University of South Florida, and her program director, Dr. Deborah Cragun.

Purpose: We want to get opinions from multiple people in order to help us improve the material and ensure the 7-minute educational tool is understandable and acceptable.

Procedures: This evaluation will consist of a one-time interview between yourself and Celestyn that is expected to last about 20 to 30 minutes. You will be asked about your knowledge and opinions on the 7-minute audio visual designed for people who have not had genetic testing for hereditary cancer. There are no right or wrong answers. With your permission, the interview will be recorded so that Celestyn can listen to it again and take and/or verify her notes.

Benefits, Compensation, and Risks: We do not know if you will receive any benefit from your participation.

This evaluation is considered minimal risk. The main risk is the possibility of loss of confidentiality. However, very limited personal data is being obtained and only Celestyn will have your contact information (name and email). Your contact information will be kept separate from the recordings and interview notes. All data will be stored on USF's secure Box Platform that only Celestyn and Dr. Cragun will be able to access.

Contact Information: If you have any questions, concerns or complaints about this evaluation, call Celestyn Angot at 786-271-2620, or email Celestyn at cangot@usf.edu.

APPENDIX C:

IRB EXEMPTION LETTER



NOT HUMAN SUBJECTS RESEARCH DETERMINATION

November 29, 2022



Dear Celestyn Angot:

On 11/23/2022, the IRB reviewed the following protocol:

| | |
|---------|--|
| IRB ID: | STUDY005041 |
| Title: | Evaluation of Educational Materials on Inherited Cancer Targeted to Minority Populations |

The IRB determined that the proposed activity does not constitute research involving human subjects as defined by DHHS and FDA regulations.

IRB review and approval is not required. This determination applies only to the activities described in the IRB submission. If changes are made and there are questions about whether these activities constitute human subjects research, please submit a new application to the IRB for a determination.

While not requiring IRB approval and oversight, your project activities should be conducted in a manner that is consistent with the ethical principles of your profession. If this project is program evaluation or quality improvement, do not refer to the project as research and do not include the assigned IRB ID or IRB contact information in the consent document or any resulting publications or presentations.

Sincerely,

Andi Encinas
IRB Manager