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Participation of low-income women in genetic cancer risk assessment and *BRCA 1/2* testing: the experience of a safety-net institution

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Abstract Some communities and populations lack access to genetic cancer risk assessment (GCRA) and testing. This is particularly evident in safety-net institutions, which serve a large segment of low-income, uninsured individuals. We describe the experience of a safety-net clinic with limited resources in providing GCRA and *BRCA1/2* testing. We compared the proportion and characteristics of high-risk women who were offered and underwent GCRA and genetic testing. We also provide a description of the mutation profile for affected women. All 125 patients who were offered GCRA accepted to undergo GCRA. Of these, 72 % had a breast cancer diagnosis, 70 % were Hispanic, 52.8 % were non-English speakers, and 66 % did not have health insurance. Eighty four (67 %) were offered genetic testing and 81 (96 %) agreed. Hispanic women, those with no medical insurance, and those with a family history of breast cancer were significantly more likely to undergo testing ($p > 0.01$). Twelve of 81 (15 %) patients were found to have deleterious mutations, seven *BRCA1*, and five *BRCA2*. Our experience shows that it is possible to offer GCRA and genetic testing even in the setting of limited resources for these services. This is important given

that a large majority of the low-income women in our study agreed to undergo counseling and testing. Our experience could serve as a model for similar low-resource safety-net health settings.

Keywords Disparity · Genetic cancer risk assessment · Underinsured · Hispanic · Latina · Minority

Introduction

Approximately 5–10 % of breast cancers are associated with hereditary risk factors. Mutations in the *BRCA1* and *BRCA2* (*BRCA*) genes convey greatly elevated lifetime risks of breast and ovarian cancers (Chen and Parmigiani 2007), and several other genes have been firmly established as high- and moderate-risk genes for breast and other cancers (Njiaju and Olopade 2012). *BRCA* mutation carriers also tend to have an early age of onset of breast cancer, often before the age of 40 years (Daly et al. 2010), which is when breast cancer screening typically starts for average-risk populations. Identification of individuals and family members who carry a mutation is important in order to implement appropriate breast cancer screening and initiate discussion of management options. Breast cancer treatment options may be affected by the mutation status of a patient and could impact prognosis (Goodwin et al. 2012). In addition, consideration for risk-reducing bilateral salpingo-oophorectomy (RRSO) is important for mutation carriers as there remains no effective strategy to screen for ovarian cancer (Buys et al. 2011), and RRSO has recently been associated with large reductions in all-cause mortality in *BRCA* mutation carriers (Finch et al. 2014; Domchek et al. 2010). Identifying appropriate patients for genetic cancer risk assessment (GCRA) is now recognized

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as an important component of clinical care for breast cancer patients and women with a family history of breast/ovarian cancer (Robson et al. 2010; Moyer and U.S. Preventive Services Task Force 2014), and occurs in a variety of clinical settings under several different service delivery models (Weitzel et al. 2011). Despite these critical benefits, racial/ethnic minorities are less likely to undergo GCRA and be offered genetic testing than non-Hispanic white (NHW) women (Levy et al. 2011) even when results are corrected for risk factors for carrying a *BRCA* mutation, socioeconomic factors, risk perception, and attitudes (Armstrong et al. 2005).

Breast cancer is the most common cancer in Hispanic/Latina women and also the most common cause of cancer death (Siegel et al. 2014). Hispanic/Latina women also have an earlier onset of breast cancer, later stage at presentation, and have more aggressive histologic phenotypes than NHW (Martínez et al. 2007; Ooi et al. 2011; Lara-Medina et al. 2011). Furthermore, a large study of Hispanic/Latina breast/ovarian cancer families in the USA confirmed a high prevalence of *BRCA* mutations (25 %) and a pattern of multiple recurrent mutations (Weitzel et al. 2013). Despite these adverse clinical features in Hispanic/Latina women, they are less likely to undergo genetic cancer risk assessment than NHW women. Results of a national sample of newly diagnosed breast cancer patients under 40 years of age showed that Hispanic women were half as likely to undergo genetic testing compared to NHWs (Levy et al. 2011). Reasons for the lower rate could be due to factors such as cost, inadequate insurance coverage, lack of awareness on the part of the patient and/or physician, and limited availability of GCRA services and providers (Wideroff et al. 2003), the latter being a particular issue for safety-net institutions. In addition, there is a general perception that some racial/ethnic minorities may be more hesitant to undergo genetic testing than NHWs. However, recent reports underscore a demonstrated need for GCRA in diverse settings, and demand may be even higher among Hispanic/Latina women and younger BC patients (Larsen Haidle and Whitworth 2015; Jagsi et al. 2015).

Academic-community clinic partnerships offer great potential to provide access to GCRA to individuals from underserved communities, including Hispanic/Latina women. This is important given published reports showing that Hispanic/Latina women participate in cancer genetic services (Ricker et al. 2010) and with appropriate cultural tailoring can successfully embrace and act upon GCRA information (Lagos et al. 2008). Here we provide the experience of a safety-net institution's efforts to develop a GCRA program by leveraging resources from larger tertiary academic institutions. In doing so, we compare the proportion and characteristics of high-risk women who were offered and accepted GCRA as well as those who underwent genetic testing for *BRCA 1/2*. Lastly, we provide a description of the mutation profile for affected patients.

Materials and methods

Setting

The experience of setting up a limited GCRA service depicted here is based on a patient population at Maricopa Medical Center (MMC) in Phoenix, AZ. MMC is the safety-net hospital for Maricopa County, which includes the city of Phoenix and the surrounding metropolitan area. Maricopa County is the state's most populous area with nearly four million of Arizona's 6.5 million inhabitants. MMC serves a patient population of which 78 % of patients are from racial/ethnic minority groups and 79 % are underinsured, uninsured, or insured by Medicaid. This article does not contain any studies with human or animal subjects performed by the any of the authors. The research materials and methods of this study were approved by the medical center's Institutional Review Board.

At the MMC Breast Clinic, all breast cancer patients have their surgical management performed by one breast surgical oncologist with the assistance of one physician assistant and rotating surgical residents. Patients with benign diseases of the breast are also managed at the MMC Breast Clinic and make up the majority of the clinic visits at this safety-net clinic. The MMC Breast Clinic has approximately 2000 patient visits per year and between 50 and 100 new breast cancer diagnoses per year. Approximately 60 % of the patients are Hispanic and 65 % are uninsured. While MMC has an oncology clinic, which provides services for patients with all types of cancer, it has no radiation oncology services.

The inability to perform GCRA at MMC was recognized as a critical area of need, as many of the patients were young, uninsured breast cancer patients. In the 10 years prior to June 30, 2011, there were no genetic counseling or testing services available at MCC and only two patients underwent genetic counseling, and both were insured. To address this need, the breast surgical oncologist (IK) received training through the City of Hope Intensive Course in Cancer Risk Counseling (City of Hope, Duarte, CA) (Blazer et al. 2008). The goal of the training is to enable clinicians to acquire the appropriate skills to achieve practitioner level competence to provide GCRA services in institutions and areas where these are not currently available. The course curriculum includes distant learning modules (i.e., video presentations and participation in web conferences) as well as in-person predominantly case-based training (accredited for 90 CME hours). The course also provides content on financial assistance guidelines to help obtain testing for under/uninsured patients, as well as principles of cultural tailoring. Further information on the training at the City of Hope has been published previously and is available online (<http://www.cityofhope.org/education/health-professional-education/cancer-genetics-education-program>). Since that time, a GCRA service was

implemented under the surgical oncologist (IK). Because the breast surgical oncologist is a full-time surgeon practicing in a health care setting with limited resources, the service was not meant to provide genetic counseling services for the entire MMC health system. This would require several full-time genetic counselors, which the safety-net institution has insufficient resources to support. Therefore, there was no education for other providers at the institution about the new service. The service was meant to provide counseling and testing services for the numerous underinsured young women with breast cancer, suspicious for having a hereditary breast/ovarian cancer syndrome, seen by the breast surgical oncologist (Larsen Haidle and Whitworth 2015).

Patient population and data collection

The period of analysis for the experience depicted here was from July 1, 2011 to December 31, 2013 and included women receiving care at the MMC Breast Clinic. Inclusion criteria for patients to be considered for GCRA adhered to the respective NCCN guidelines (NCCN 2013), and patients entered the program by either of the following: (1) referral from their primary care provider for evaluation because of a family history of breast cancer or (2) patient was affected by breast cancer and expressed an interest or concern about her family's risk of developing breast cancer. Multi-generational pedigrees were obtained. Patients were generally offered genetic testing unless a relative with breast cancer was identified who was more appropriate for initiating genetic testing within the family, or, the estimated probability of carrying a *BRCA* mutation was <10 % using the Myriad, Couch, or BRCAPRO models (Couch et al. 1997; Frank et al. 2002; Parmigiani et al. 1998).

For all patients, sociodemographic information is routinely collected, which includes education, self-reported monthly income, employment status, and insurance status. Health literacy assessment is also routinely conducted at the MMC Breast Clinic using the newest vital sign (NVS) (Weiss et al. 2005), which can be administered in about 2 min, has been validated in English and Spanish, and is well accepted in this patient population (Komenaka et al. 2014).

To describe our experience, we provide an account of the proportions of women who were offered and accepted GCRA as well as those who underwent genetic testing. We also conducted a comparison of the patient characteristics for women who underwent *BRCA 1/2* testing vs. those who did not. Lastly, we provide a description of the mutation profile for affected patients.

Results

During the 2.5-year study period, 125 patients were offered GCRA and all accepted. Characteristics of this population are

shown in Table 1. Close to 70 % of this patient population was Hispanic, largely of Mexican descent, and slightly less than half were English speakers; the majority (66.4 %) did not have health insurance. Of the 125 participants, 84 (67 %) were recommended to undergo genetic testing for *BRCA 1/2* and of these, 81 (96.4 %) agreed to do so. For the three patients who did not undergo testing, two were not authorized by their insurance plan and one patient did not follow up for the testing. Of the 41 patients who underwent GCRA but were not recommended to undergo testing, four were recommended to obtain additional information about their family histories but did not follow up.

As shown in Table 1, significant differences between patients who had genetic testing and those who did not were shown for race/ethnicity, insurance, and family history. A higher percentage of Hispanics underwent testing while a higher percentage of patients with no insurance also underwent testing. Expectantly, a higher proportion of patients with a family history of breast cancer had genetic testing than those with no family history. Additional trends in differences between patients who were tested vs. those who were not were observed for education and health literacy, but these were not statistically significant. Few differences were observed between women who had uninformative genetic testing and those with a *BRCA* mutation; however, the number of carriers was too small to merit statistical testing.

Among the patients who underwent genetic testing, 12/81 (15 %) were found to have deleterious *BRCA* mutation (7-*BRCA1*; 5-*BRCA2*). The 12 mutation carriers represented nine distinct families: two patients were daughters of one of the other patients in the series. A second extended family had multiple family members treated for breast cancer at MMC. A mother and two daughters as well as four cousins received breast cancer treatment. Three of the four cousins treated were found to be carriers of a large rearrangement mutation (*BRCA1* ex9-12del), thought to be a Mexican founder mutation (Weitzel et al. 2007a, 2007b; Weitzel et al. 2013). In terms of post-GCRA clinical outcomes for the 12 mutation carriers, 1 patient had ovarian cancer and therefore had already undergone bilateral salpingo-oophorectomy and 2 others underwent RRSO. Six are either considering RRSO or getting financial assistance for the operation. The last three were recently diagnosed and are still undergoing breast cancer treatment and planning.

We identified several barriers to implementation of GCRA services. The primary limitation was provider time, given that he (IK) is a full-time breast surgical oncologist. Consequently, the GCRA service is provided in addition to a full schedule of patients in both the clinic and the operating room. Patient compliance with scheduled appointments, scheduling, and space resources were also barriers. It was not uncommon to have up to eight new patients scheduled in a 1-h time slot in a clinic with only four examining rooms. This type of schedule

Table 1 Characteristics of patients undergoing genetic counseling and risk assessment (GCRA), those undergoing genetic testing, and those found to be mutation carriers

Characteristic	Total population (N=125)	GCRA, no testing (N=44)	GCRA, genetic testing (N=81)	Mutation carriers (N=12)
Age, mean (SD)	45.7 (11.1)	45.4 (12.2)	46.0 (10.6)	45.7 (12.1)
Race/ethnicity				
Non-Hispanic white	25 (20 %)	11 (25 %)	14 (17.3 %)*	2 (16.7 %)
African-American	12 (9.6 %)	8 (18.2 %)	4 (4.9 %)	1 (8.3 %)
Hispanic	87 (69.6 %)	24 (54.5 %)	63 (77.8 %)	9 (75 %)
Mexican	82	21	61	9
Other Hispanic	5	3	2	0
Language, English	59 (47.2 %)	22 (50 %)	37 (45.6 %)	7 (58.3 %)
Education, years				
11 or less	48 (38.4 %)	19 (43.2 %)	29 (35.8 %)	4 (33.3 %)
High school (12)	34 (27.2 %)	10 (22.7 %)	24 (29.6 %)	4 (33.3 %)
Any college (13+)	43 (34.4 %)	15 (34.1 %)	28 (34.6 %)	5 (41.7 %)
Mean (SD)	10.6 (3.8)	10.5 (3.8)	10.6 (3.8)	10.9 (3.7)
Health literacy, adequate	37 (29.6 %)	15 (34.1 %)	22 (27.2 %)	3 (25 %)
Marital status, married	54 (43.2 %)	19 (43.2 %)	35 (43.2 %)	5 (41.7 %)
Employment, yes	32 (25.6 %)	14 (31.8 %)	18 (22.2 %)	1 (8.3 %)
Income ^a , \$, mean (SD)	1066 (877.4)	1175 (1013.2)	1006 (794.5)	1050 (888.2)
Insurance				
Private	4 (3.2 %)	4 (9.1 %)	0 ¹	0
Medicare	5 (4 %)	2 (4.5 %)	3 (3.7 %)	0
Medicaid	33 (26.4 %)	15 (34.1 %)	18 (22.2 %)	3 (25 %)
None	83 (66.4 %)	23 (52.2 %)	60 (74.1 %)	9 (75 %)
Breast cancer, affected	90 (72 %)	25 (56.8 %)	65 (80.2 %)*	9 (75 %)
Family history of breast cancer ^a	47 (37.6 %)	16 (36.3 %)	31 (38.3 %)	8 (66.7 %)

* $p < 0.01$ for differences between genetic testing and no genetic testing groups

^a Household income per month

leaves little to no room for GCRA services. Further, patients with limited health literacy frequently miss appointments or show up on the wrong day or time, again further complicating the GCRA delivery.

Discussion

Results of our experience in a safety-net hospital comprising a patient population largely of Hispanic women with low SES show that in spite of limited resources, GCRA and genetic testing can be offered. Additionally, our study demonstrates that when genetic counseling and testing services are available, a high proportion of these patients agrees to participate. This finding supports previous studies suggesting that racial/ethnic minority patients would consider GCRA if given the opportunity (Benkendorf et al. 1997; Hughes et al. 1997; Kinney et al. 2006; Ramirez et al. 2006; Vadaparampil et al. 2010). As expected, our data also show that women with a

breast cancer diagnosis and those with family history were more likely to undergo *BRCA 1/2 testing*. However, these data also show that Hispanics and women who lack insurance were also more likely to undergo testing.

While there are various models available for providing GCRA, one that has been suggested by the leading genetic counseling and breast cancer surgical societies (Larsen Haidle and Whitworth 2015) is a practice model where the surgeon identifies appropriate patients and provides GCRA services but has access to a genetics specialist for complex cases. This is consistent with our experience at MMC, which was made possible through its partnerships with academic institutions. These partnerships began in 2006, when MMC's Breast Clinic providers participated in the *Ella* Binational Breast Cancer Study (Martínez et al. 2013b). The MMC served as the largest recruitment site for the University of Arizona study-based *Ella* study site and has resulted in several publications (Cruz et al. 2013; Martínez et al. 2010, 2013a). This initial partnership facilitated a second collaboration between

MMC and the City of Hope, which led to MMC's breast surgical oncologist being trained in genetic cancer risk assessment at the City of Hope.

The City of Hope training is offered via an annual CME/CEU-accredited multi-modal intensive course designed to address the need for professional training in clinical cancer genetics for community-based clinics, such as MMC, where genetics specialists may not be available (Blazer et al. 2008). Training provided the clinician with the appropriate knowledge and skills to provide GCRA and testing to breast cancer patients at MMC. Discussion for complex cases is available through weekly telemedicine conferences with genetic specialists at the City of Hope. Further information on the extensive collaboration network at the City of Hope is available (<http://www.cityofhope.org/education/health-professional-education/cancer-genetics-education-program/ccg-community-of-practice>). Currently at MMC, genetic counseling occurs as part of routine follow-up or cancer care and testing is offered at no cost for those patients without insurance. This critical patient service was accomplished by leveraging resources from larger institutions with significantly greater funding, personnel, and resources. Implementation of this service has made significant clinical impact as the rate of patients undergoing genetic testing increased from 0.2 patients per year (2 patients in 10 years prior to implementation of the service) to 32 patients per year from 2010 to 2012. This training also provided the clinician skills to be able to identify and manage more complex family histories. In this largely Mexican descent Hispanic patient population, potential underreporting of family history is a concern, especially among non-US born individuals (Orom et al. 2010). Current clinical guidelines for *BRCA* testing now recognize that individuals with a limited family structure may be appropriate for testing (NCCN Guidelines 2014).

Our experience shows that a significant proportion of patients who underwent GCRA (44 patients, 35 %) did not need to undergo testing. This represents a clinical benefit given that many patients are referred or self-refer because they are worried about their family histories or have been told that they have concerning family histories. GCRA can identify patients where testing would not be indicated and allay many of those concerns by showing the patient that according to validated models, their risk of carrying a mutation is very small, while still providing empiric risk-appropriate screening and prevention recommendations. This would then also avoid unnecessary testing that impacts medical costs. This experience is consistent with a recent published report showing that breast cancer patients from racial/ethnic minorities who express a strong desire for genetic testing benefit from discussion to clarify risks urging clinicians to discuss these even with patients they perceive to be at low risk (Jagsi et al. 2015).

This GCRA program had a number of beneficial effects, including making GCRA services and genetic testing

available to an underserved population who would otherwise not have these services available to them. This also engages these women in discussions related to GCRA. In addition, important new information can be uncovered through the provision of such programs. For example, one large family was found to carry a Mexican founder mutation. This large rearrangement mutation is thought to be of ancient (1480 years) Amerindian origin (Weitzel et al. 2007a, 2007b; Weitzel et al. 2013). Notably, these types of mutations were not detectable in routine commercial *BRCA* sequencing at the time and would not have been identified. Thus, the value of an academic-community clinic partnership such as ours cannot be overstated.

This work highlights the significant opportunities that exist to improve care in underserved populations through academic-community clinic partnerships. Telemedicine-based genetic counseling may also be useful in these setting where community personnel are unable to obtain necessary training or to address the increasing complexity of genetic testing options (e.g., panel testing or whole exome sequencing (Schwartz et al. 2014)). Additional opportunities exist in leveraging the Electronic Health Record (EHR) to improve care and facilitate research. Inclusion of genetic testing results in the EHR may allow for the following: decision-making tools to trigger repeat GCRA based on the availability of new tests and well-powered multicenter studies of genetic cancer susceptibility genes particularly in racial/ethnic minority patients.

In the most recent recommendations from the US Preventive Services Task Force regarding genetic counseling and testing for *BRCA*⁹. It is noted that genetic counseling may be done by trained health professionals, including trained primary care providers. Several professional organizations describe the skills and training necessary to provide comprehensive genetic counseling (Berliner et al. 2013; Robson et al. 2010).

The process of genetic counseling includes detailed kindred analysis and risk assessment for potentially harmful *BRCA* mutations; education about the possible results of testing and their implications; identification of affected family members who may be preferred candidates for testing; outlining options for screening, risk-reducing medications, or surgery for eligible patients; and follow-up counseling for interpretation of test results. Results of a recent survey show that these recommendations are far from being met (Wood et al. 2014). The experience described here show that MMC is well underway to meeting these recommendations and could serve as a model for similar safety-net institutions with limited resources.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

Ethics approval This article does not contain any studies with human or animal subjects performed by the any of the authors.

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