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Healthcare Predictors of Information Dissemination About Genetic Risks

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Abstract

Objectives: Despite the benefits of genetic counseling and testing (GCT), utilization is particularly low among African American (AA) women who exhibit breast cancer features that are common in BRCA-associated cancer. Underutilization is especially problematic for AA women who are more likely to die from breast cancer than women from any other race or ethnicity. Due to medical mistrust, fear, and stigma that can be associated with genetic services among racial/ethnic minorities, reliance on trusted social networks may be an impactful strategy to increase dissemination of knowledge about hereditary cancer risk. Informed by the social cognitive theory, the purpose of this study is to determine: 1) which AA patients diagnosed with breast cancer and with identified hereditary risk are sharing information about hereditary risk with their networks; 2) the nature of the information dissemination; and 3) if personal GCT experiences is associated with dissemination of information about hereditary risk.

Methods: Among consented participants (n = 100) that completed an interview administered using a 202-item questionnaire consisting of open- and closed-ended questions, 62 patients were identified to be at higher risk for breast cancer. Descriptive statistics, bivariable chi-square, Pearson's exact tests, and regression analyses were conducted to examine differences in characteristics between high-risk participants who disseminated hereditary risk information and participants who did not.

Results: Among high-risk participants, 25 (40%) indicated they had disseminated information about hereditary risk to at least one member in their family/friend network and 37 (60%) had not. Receipt of both provider recommendations and receipt of GCT services was associated with greater odds of disseminating information about hereditary risk with networks, OR = 4.53, 95%CI [1.33, 15.50], p = .02.

Conclusion: Interventions that increase self-efficacy gained through additional personalized knowledge and experience gained through provider recommendations and by undergoing GCT may facilitate information dissemination among social/familial networks.

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Introduction

African American (AA) women are more likely to die from breast cancer than women from any other race or ethnicity and exhibit breast cancer features that are common in *BRCA1*-associated cancers such as younger onset, high tumor grade, and negative hormone receptor status.[1-5] Cancer genetic risk assessment for breast cancer identifies patients with personal or family histories of cancer, family members with known harmful pathogenic variants, or ancestry associated with harmful pathogenic variants.[6] The United States Preventive Task Force (USPSTF) currently recommends that primary care providers incorporate genetic risk assessment into routine care and that women with identified increased risk for breast cancer receive genetic counseling and potentially genetic testing if indicated.[6] Genetic counseling and genetic testing (GCT) are crucial preventive services that can reduce mortality from breast cancer associated with the *BRCA* genes and non-*BRCA* genes by enabling those at risk to make informed choices about preventive and early detection interventions.[7-9] Genetic counseling guides patients through the genetic testing process and is conducted by a trained counselor who assesses personal and familial risk for cancer, explains benefits and limitations of genetic testing, helps patients understand test results and make informed decisions, identifies strategies for risk reduction, and identifies blood relatives at high-risk for cancer.[10] Genetic testing allows for the detection of *BRCA* and non-*BRCA* germline pathogenic variants to identify individuals with hereditary breast cancer syndromes.[10]

Despite the benefit of genetic risk assessment and GCT services, utilization is particularly low among AA women. Underutilization of GCT services is due to multi-level *modifiable* factors such as lack of: provider recommendations, perceived benefits, access to and awareness of genetic services, and cost.[11-26] For women with breast cancer, the rate of *BRCA1/2* pathogenic variants is comparable regardless of race – however, AA women with a personal history of breast cancer are 44% less likely to have genetic testing recommended by a provider and are 56% less likely to have genetic testing performed than non-Hispanic White (NHW) women.[7,12,27] Providers are less likely to refer AA women as compared to White women due to discriminatory biases and perceived concerns about costs, level of interests, age, and rates of variants of unknown significance.[7,16,27-29] Importantly, research shows strong associations between provider recommendations for genetic services and actual uptake among AA women and studies have shown that high-risk AA and Latino patients exhibit high interest in learning about risk assessment results from primary care providers.[7,16,29-31]

Additionally, White patients are more likely to be referred for genetic testing due to family history, whereas AA, Latino, and Asian patients are more likely to be referred due to personal history, further perpetuating missed opportunities for early detection and prevention in minority populations.[28]

Personal GCT experiences play an important role in patient outcomes – they also contribute to community awareness about the potential benefits of knowledge about hereditary risks and associated services. Specifically, patients who receive provider recommendations and undergo GCT do not *only* have hereditary risks for breast cancer, but they *also* represent trusted community members, friends, and family members. These patients may be impactful for increasing information dissemination about hereditary cancer risk, as they can convey information through the salient, appealing lens of their lived experiences. These testimonials may mitigate, in part, medical mistrust, fear, and stigma that can be associated with GCT services among racial/ethnic minorities. Thus, we propose that patient GCT outcomes are not only important for outcomes – but also for enabling patients with hereditary risks to become change agents in their networks. Characterizing such patient-driven awareness about hereditary risk and associated services is crucial in the era of precision medicine, as it opens venues for future patient- and community-driven precision prevention and detection. For example, patient-driven information dissemination may be particularly dependent on experiences with GCT and GCT results.

Theoretical Framework

To understand the role of personal GCT experiences in patient-driven information dissemination about hereditary risk, we leverage the well-established social cognitive theory (SCT). Below, we provide a brief summary of SCT and then apply its principles within the context of patients' personal GCT experiences and patient-driven information dissemination about hereditary risk.

Social cognitive theory postulates that an individual's feelings and behaviors influence and are influenced by personal and environmental factors.[32,33] SCT comprises 6 constructs that motivate behaviors: (1) reciprocal determinism – dynamic interaction between an individual, behavior, and environment; (2) behavioral capability – knowledge and skill to perform behavior; (3) expectations – anticipated results from taking action; (4) self-efficacy – confidence in ability to perform a behavior and overcome barriers; (5) observational modeling – learning through the experiences of credible others; (6) and reinforcements – internal or external rewards. Self-efficacy is

the confidence in the ability to take action and overcome barriers to engage in a behavior. Reciprocal determinism is the dynamic interaction between an individual, a behavior, and the environment.[32,33]

We assert that patients' GCT behaviors and experiences iteratively build upon personal and environmental factors. Receiving a provider recommendation for genetic risk screening and services increases GCT uptake by enhancing a patient's awareness about their hereditary risks, GCT services, and how to access them (provider-driven behavioral capability). Receiving a recommendation to use GCT services from a reliable, expert source may improve positive expectations (e.g., awareness of risk; eligibility for risk-stratified care), knowledge, and awareness, which in turn may enhance the patient's self-efficacy and, ultimately, receipt of GCT services.

Patients' personal GCT experiences, especially their results, are not only endpoints – we posit that they also serve as the beginning of patients becoming change agents. First, we posit that patients' personal experiences with provider recommendations GCT may compel and empower patients to share information about hereditary risk with their familial and social networks. Such dissemination aligns with past work that has suggested AA patients diagnosed with breast cancer can feel motivated to become agents of change and provide informational support to other AA women, especially if they feel supported during their own personal journeys.[34,35] In relation to GCT services, AA breast cancer patients with hereditary risks may be particularly effective in encouraging others to become aware of their risks for breast cancer (e.g., via risk assessments) and advocate for risk-optimized cancer care (e.g., eligibility for chemoprevention, age to initiate screening). Associations may be stronger for patients with confirmed pathogenic variants, for whom there may be particularly greater awareness of risk-based care (e.g., MRIs) and resources.

Because of patient-driven health promotion, network members may be compelled to seek additional knowledge about hereditary risk and associated services by witnessing actions and acknowledging attitudes of credible, trusted sources with relevant personal lived experiences (patient-driven behavioral capability). Redeeming the potential benefits of engaging in GCT services (e.g., enhanced screening, targeted therapies) may reinforce the utility of genetic risk assessment for patients and their networks. Thus, patients' personal GCT experiences (e.g., provider recommendation, receipt of services) may have more broad community impacts, beyond patient health outcomes, than have been previously measured.

Current Study

Understanding if and the extent to which such patient-driven dissemination happens can help guide future interventions that strategically amplify patients' efforts to share information and address health disparities. Guided by our theoretical framework, our study focuses on 62 AA patients diagnosed with breast cancer with hereditary risk and focuses on 3 objectives. First, we examine demographic and clinical characteristics to determine *which* AA patients diagnosed with breast cancer and with identified hereditary risk are sharing information about hereditary risk with their networks. Second, we describe the nature of the information dissemination, including information on frequency of dissemination, relationship types and open-ended data on conversations about hereditary risk. Third, we examine if personal GCT experiences is associated with dissemination of information about hereditary risk.

Methods

Data Collection Procedures

All data were derived from the Offering African American Survivors Increased Support (OASIS) cross-sectional study. Data collection procedures for this study were described in detail previously.[36,37] In brief, hospital staff were trained to review medical records to identify patients who were eligible to participate in this study. Eligibility criteria included: (1) breast cancer patient at least 18 years of age or older, (2) self-identified as African American female and a breast cancer patient at 1 of the 3 hospitals involved in this study, (3) and participated in the Patient Navigation in Medically Underserved Areas Study, a randomized controlled trial of patient navigation.[36-43] This pilot study had a target sample size of 100 patients, given our sampling frame (i.e., PNMUA patients who were AA and diagnosed with BC (n = 173), response rates from past research with Chicago-based AA BC survivors (56%), and a priori power analyses regarding the effect of navigation on patient-driven dissemination of breast health information at large.[36,37] Invitation letters and flyers were given to participants who met the eligibility criteria. Institutional Review Boards at each participating institution approved the study, which took place between March 2019 and June 2020.

Eligible breast cancer patients who consented to study participation were enrolled by hospital staff. Participants gave hospital staff permission to share their contact information with trained research personnel. Members of the research team scheduled one-on-one interviews (telephone or in-person) with each participant. Interviews consisted of open- and closed-ended questions from a 202-item questionnaire and lasted 60 to 90 minutes. Participants who completed the interview were provided with a $75 stipend. Survey results were manually entered into the Qualtrics[44] secure, online survey application.

The current study focused on AA patients with hereditary risk for breast cancer. Specifically, we include 62 patients from the OASIS study who met the criteria for Genetic Counseling (GC) referral and Genetic Testing (GT) based on personal characteristics adapted from the National Comprehensive

Cancer Network (NCCN) Genetic/Familial High-Risk Assessment. The NCCN assessment is an "assessment of pathogenic or likely pathogenic variants associated with increased risk of breast, ovarian, and pancreatic cancer and recommended approaches to genetic testing/counseling and management strategies in individuals with these pathogenic or likely pathogenic variants."[45]

Measures

Demographics. Behavioral Risk Factor Surveillance System survey items were used to obtain the following demographic information: age, relationship status, education, household annual income, and insurance status.[46,47]

Clinical Characteristics. Clinical characteristics assessed include: established primary care provider (yes, no), mode of cancer detection (i.e., screening; symptomatic/presented with lump, breast pain, or discharge from nipple), years since diagnosis, treatment variables (i.e., for surgery, radiation therapy, chemotherapy, hormone therapy), receipt of multiple types of treatment (yes, no), clinical trial participation, and receipt of navigation services (navigated, not navigated).[48-50]

Personal GCT Experiences. Assessed personal GCT experiences were based on self-report data. We used self-report data for the following experiences: GCT recommendation (any, none) defined as any provider recommendation for either GC or GT; GCT receipt (any, none); and self-reported pathogenic variant confirmation (yes, no). Given our limited sample size, we created a composite variable to reflect personal GCT experiences, wherein patients were classified as: (1) not having received a provider recommendation for GCT services; (2) having received a provider recommendation for GCT services only; and (3) having received a provider recommendation for GCT services and received GCT services. We describe patients by these categories in Table 1. Unfortunately, due to our small analytic sample, we were unable to incorporate information about pathogenic variant confirmation in this variable. Further, due to our small sample, we use a dichotomous variable in inferential analyses, wherein patients are classified as (1) having received a provider recommendation *and* GCT services; and (2) having not received both provider recommendation *and* GCT services.

Information Dissemination About Hereditary Risk. Information dissemination about hereditary risk was first assessed in terms of whether participants shared any information about hereditary risks within their networks. Given our frequency distribution (Table 2), our outcome variable was dichotomized. Participants were classified as having disseminated information to at least 1 network member or not having disseminated information to any network members. We also collected information from participants about the relationship to network members and network members' subsequent GCT behaviors. Dissemination behaviors related to breast cancer risks were also assessed with an open-ended question, "What information have you given them [individuals' with whom information was shared] to help them understand their potential risk for getting breast cancer?"

Analysis

We first examined missingness and descriptive statistics for demographic, clinical, and personal GCT characteristics. Descriptive statistics are reported as counts (%) (Table 1). Bivariable chi-square, Pearson's exact tests, and regression analyses were conducted to examine differences in these characteristics between patients who disseminated and patients who did not disseminate information about hereditary risk. These analyses further informed covariate selection for subsequent models.

Descriptive statistics were calculated to describe relationship types among networks with whom patients disseminated information and whether the network member who received information utilized GC or GT. Open-ended questions were subsequently analyzed using inductive content analysis methods. Interviewers transcribed patient responses verbatim. Two coders reviewed each transcript using memos to capture participants' expressions. Memos were refined and used to develop initial codes that were used to code transcripts. Each transcript was independently coded by each coder. The research team examined coded data and discussed patterns among concepts to identify salient themes. Data discussion and reflection among the research team were embedded throughout the analysis process.

Finally, crude and adjusted logistic regression models were conducted to examine whether personal GCT experiences were associated with information dissemination about hereditary risks with at least 1 person in their social networks. Adjusted models included covariates based on bivariate analyses (Table 1).

Results

Characteristics of Study Participants

Of the 173 eligible patients who were invited to participate, 100 patients were enrolled, consented, and completed surveys (58% response rate). Of the 100 patients, 62 were identified as having hereditary risks, based on the NCCN screener noted above. These 62 patients comprised our final analytic sample (Table 1).

Overall, our sample had relatively low missingness, except for income (8%). With regard to demographic characteristics (Table 1), the majority of participants were 50-74 years old at the point of study participation (82%), single/not in relationships (57%); had more than a high school education (77%); had private insurance (77%); and over half had an income $\leq$ $50,000 (67%). With regard to clinical characteristics, the majority of participants reported having a primary

Table 1. Demographic, clinical, and personal Genetic counseling or genetic testing characteristics among patients who disseminated and did not disseminate information about hereditary risk to networks.

		No dissemination N = 37	Disseminate to at least 1 person N = 25	Total (n = 62)	Disseminate vs not differences
	Missing n	n (%)	n (%)	n (%)	*P*-value
Demographic characteristics					
Age[a]	0				**.02**
50-74 years old		**29 (78%)**	**22 (88%)**	**51 (82%)**	
75+ years old		**8 (22%)**	**3 (12%)**	**11 (18%)**	
Relationship status	0				.10
In a relationship		35% (13)	14 (56%)	27 (44%)	
Single		24 (65%)	11 (44%)	35 (57%)	
Education[a]	0				**.003**
≤High school		**11 (30%)**	**3 (12%)**	**14 (23%)**	
>High school		**26 (70%)**	**22 (88%)**	**48 (77%)**	
Income[a]	5				.17
≤$50,000		24 (73%)	14 (58%)	38 (67%)	
>$50,000		9 (27%)	10 (42%)	19 (33%)	
Private insurance	0				.70
No		13 (35%)	10 (40%)	23 (37%)	
Yes		24 (65%)	15 (60%)	39 (63%)	
Clinical characteristics					
Primary care provider	0				.56
No		1 (3%)	2 (8%)	3 (5%)	
Yes		36 (97%)	23 (92%)	59 (95%)	
Type of detection	0				.97
Screening		22 (60%)	15 (60%)	37 (60%)	
Symptomatic		15 (41%)	10(40%)	25 (40%)	
Age at first BC diagnosis[a]	0				**.003**
42-50 years old		**8 (22%)**	**11 (44%)**	**19 (31%)**	
50-86 years old		**29 (78%)**	**14 (56%)**	**43 (69%)**	
Years since latest BC diagnosis	0				.92
2-7 years		24 (67%)	12 (48%)	36 (58%)	
8 years		13 (35%)	13 (52%)	26 (42%)	
Navigation	0				.80
No		18 (49%)	13 (52%)	31 (50%)	
Yes		19 (51%)	12 (48%)	31 (50%)	
Surgery	0				.64
No		3 (8%)	1 (4%)	4 (7%)	
Yes		34 (92%)	24 (96%)	58 (94%)	
Radiation	0				.32

(continued)

Table 1. (continued)

		No dissemination N = 37	Disseminate to at least 1 person N = 25	Total (n = 62)	Disseminate vs not differences
No		18 (49%)	9 (36%)	27 (44%)	
Yes		19 (51%)	16 (64%)	35 (57%)	
Chemotherapy	0				.57
No		18 (49%)	14 (56%)	32 (52%)	
Yes		19 (51%)	11 (44%)	30 (48%)	
Hormone therapy	0				.10
No		18 (49%)	7 (28%)	25 (40%)	
Yes		19 (51%)	18 (72%)	37 (60%)	
Clinical trial participation	0				.08
No		37 (100%)	23 (92%)	60 (97%)	
Yes		0 (0%)	2 (8%)	2 (3%)	
Multiple primary cancer treatments	0				.89
No		4 (11%)	3 (12%)	7 (11%)	
Yes		33 (89%)	22 (88%)	55 (89%)	
Personal GCT experiences					
Provider recommended either GCT[b]	0				**<.0001**
No		**26 (70%)**	**5 (20%)**	**31 (50%)**	
Yes		**11 (30%)**	**20 (80%)**	**31 (50%)**	
Composite GCT experiences[c]	0				
Not having received provider rec or GCT		**25 (70%)**	**5 (20%)**	**31 (50%)**	**<.0001**
Having received provider rec only		**3 (8%)**	**4 (16%)**	**7 (11%)**	
Having received both recommendation + GCT services		**8 (22%)**	**16 (64%)**	**24 (39%)**	
Genetic counseling outcomes					
Results confirmed pathogenic variant	0				**.004**
No		**6 (75%)**	**2 (14%)**	**8 (36%)**	
Yes		**2 (25%)**	**12 (86%)**	**14 (64%)**	

Notes. GC = Genetic Counseling. GT = Genetic Testing. GCT = Genetic counseling or genetic testing. he signficance level was set as $P \leq .05$.
[a]Variables analyzed continuously, but depicted categorically to facilitate interpretability.
[b]Recommendation resulted from a patient discussion with the provider regarding family history and/or personal cancer history.
[c]Composite GCT variable classifies patients as: (1) having received no recommendation; (2) having received only a provider recommendation for GCT services; and, (3) having received a provider recommendation for GCT services and having received GCT services.

Table 2. Relationship Types and Genetic counseling or genetic testing Utilization Outcomes among Network Members who Received Information about Hereditary Risk from Participants (n = 25).

		Total (n = 25)
	Missing n	n (%)
Total # of network members who received information	0	
1 network member		8 (29%)
2-3 network members		6 (25%)
4+ network members		11 (46%)
Relationship type to network members[a]	0	
First degree female relatives		18 (72%)
Family, including first degree female relatives and other relatives		19 (76%)
Friends		5 (20%)
Reported that at least 1 network member received GCT	0	
No		20 (80%)
Yes		5 (20%)

Notes. GC = Genetic Counseling. GT = Genetic Testing. GCT = Genetic counseling or genetic testing.
[a]Frequencies are not mutually exclusive, but rather note the proportion of participants who recommended GCT to first degree relatives, family, and friends.

Table 3. Odds of Disseminating Information About Hereditary Risks by Experiences With Provider Recommendations and Genetic counseling or genetic testing Services.

Predictor	OR	95% CI		*P*-value
Crude models (n = 62)				
Composite GCT Experiences[a]				
Not having received both recommendation + GCT services	**REF**	**REF**	**REF**	**REF**
Having received both recommendation + GCT services	**6.44**	**2.08**	**19.97**	**.001**
Adjusted models (n = 62)[b]				
Composite GCT experiences[a]				
Not having received both recommendation + GCT services	**REF**	**REF**	**REF**	**REF**
Having received both recommendation + GCT services	**4.53**	**1.33**	**15.50**	**.02**
Age (continuous)	1.01	.91	1.13	.30
Education (continuous)	1.60	.98	2.62	.06
Age at first diagnosis (continuous)	1.01	.91	1.13	.81

Notes. GC = Genetic Counseling. GT = Genetic Testing. GCT = Genetic counseling or genetic testing.
[a]Recommendation resulted from a patient discussion with the provider regarding family history and/or personal cancer history.
[b]All models adjusted for age, education, and age at diagnosis.

care provider (95%); had their breast cancer detected via screening (60%); were diagnosed when 50 years or older (69%); were diagnosed within the past 7 years (58%); and had multiple types of primary treatments (89%). Only 4% reported having participated in clinical trials.

Which AA patients Are Sharing Information About Hereditary Risk?

Twenty-five (40%) patients indicated they had disseminated information about hereditary risk to at least 1 member in their family/friend network and 37 (60%) had not disseminated any information about hereditary risk. Women who disseminated information were younger (P = .02), were more educated (P = .003), and were more likely to be diagnosed with breast cancer before they were 50 years old (P = .001) than women who had not disseminated information.

Participants who disseminated information were more likely to self-report having been personally recommended for GCT (80% vs 30%, $P < .0001$) and being more likely to report having received GCT after the recommendation (64% vs 22%, $P < .0001$) than patients who did not disseminate information. Further, participants who disseminated information about hereditary risk were more likely to have a confirmed pathogenic variant than participants who did not disseminate information (86% vs 25%, P = .004). To note, this bivariable analysis only compared the role of confirmed pathogenic variants among participants who received genetic testing (n =

22). Participants who did not receive genetic testing (n = 40) could not provide information regarding a confirmed pathogenic variant.

What Is the Nature of Information Dissemination?

Table 2 describes the number and relationship types of individuals with whom participants shared information about hereditary risk and whether those individuals received GCT, based on participants' self-report data. Notably, among the 25 participants who shared information, 17 participants disseminated information to more than 1 network member and 18 participants specifically disseminated information to first degree female relatives. Five reported that at least 1 of their network members received GCT.

Patients' open-ended responses about dissemination corresponded well with our descriptive findings in Table 2. When asked what information was shared with social networks to help them understand their potential risk of getting breast cancer, participants emphasized the importance of sharing information with their children. Genetic risk was specifically discussed in the context of recommending breast cancer screening to their daughters and educating their sons about breast cancer. However, few women reported discussing genetic risk assessment or GCT with their children.

Personal GCT Experiences and Information Dissemination About Hereditary Risk

Next, we examined if personal GCT experiences – specifically, receiving both provider recommendation and GCT services - was associated with odds of disseminating information about hereditary risk to at least 1 person in participants' social networks (Table 3). Given our small sample, we compared dissemination across patients who had received *both* provider recommendation and GCT services (n = 28) relative to other participants who did *not* receive *both* provider recommendation and GCT services (n = 38). Adjusted models included the following covariates, based on Table 1 and bivariate analyses: age, education, and age at diagnosis.

As shown in Table 3, receipt of *both* provider recommendations about GCT services was associated with greater odds of disseminating information about hereditary risk with network members, OR = 4.53, 95%CI [1.33, 15.50], $P = .02$. There was also a statistically non-significant association between education and information dissemination (OR = 1.60, 95%CI (.98, 2.62), $P = .06$).

Discussion

Our study clarified (1) which AA patients with hereditary risks were likely to share information about hereditary risk; (2) the nature of the dissemination; and (3) the association of personal GCT experiences and dissemination. AA patients with hereditary risks who received both provider recommendations and GCT services were more likely to disseminate information about hereditary risks compared to other patients. Our study is aligned with previous studies that have clearly demonstrated that provider referrals are strongly associated with GCT utilization.[7,12,16,25,29,51] However, our study provides expanded insight via a preliminary framework and pilot data for understanding how patient GCT experiences may impact familial health, in addition to patient health outcomes.

A number of factors have been shown to motivate communication about hereditary risks, including: general sense of responsibility toward family members, a desire for relatives to be tested, and emotional support.[52,53] However, the majority of interventions examining dissemination of knowledge and testing family members of those identified with a pathogenic variant (i.e., cascade testing) have been conducted with primarily NHW populations.[54] Dissemination of health information among racial/ethnic minorities may be even more prevalent due to cultural norms and beliefs, racialized histories, and societal experiences.[55] For example, previous research shows that the well-being of breast cancer survivors who identify as AA is tied to a sense of reciprocity in giving back to and sharing knowledge with their social networks; that different forms of social support often translate into personal, interpersonal, and community advocacy for others; and that information sharing with networks is linked to a sense of responsibility and collective experience.[35,55,56] Thus, increasing the capacity for, quality, and frequency of patient GCT experiences may not only lead to better outcomes – but together, may lead to broader community impact on knowledge about hereditary risk and GCT services. Our study is among the first to suggest that intervention strategies aimed at mitigating racial breast cancer mortality disparities should leverage patients' medical lived experiences to broadcast knowledge about hereditary risk and GCT services throughout AA familial and friend networks. In line, SCT asserts that self-efficacy may be 1 of the most influential constructs in promoting behavior change. Although our study sample is small and results are not generalizable, we predict that self-efficacy gained through additional personalized knowledge and experience gained by undergoing GCT contributed to increased information dissemination among patients with hereditary risks.

Our crude analyses suggest that being armed with knowledge about confirmed pathogenic variants may, in particular, motivate patients to share information more broadly. Greater motivation may be due to an understanding that one's results may have implications for affected family members who might share pathogenic variants. Simultaneously, patients with variants may be more motivated to share information more broadly in networks, given their firsthand experiences with how knowledge about risk facilitates access to risk-based care (e.g., MRIs). Disentangling the role of GCT from the results 1 receives is however analytically

challenging, given patients will not know whether they have a pathogenic variant *unless* they undergo GCT, as reflected in our pilot study. Future studies, whose primary focus regards the psychosocial underpinnings of dissemination among patients with pathogenic variants, is warranted to assess these nuanced relationships in more detail.

Overall, 40% (25 out 62) of patients in our sample disseminated information about hereditary risk throughout their networks. Most of these patients shared information with more than 1 person and, in particular, spoke with first degree female relatives. This finding is significant because having a first-degree relative with breast cancer doubles a woman's risk for breast cancer and only 30% of at-risk relatives receive genetic testing.[54,57] However, most participants reported that no network members subsequently underwent GCT. Our study is aligned with current research that showed while disclosure rates regarding deleterious pathogenic variants are generally high, subsequent cascade testing among relatives remains low.[52,53,58] A recent meta-analysis found small and statistically non-significant effect sizes in both familial communication about genetic risk and cascade testing among randomized controlled interventions aimed at improving familial communication and cascade testing.[54] Our findings suggest that patients are interested in sharing information and promoting behavior change among their family and friends – yet, there is a need for interventions that can make them more effective as change agents in their networks. Interventions that target increasing self-efficacy and models such as "train the trainer" may be effective strategy in knowledge dissemination. Strategies can also clarify to patients *which* information would be helpful to disseminate, as reflected in our open-ended responses, wherein patients were more likely to discuss screening/mammography in the context of risk discussions. For example, interventions that increase providers' capacities to discuss genetic risks with patients, may equip patients with information that allows them to promote the need to 'know your risk' to broader communities, and mitigate biased patient perceptions among providers may be impactful in promoting knowledge about genetic risks among individuals.

Although increased knowledge about genetic risks and cascade testing may be an effective strategy for early detection and in identifying and testing at-risk individuals, GCT is not appropriate for everyone and a number of factors must be considered. Known carriers may experience emotional distress in disclosing their cancer risk to family members, may be estranged from at-risk relatives; and may find it difficult to explain genetic risks to others.[53,59] Additionally, limited access to genetic counseling, variability/uncertainty about costs and insurance coverage, and inequitable access to genetic services among under-resourced communities are also barriers to GCT use.[10,59,60] Interventions that help patients learn about their hereditary risks, make informed decisions about GCT, facilitate communication about heritable cancer risks to family members, assesses and facilitates knowledge that is shared and received, and that are cost-effective are needed to increase information sharing and use of cascade testing among at-risk individuals.[54] Further, interventions focused on genetic risks that are culturally responsive; can be implemented in community settings; are accessible to diverse socio-economic populations; increase rates of provider referrals, knowledge, and quality of patient-provider communication; and increase availability and cultural sensitivity of trained genetic counselors may help to curtail widening health disparities that may be perpetuated with advances in precision medicine.[56,60,61]

Our study has many limitations. Receipt of GCT among participants and social networks relied on self-reporting and were not confirmed using medical records. A study that examined the accuracy of self-reported GCT use among breast cancer survivors showed 86-88% concordance between self-report and electronic medical records, however survivors who were non-White, under 50, and had a family history of breast cancer were more likely to over-report genetic counseling and/or genetic testing.[62] It is plausible that discussions about GCT and family history with providers and tumor test results may be misinterpreted as receipt of GCT.[62] Moreover, although receipt of GCT among social networks was evaluated, data were collected from study participants and not social network members themselves and were also not confirmed by the recipient or through medical records. Additionally, we did not collect data on the quality of patient-provider communication, which could have impacted difficulty in conveying information and accuracy of information shared with networks. The quality of GCT experiences may also have impacted how these lived experiences resulted in information dissemination, in that positive experiences may lead to greater uptake among networks, whereas challenging experiences may negatively impact uptake. Likewise, we did not collect data on the content of information about hereditary risk that was shared or how information was shared with networks. Only 40% of high-risk patients shared information about hereditary risks and services with their networks. We found that younger patients were more likely to disseminate information, however our findings may have been impacted by our difficulty in recruiting patients diagnosed at younger ages. Interventions that intentionally train patients to be change agents may lead to greater information dissemination overall.[37] Among the 25 participants who disseminated information about hereditary risk, 5 had not discussed GCT with a provider and we did not collect data on the source prior GCT knowledge among these participants. Although medical mistrust may impact dissemination behaviors, it was not a primary outcome or focus for the larger study and data regarding medical mistrust was not collected. Another potential confounder concerns information seeking behaviors, which may also affect patients' interest and decision to disseminate health information. These factors must be studied in future original prospective studies to assess the role of different psychosocial confounders and confirm the role of GCT on dissemination.

Conclusion

Our study suggests that interventions that train patients to disseminate information about hereditary risks may be worthwhile to integrate with interventions that prioritize increasing GCT among AA patients. More research is needed to understand patients' dissemination of information throughout their networks. It is important to identify interventions that facilitate communication about genetic risks among the social networks of AA women impacted by breast cancer in order to promote shared decision making and trust in AA communities.[63] Our study adds to the extremely small body of literature that examines factors impacting information sharing about genetic risks among social networks specifically among AA women with a personal history of breast cancer.[64,65] Factors that impact dissemination of knowledge about genetic risks, especially among high cancer risk populations, must be further examined and inform intervention and implementation strategies that identify those with hereditary risk for cancer to prevent further exacerbation of cancer disparities with precision medicine advances.

Declaration of Conflicting Interests

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Ethics Approval

Approval to conduct this human subjects research was obtained by the University of Illinois at Chicago institutional review board (protocol # 2018-0063). All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.

Consent to Participate

Informed consent was obtained from all patients for being included in the study.

Availability of Data and Materials

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

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