Breast Cancer Research and Treatment (2019) 174:469–477
https://doi.org/10.1007/s10549-018-5045-y

EPIDEMIOLOGY

A clinically structured and partnered approach to genetic testing in Trinidadian women with breast cancer and their families

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Received: 1 November 2018 / Accepted: 8 November 2018 / Published online: 4 December 2018

Abstract

Introduction Breast cancer (BC) is the leading cause of cancer death in Caribbean women. Across the Caribbean islands, the prevalence of hereditary breast cancer among unselected breast cancer patients ranges from 5 to 25%. Moreover, the prevalence of BC among younger women and the high mortality in the Caribbean region are notable. This BC burden presents an opportunity for cancer prevention and control that begins with genetic testing among high-risk women. Measured response to positive genetic test results includes the number of preventive procedures and cascade testing in family members. We previously reported data on an active approach to promote cascade testing in the Bahamas and report on preventive procedures showing moderate uptake. Here, we describe a clinically structured and community-partnered approach to the dissemination and follow-up of genetic test results including family counseling for the promotion of risk mitigation strategies and cascade testing in our Trinidadian cohort of patients tested positive for BC predisposition genes.

Methods As a part of our initial study of BC genetic testing in Trinidad and Tobago, all participants received pre-test counseling including three-generation pedigree and genetic testing for BRCA1/2, PALB2, and RAD51C. The study was approved by the University of Miami IRB and the Ethics Committee of the Ministry of Health, Trinidad and Tobago. We prospectively evaluated a clinically structured approach to genetic counseling and follow-up of BC mutation carriers in Trinidad and Tobago in 2015. The intervention consisted of (1) engaging twenty-nine BC patients with a deleterious gene mutation (probands), and (2) invitation of their at-risk relatives to attend to a family counseling session. The session included information on the meaning of their results, risk of inheritance, risk of cancer, risk-reduction options, offering of cascade testing to family members, and follow-up of proband decision-making over two years.

Results Twenty-four of twenty-nine mutation carriers (82.8%) consented to enroll in the study. At initial pedigree review, we identified 125 at-risk relatives (ARR). Seventy-seven ARR (62%) attended the family counseling sessions; of these, 76 ARR (99%) consented to be tested for their family gene mutation. Genetic sequencing revealed that of the 76 tested, 35 (46%) ARR were carriers of their family mutation. The ARR received their results and were urged to take preventative measures at post-test counseling. At 2-year follow-up, 6 of 21 probands with intact breasts elected to pursue preventive mastectomy (28.5%) and 4 of 20 women with intact ovaries underwent RRSO (20%).

Conclusions In Trinidad and Tobago, a clinically structured and partnered approach to our testing program led to a significant rate of proband response by completing the intervention counseling session, executing risk-reducing procedures as well as informing and motivating at-risk relatives, thereby demonstrating the utility and efficacy of this BC control program.

Keywords Breast cancer · BRCA1 · BRCA2 · PALB2 · RRSO · RRM · Trinidad and Tobago

Introduction

Breast cancer (BC) is the most common cancer found in Caribbean women [1]. Across the Caribbean islands, the prevalence of hereditary BC among unselected BC patients varies from 5 to 25% [2–4]. Our previous study showed that over 10% of unselected Trinidadian women with breast

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cancer have a deleterious mutation in the *BRCA1, BRCA2,* and *PALB2* genes [2]. The prevalence of BC among younger women and the high mortality in the Caribbean region are notable. Trinidad and Tobago has one of the highest BC mortality rates in the world [2, 5–7]. This BC burden presents an opportunity for cancer prevention and control that begins with genetic testing among high-risk women.

It has been shown that those who are aware of their genetic risks are more compliant with early detection and are more likely to engage in risk-reduction strategies [8]. Options for management in those with hereditary breast/ovarian cancer syndrome include chemoprevention, surveillance, salpingo-oophorectomy (RRSO), and mastectomy (RRM) [9]. In BC patients with BRCA1/2 mutations carriers, contralateral prophylactic mastectomy (CPM) reduces the risk of death by approximately 50% [10, 11] and RRSO has been associated with a 70% reduction in all-cause mortality [12].

Gaps in genetic studies with African ancestry and the African diaspora

The literature shows that African ancestry populations are understudied in genetics research, and even when available, there is underuse in genetic-related services [13–15]. However, our group's work reveals that residents of Caribbean island nations are interested in participating in genetic studies and testing. Partnering with local health care providers and community leaders, we have recruited and provided genetic counseling and testing to over 1000 breast cancer patients in the Bahamas, Jamaica, Barbados, Cayman Islands, Dominica, and Haiti [2–4, 16, 17]. Recruitment and testing are only the first step toward achieving cancer prevention. The acceptance of cascade testing and cancer risk-management practices is critical to reduce morbidity and mortality from cancer and defines the success of a cancer genetics program.

To date, little follow-up data are available about preventive uptake and cascade testing in the Caribbean [18, 19]. We recently reported low–moderate uptake of RRM and RRSO after mean follow-up of 4.4 years in BRCA1 and BRCA2 carriers in Bahamas [19]. Sensitivity to cultural differences resulted in a high rate of participation in cascade testing after an active approach was employed to reach ARR [18].

This work required community initiative, education, and cooperation of local health care providers and an onsite certified genetic counselor as well as no cost genetic testing.

As genetic testing becomes more globally accessible, complexities aside, integrating genetic counseling and testing programs in Caribbean cancer practices may enhance risk stratification, prevention, and treatment of cancer [20]. While cancer genetics services may not be widely available in all of the Caribbean, genetic services are increasingly offered in Trinidad and Tobago. Therefore, this investigation aims to better understand the uptake of genetic testing, risk-reducing preventive measures, and cascade testing in BC patients with a deleterious gene mutation. To achieve our aims, we performed the first known genetic testing prospective single-institution study in twin island nation of Trinidad and Tobago, part of the English-Speaking Caribbean. In this study, we describe a clinically structured and partnered approach to genetic testing for BC patients with high-risk breast and/or ovarian cancer gene mutations and their family members. We measured attendance to a family counseling session, recruitment of at-risk relatives (ARR) for cascade testing and documented 2-year follow-up of cancer risk-reducing measures in probands (preventive uptake, decrease in cancer recurrence, and morbidity). Secondly, we examined the impact of the intervention on the participant's perceptions of risk, their psychological response to testing, and reasons why family members declined participation.

Methods

Study participants: cohort

The study protocol was approved by the Ethics Committee of the North West Regional Health Authority of Trinidad and Tobago and the University of Miami IRB. Study subjects were recruited from unselected BC patients previously found to have a deleterious mutation in one of the breast cancer genes in our previous study [2] and who lived in Trinidad and Tobago were offered participation on this study. Probands were invited for disclosure of their genetic test results. At this meeting, they were offered participation in this study and informed consent was obtained.

Study procedures

All participants attended a post-test disclosure session with the local study investigator (co-PI), Dr. Jameel Ali, a surgical oncologist who leads the breast cancer program. The study was composed of a personal disclosure session, a family counseling session, a questionnaire, no cost single-site genetic testing for ARR who attended the counseling session, and follow-up of the probands for 2 years for uptake of risk mitigation strategies.

Initial visit

The initial visit was highly structured and included seven elements: (1) communication of test results, (2) provision of literature about genetic mutations and risk mitigation, (3) detailed review of the family tree to identify ARR, (4) scheduling of family counseling session within 14 days, (5)

provision of a written invitation to family members for the family counseling session which included time, date, and location of session, (6) offer of help with contacting family members, and (7) an offer to provide free cascade testing to family members. Before this visit, the study PIs identified ARR at 25–50% risk of inheriting the family mutation over the age of 18 through the previously elicited family pedigree at the time of initial study enrollment to the genetic testing [2]. This information was shared with the local PI (Fig. 1).

Family counseling session

Within 14 days of the initial visit, the Miami-based study team partnered with the local PI and support staff to deliver a family counseling session led by a board-certified genetic counselor. The positive genetic test results, gene-associated cancer risks, risks for cancer recurrence, and options for screening and risk reduction as per current NCCN guidelines were reviewed at the family counseling session [21]. Risk to family members to have inherited the mutation was reviewed along Mendelian inheritance patterns, and risks to offspring for biallelic conditions were described when appropriate and questions were answered. An opportunity was given to the proband and family members to consult the genetic counselor in private to answer personal questions and/or concerns. At the end of the counseling session, the ARR family members were offered no cost single-site genetic sequencing testing; the proband was asked to fill in a questionnaire about her experience; and the family pedigree was reviewed and the reason for non-attendance of ARR was ascertained. Probands were followed every 6 months by phone to determine risk mitigation strategies employed.

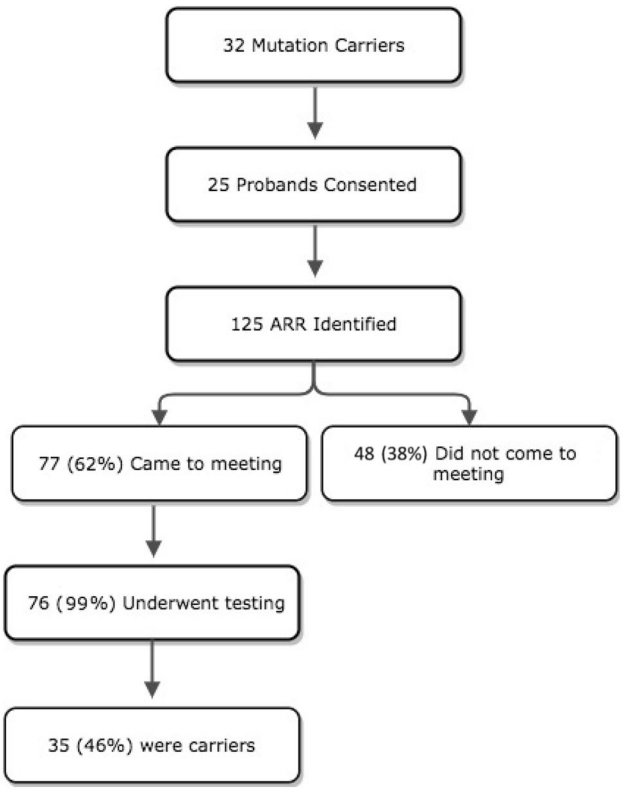

Fig. 1 Study schema of enrollment of probands and identification of their at-risk relatives

Questionnaire

To assess probands' reaction to positive genetic test results and the increased risk of cancer, the Impact of Event Scale [22] was administered. The Impact of Event Scale (IES) is used to assess current subjective distress for any life event. The questionnaire consisted of 15 items. The survey captured participants' thoughts, attitudes, and perceptions around genetic testing by asking the following items: perceived risk of developing breast cancer and ovarian cancer; review of written information prior to enrollment; satisfaction with written information; preferences for receiving genetic test results; whether they would recommend genetic testing to other Trinidadian women; attitudes toward medical research in general; actions undertaken since genetic testing (e.g., mammography, MRI for breast cancer screening; tamoxifen use; oophorectomy; hysterectomy; and whether she was diagnosed with cancer).

DNA sample processing

The Oragene® DNA sample collection kit (OG-250 format, DNA Genotek, Kanata, ON, Canada) was used to collect saliva. The NanoDrop ND-1000 Spectrophotometer (Thermo Scientific Inc., Wilmington, DE) was used to quantify DNA. Genetic sequencing for single-site mutation was performed.

Follow-up of the proband

The proband was contacted by phone every 6 months to determine the rate of breast cancer relapse, the uptake of mammography, MRI, RRSO, and RRM.

Results

Demographics

Thirty-two of 298 breast and ovarian cancer patients (10.7%) tested positive for BRCA1, BRCA2, PALB2, and/or RAD51C germline mutations in Trinidadian born women. Two women received their test results in Miami so they did not meet eligibility criteria for this study. One patient was lost to follow up and was believed to have emmigrated.

Twenty-nine patients from 28 families who tested positive for mutations were informed about results by the local study PI and invited to return for post-test disclosures. Fifteen had a BRCA1 mutation, 11 had a BRCA2 mutation, 2 had a PALB2 mutation, and one had RAD51C. Twenty-six (26) patients attended the post-test disclosure in person. In total, three (3) did not attend due to pregnancy related bedrest in two patients and one was out of the country for a prolonged period. Of the twenty-six who attended the post-test disclosure, twenty-four (24) returned for the Family Counseling session. One patient declined study participation and one did not return due to illness from progressive metastatic breast cancer (Fig. 1).

Proband reaction to genetic testing

All 24 probands filled out the IES. Seventy-five percent ($n=19$) of probands answered that they read the educational booklet/handout before the family genetic counseling session and seventy-nine percent ($n=18$) reported the information was easy to understand. The knowledge of risk assessment conducted prior the post genetic testing counseling session revealed that 46% ($n=11$) and 54% ($n=13$) were unable to quantify their risk of developing BC or OC, respectively. Eighty-three percent of the probands preferred a face-to-face meeting with a genetic counselor for their initial genetic test results compared to mailed test results—prior to the post genetic testing counseling session. Eighty-three percent ($n=20$) were satisfied while seventeen percent ($n=4$) probands were dissatisfied with testing process.

Psychological response and attitudes

The Impact of Event Scale showed no defined pattern in the way the probands perceived how the event impacted their lives. Thirteen participants (54%) showed that the event had either severe ($n=6$) or powerful ($n=7$) impact on them, while 25% ($n=6$) showed the event had no meaningful impact on their lives. Despite these results, 96% ($n=23$) of women were glad they took part in the study, as well as 96% indicated that they would both participate and recommend others to participate in a future research study.

Pre-study breast/ovarian surgical intervention

Prior to genetic testing, ten probands (42%) had wide local excision (WLE) of the affected breast (4 BRCA2, 4 BRCA1, 2 PALB2). Nine probands (38%) were treated surgically with unilateral mastectomy (5 BRCA1, 4 BRCA2). Three (13%) had unilateral mastectomy and contralateral preventive mastectomy at the time of initial diagnosis (1 RAD51C, 1 BRCA2, 1 BRCA1). There was no information about surgical treatment in two patients. Two women had previously undergone total-abdominal hysterectomy bilateral salpingo-oophorectomy (TAH-BSO) for benign indications (Table 1).

Risk-reduction uptake post testing

At the 2-year follow-up of probands, 6 of 21 (29%) probands with intact breasts underwent risk-reducing mastectomy (RRM) with reconstruction (4 bilateral, 2 contralateral). Two were BRCA1 carriers, three BRCA2, and one PALB2. Only carriers of BRCA1, BRCA2, and RAD51C mutations were counseled to consider risk-reducing salpingo-oophorectomy (RRSO) per current 2015 NCCN guidelines (by age 35 for BRCA1, age 40 for BRCA2, age 45 for RAD51C, or when finished childbearing) [21]. Four of the twenty (20%) probands who had intact ovaries and who were counseled for RRSO underwent the procedure (1 BRCA1, 3 BRCA2). These four were among those who had also undergone prophylactic mastectomy during the 2-year follow-up. Eight patients elected not to undergo any prophylactic surgical procedures; three probands had progression of disease; three passed away from metastatic breast cancer; one RRM was canceled due to pregnancy; one developed a new contralateral primary breast cancer within the first year of study follow-up; and one proband developed colon cancer. In addition, during the 2-year follow-up period, there were 33 instances of breast imaging of the study cohort: 16 women received a mammogram, 5 received breast MRIs, and 12 underwent breast ultrasounds (Table 2).

Testing at-risk relatives

Twenty-four of the twenty-nine probands (83%) brought at least one ARR to the family counseling session. Pedigree review initially identified 125 ARR and 77 ARR (62%) attended the family counseling sessions. Seventy-six ARR (98.7%) of those who attended elected to be tested (or 61% of original 125 ARR). Those who elected to be tested included four mothers, one father, 19 sisters, 11 half-sisters, 14 daughters, 1 son, 5 aunts, 3 nieces, and 18 cousins. Genetic testing by single-site analysis revealed that 35 out of 76 (46%) ARR tested positive for their family mutation. Fifty-four percent were pre-menopausal (Table 3). As is standard of care during post-test counseling for positive results, pedigrees were reviewed to identify additional relatives at 25–50% risk to carry a mutation who are over age 18. This expanded the number of ARR to 225. The most frequent reasons probands gave for ARR not attending the family counseling session were living abroad (18%), unable to be contacted (17%), refusal to participate

Table 1 Demographic data of probands and uptake risk-reducing interventions at 2-year follow-up

	BRCA1	BRCA2	PALB2	RAD51C	Total	Average (%)
Number of individuals ($n=24$)	12	9	2	1	24	
Age at breast cancer diagnosis						
20–29	1				1	4.2
30–39	3	3		1	7	29.2
40–49	8	6	2		16	66.7
Average BMI	32.7	26.9	30.5	26.0		29.0
Age of menarche	12.2 (9–15)	12.4 (10–15)	11.5 (11–12)	16		12.9
Menopausal state						
Post-menopause	3		1		4	16.7
Pre-menopause	9	9	1	1	20	83.3
Breast cancer stage						
I	1	2			3	12.5
II	7	2	2		11	45.8
III	2	5		1	8	33.3
IV	1				1	4.2
Unstaged	1				1	4.2
Breast cancer type						
Estrogen receptor +		6	1		7	29.2
Estrogen receptor −	10	2	1	1		
Progesterone receptor +	1	6	1		8	33.3
Progesterone receptor −	9	2	1	1		
HER 2+			1	1	2	8.3
HER 2−	10	8	1			
TNB	9	1			10	41.7
Mammogram						
Yearly	7	1	6	2	16	72.7
None		2		2	4	18.2
Not applicable	1		1		2	9.1
Pelvic ultrasound						
Yearly	5	1	5	1	12	54.5
None	4		2	1	7	31.8
Not applicable	1		1		2	9.1
MRI						
Yearly	1		1		2	9.1
2015	1		1		2	9.1
2016			1		1	4.5
None	7	1	3	1	12	54.5
Not applicable	1		1		2	9.1
Risk-reducing mastectomy (RRM)[a]	1	2	1		4	19
Contralateral prophylactic mastectomy	1				1	5
Mastectomy		1			1	5
Risk-reducing salpingo-oophorectomy (RRSO)	1	3			4	2
Dead of disease		2		1	3	13

[a]RRM done in women with intact breasts

Table 2 Demographics of at-risk relatives (ARR) with germline mutations

	BRCA1	BRCA2	PALB2	RAD51C	Total	Average (%)
Sex						
Female	16	11	4	2	33	94.3
Male	1	1			2	5.7
Age at testing						
20–29	7	1	3		11	31.4
30–39	2	5	1	1	9	25.7
40–49		2			2	5.7
50–59	7	2			9	25.7
60+	1	2		1	4	11.4
Average BMI	31.4	27.3	23.5	24.5		26.7
Age of menarche	12.5 (9–14)	12.4 (11–14)	10.7 (9–12)	12		11.9
Menopausal state						
Post-menopause	5	2			7	21.2
Pre-menopause	7	7	3	1	18	54.5

Table 3 Distribution of germline mutations of at-risk relatives

Gene	Exon	Confirmed mutation	Number of subjects	Percentage of subjects with mutation (%)
BRCA1	10	c.2138C>A	2	5.7
		c.2389_2390delGA	1	2.9
		c.2766delA	3	8.6
	12	c.4327C>T	6	17.1
	15	c.4945_4947delAGAinsTTTT	4	11.4
	18	c.5177_5180delGAAA	1	2.9
BRCA2	10	c.1763_1766delATAA	1	2.9
	11	c.5909C>A	3	8.6
		c.6373_6375delACCinsG	4	11.4
	18	c.7977-1G>A	2	5.7
	25	c.9382C>T	2	5.7
PALB2	4	c.1571C>G	4	11.4
RAD51C	4	c.656T>A	2	5.7

(17%), no-show after confirming attendance (17%), being estranged from probands (12%), or ARR were afraid to know the results of the test (7%) (Fig. 2).

Discussion

To our knowledge, this is the first study among Caribbean women to prospectively assess the impact of genetic counseling and testing on follow-up preventive action and testing choice in ARR. This study reports on a 2-year clinical follow-up and cascade testing in a cohort of breast cancer patients with high-risk breast/ovarian cancer mutations in Trinidad and Tobago. The majority (82.8%) of the cohort—mutation-positive probands, attended the Family Counseling session and consented to participate in this prospective study. In the 2-year follow-up period, 29% of our probands underwent RRM and 20% had an RRSO. In comparison, cancer risk-reducing uptake in our previous retrospective follow-up study in the Bahamas [19] demonstrated that among BC probands, 17% had RRM and 29% had RRSO after a mean follow-up of 4.4 years. Previous studies show RRM rates from 18 to 51% and RRSO 51–75%, in BRCA1/2 carriers but have focused on Caucasian populations in the US, Canada, and Europe [23–25]. Cragun et al. compared cancer risk-management practices across a diverse population-based sample of BRCA mutation carriers with breast cancer aged 50 and younger in the US including Non-Hispanic Whites (NHW), Hispanics, and Blacks [26]. Among Blacks, there were lower rates of RRM (68.8%) as compared with NHW (95.7%) and Hispanics (81.8%). Uptake of RRSO in blacks in the Cragun

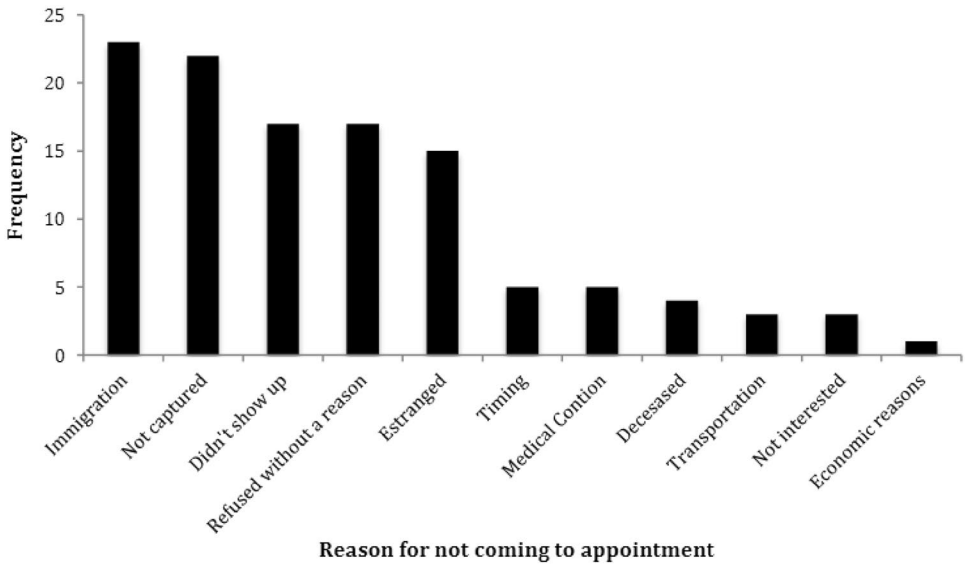

Fig. 2 At-risk relatives' reasons for not coming to genetic counseling session

group was 28.1% which is comparable to our Bahamian cohort and slightly higher than in Trinidad and Tobago. However, the fact that one-third of probands had disease progression, new primaries, or succumbed to their disease within the 2-year time period must be taken into consideration. It is clear because of the advanced stage of breast cancer diagnosis in the Caribbean population that the most impactful use of genetic testing would be in the prevention of breast cancer in unaffected mutations carriers, rather than in women already diagnosed with breast cancer.

Eighty-three percent (83%) of the proband cohort brought one or more ARR to the Family Counseling. Seventy-seven of the at-risk relatives attended the Family Counseling session and 98.7% of those who attended, elected to undergo testing. In the Bahamas, rates of ARR testing increased from 9 to 84% after direct contact by a genetic counselor [18]. In Trinidad, probands preferred to contact and inform their ARR themselves. We believe that our structured approach which included pre-set appointments, written materials as well as the proximity in time to the initial results disclosure (2 weeks) may have facilitated attendance to the family counseling session by both probands and ARR. Participants were also made aware of their very brief window of opportunity (1 week) to access complimentary testing and receive genetic counseling which at the time was not readily available in Trinidad and Tobago. Genetic testing in Trinidad is perceived to be very expensive due to costs of a local private lab although additional options are rapidly becoming available.

In general, literature reveals cascade testing rates to be low, at 31–53% and fraught with challenges [27, 28]. The most common reason for a low turn-out rate is lack of family members being informed [19, 27]. Populations clearly differ in their adaptation to information and practitioners need to be sensitive to social and cultural cues that might assist informing at-risk relatives in a safe way.

Forty-six percent ($n = 53/115$) of ARR who declined the invitation to attend and participate in the family counseling session had fears of testing positive. These findings highlight a great need for community awareness, culturally sensitive counseling, and health literacy initiatives to educate and activate both affected and high-risk families. Availability and high costs of genetic testing and preventive/risk mitigation strategies may limit options in island nations due to lack of coverage by national and/or private health insurance or fear of post-testing outcomes including medical bias, i.e., losing medical insurance. In addition, limited access to breast reconstructive surgery after prophylactic surgery may also be a deterrent to opting for mastectomy as a BC risk reduction.

Promoting awareness, empowerment, and creation of a cancer prevention program promises to increase understanding in a community and inspire trust in those with hesitation. Training programs for genetic cancer risk assessment offer a formal approach toward building local programs [29]. During our initial recruitment, the US-based study team leveraged and engaged the local Principal Investigator and medical team's willingness to learn the elements of pedigree drawing, analysis, genetic counseling, and testing. This partnered interaction, engagement, and training of the local study team launched their expertise to assist future clinical endeavors in their local population. Moreover, our success was hinged upon working with our partners with knowledge of local culture, and a previously built trust with patients.

There were several limitations and strengths of our study. The first is that it was conducted at a single facility which may not be a true representative of all of Trinidad and Tobago. However, this may also be a relative strength

given that it enhanced our ability to collect clinical follow-up data. Most probands were treated and followed up at the same facility and the familiarity of the co-PI and his team by extension led to a built-in trust. The study cohort is small and our follow-up study did not include data collection of ARR who tested positive. This was outside both the resources and scope of this initial study. Plans for a near future follow-up study of the ARR are underway. Our local study partners continue to provide clinical care to probands and any ARR interested in prophylactic procedures. The team has engaged in a larger effort with civil society to promote awareness of hereditary cancers and genetic testing. We would encourage more collaborative approaches to promote genetic counseling and testing services in ways that work best for each island or cultural group as an important mechanism to promote cancer prevention.

Acknowledgements This research was supported by a grant from Komen For the Cure. The authors thank the staff of the North West Regional Health Authority: Dr. Dylan Narinesingh, Dr. Cemonne Nixon, Dr. Jamie Morton-Gittens, Dr. Zahir Mohammed, Dr. Suzanne Chapman, Nurse Patrice Carrington, and Nurse Netasha Celestine.

Author contributions TD: Conceptualization, formal analysis, data curation, writing—original draft. SG: Conceptualization, data curation, formal analysis, writing—original draft, writing—review and editing. JA: Conceptualization, data collection, formal analysis, writing—review and editing GB: Formal analysis, writing—original draft. KH: Formal analysis, writing—review and editing. NS: Data collection, writing—review and editing. KTA: Writing—review and editing. MRA: Formal analysis, writing—review and editing. SAN: Formal analysis, writing—review and editing. JH: Conceptualization, data curation, formal analysis, writing—original draft, writing—review and editing.

Funding This work was supported by grants from the Susan G. Komen Foundation (PI: Hurley).

Compliance with ethical standards

Conflict of interest There are no conflicts of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Human and Animal rights This study did not involve animals.

Informed consent Informed consent was obtained from all individual participants included in the study.

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