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Understanding factors associated with uptake of *BRCA1/2* genetic testing among Orthodox Jewish women in the United States using a mixed-methods approach

Meghna S. Trivedi, MD[1,2], **Hilary Colbeth, MPH**[3], **Haeseung Yi, MPA**[4], **Alejandro Vanegas, MS**[5], **Rebecca Starck, PsyD**[6], **Wendy K. Chung, MD, PhD**[1,2,7], **Paul S. Appelbaum, MD**[8], **Rita Kukafka, DrPH, MA**[5,9], **Isaac Schechter, PsyD**[6], **Katherine D. Crew, MD, MS**[1,2,3]

[1]Department of Medicine, College of Physicians and Surgeons, Columbia University, NY, NY

[2]Herbert Irving Comprehensive Cancer Center, Columbia University Medical Center, NY, NY

[3]Department of Epidemiology, Mailman School of Public Health, Columbia University, NY, NY

[4]Department of Health and Behavior Studies, Teachers College, Columbia University, NY, NY

[5]Department of Biomedical Informatics, College of Physicians and Surgeons, Columbia University, NY, NY

[6]Institute for Applied Research and Community Collaboration (ARCC), Spring Valley, NY

[7]Department of Pediatrics, College of Physicians and Surgeons, Columbia University, NY, NY

[8]Department of Psychiatry, College of Physicians and Surgeons, Columbia University, NY, NY

[9]Department of Sociomedical Sciences, Mailman School of Public Health, Columbia University, NY, NY

Abstract

Background/Aims—Ashkenazi Jews have a 1:40 prevalence of *BRCA1/2* mutations. Orthodox Jews (OJ) are an understudied population with unique cultural and religious factors that may influence *BRCA1/2* genetic testing uptake.

Methods—Using a mixed-methods approach, we conducted a cross-sectional survey and focus groups among OJ women in New York/New Jersey to explore factors affecting decision-making about *BRCA1/2* genetic testing.

Results—Among 321 evaluable survey participants, median age was 47 years (range, 25–82); 56% Modern Orthodox and 44% Yeshivish/Chassidish/other; 84% were married; 7% had a personal history of breast or ovarian cancer. Nearly 20% of women had undergone *BRCA1/2* genetic testing. Predictors of genetic testing uptake included being Modern Orthodox (odds ratio [OR]=2.31), married (OR=3.49), and having a personal or family history of breast or ovarian cancer (OR=9.74). Focus group participants (N=31) confirmed the importance of rabbinic

Corresponding author: Meghna S. Trivedi, MD, 161 Fort Washington Ave, HIP 9-907, New York, NY 10032, Tel: 212-305-1945, Fax: 212-305-0178, mst2134@cumc.columbia.edu.

consultation in medical decision-making and revealed that stigma was a prominent factor in decisions about *BRCA1/2* testing due to its potential impact on marriageability.

Conclusion—In order to increase uptake of *BRCA1/2* genetic testing among the OJ population, it is crucial to understand religious and cultural factors, such as stigma and effect on marriageability, and engage religious leaders in raising awareness within the community.

Keywords

BRCA1; *BRCA2*; genetic testing; Orthodox Jewish

Introduction

Women with mutations in *BRCA1* or *BRCA2* genes are at significantly higher risk of developing breast and ovarian cancer compared to women in the general population. In a recent prospective cohort study of *BRCA1* and *BRCA2* mutation carriers, the cumulative risk to age 80 years was 72% and 69%, respectively, for breast cancer and 44% and 17%, respectively, for ovarian cancer [1]. Women who are mutation carriers have several cancer risk-management options, such as risk-reducing salpingo-oophorectomy (RRSO), prophylactic risk-reducing mastectomy (RRM), enhanced cancer screening with mammography and breast MRI, and chemoprevention [2–4]. Studies have shown that genetic counseling as well as cancer screening and preventive measures can improve quality of life, reduce psychological distress and worry about breast cancer, and increase the accuracy of risk perception and knowledge of cancer genetics [5–8].

The prevalence of the *BRCA1/2* mutations is about 1 in 400 in the general population, however, the Ashkenazi (central and eastern European) Jewish population's three founder mutations *[BRCA1* (5382insC or 185delAG) and *BRCA2* (6174delT)] have a combined population frequency of 2.5% [5,9]. Population-based screening among Ashkenazi Jews has been shown to identify 56% more mutation carriers compared to family history-based testing [6] and to be highly cost-effective in Ashkenazi Jewish women 30 years or older [10]. Despite this, there are multiple patient, provider, and systemic factors involved in implementing population-based screening of Ashkenazi Jewish women. Studies examining *BRCA1/2* genetic testing attitudes and knowledge among Ashkenazi Jewish women found that factors influencing the decision to undergo testing are related to genetic discrimination, accuracy and interpretation of results, cancer risk/prevention, and the potential impact on other family members [11–13].

Orthodox Jews represent a spectrum from Modern Orthodox to Yeshivish and Chassidish communities, which have varying levels of observance of *halacha* (Jewish law) and access to secular outlets [14]. In these communities, there are unique social, cultural, and religious factors that may influence uptake of *BRCA1/2* genetic testing. While Orthodox Jews represent the largest and fastest-growing Jewish population in the New York/New Jersey (NY/NJ) areas, they have been under-represented in studies investigating *BRCA1/2* genetic testing attitudes and knowledge [11]. We previously conducted a cross-sectional, survey-based study among mainly young Modern Orthodox Jewish women in Washington Heights, NY (median age 25 years, range 19–84). In this population, only one-third of respondents

reported that they had undergone genetic testing or would consider doing so. We found that adequate genetic testing knowledge, increased self-efficacy, higher breast cancer risk, and overestimation of risk were significantly associated with *BRCA1/2* genetic testing intention [15].

In this study, we used a mixed-methods approach to explore the social, cultural, and religious factors influencing the decision to undergo genetic testing among women across the spectrum of Orthodox Jewish communities. We hypothesized that women from more insular Orthodox Jewish communities, such as Yeshivish and Chassidish, would be less likely to seek *BRCA1/2* genetic testing and that stigma associated with being a mutation carrier would affect decision-making about genetic testing.

Patients and Methods

Study setting, dates, and population

Participant recruitment was conducted from 2015 to 2017 in collaboration with the Institute for Applied Research and Community Collaboration (ARCC). We recruited participants using electronic mailing lists from Orthodox Jewish communities including: Washington Heights, NY; Teaneck/Bergen County, NJ; Riverdale, NY; Edison/Highland Park, NJ; Monsey, NY; and Passaic/Clifton, NJ. We also conducted in-person recruitment at Refuah Health Center in Monsey, NY to enhance enrollment of more insular communities without internet access. All study activities were approved by the Columbia University Medical Center Institutional Review Board, and all participants provided informed consent.

Study procedures

Cross-sectional survey—Eligibility criteria for the survey study included: 1) Orthodox Jewish woman, age≥25 years, 2) of Ashkenazic or both Ashkenazic and Sephardic origin, 3) ability to give informed consent. Participants received an invitation to complete a one-time survey through a recruitment email and the survey was self-administered online. For patients recruited through the Refuah Health Center, the survey was self-administered on paper.

Focus group procedures—We conducted four focus groups representing married and single women and different segments of the Orthodox Jewish community. We selected participants through purposive sampling of women who participated in the Washington Heights survey [15] or the expanded NY/NJ survey, and who agreed to be re-contacted for future studies. The two focus groups of Washington Heights participants included a group of unmarried and a group of married women and were conducted in April 2015 in a synagogue multipurpose room. The two focus groups from the expanded survey participants included a group of predominantly Modern Orthodox women, which was conducted in July 2016 in a girls' yeshiva high school in Teaneck, NJ, and a group of predominantly Yeshivish/Chassidish women, which was conducted in September 2016 in a community clinic in Monsey, NY. Focus groups were moderated by a study team member using a semi-structured guide developed with input from ARCC and designed to further explore the findings from the cross-sectional survey. The focus groups were audio-recorded and transcribed for analysis.

Survey Measures

The survey collected information on demographics and breast cancer risk factors [16], as well as validated measures adapted for our study, including genetic testing knowledge [7,17], stigma [18], perceived breast cancer risk [19], breast cancer worry [19], and a measure of community involvement in *BRCA1/2* genetic testing decision-making [20]. Demographic data included age, Jewish ancestral origin (Ashkenazi/Sephardic/both), Orthodox Jewish community segment (Modern Orthodox vs. non-Modern Orthodox [Yeshivish/Chassidish/other]), highest level of secular education, highest level of Jewish education, and marital status (married vs. unmarried [single/engaged/separated/divorced/widowed]). Our primary outcome was self-reported *BRCA1/2* genetic testing uptake. Genetic testing intention and prior uptake were assessed with the following question, 'Imagine that you are offered genetic testing for breast cancer susceptibility genes *(i.e. BRCA1, BRCA2)* at some point in the future. Would you choose to have the test?' The response options included: (1) 'No, definitely not'; (2) 'No, probably not'; (3) 'Unsure'; (4) 'Yes, probably'; (5) 'Yes, definitely'; (6) 'I was already tested' [21]. For our analysis, genetic testing uptake (yes/no) was dichotomized into 'I was already tested' versus all other options.

Genetic testing knowledge was assessed through true-false items about *BRCA1/2* testing, including risks, benefits, and the limitations of genetic testing [7,17]. Adequate knowledge was defined as 50% or more correct responses. Perceived breast cancer risk was evaluated using comparative risk on a 3-point Likert scale [19]. Worry was assessed through 2 Likert-style items with a response scale that ranged from 1 (none of the time) to 7 (all of the time) [19]. Stigma was assessed by responses to the perceived consequences of genetic testing such as, 'if I were found to carry the gene mutation for breast cancer...:' (1) 'I would feel singled out', (2) 'it would cause others to view me negatively', (3) 'I would be ashamed' [18]. Religious and cultural factors involved in medical decision-making were measured on 5-point Likert scales to assess likelihood (very unlikely – very likely) and difficulty (very difficult – very easy) in consulting with a rabbi for a general medical decision or a condition concerning breast and/or ovarian health, and the importance that their healthcare provider be from the "*frum*" *(i.e.,* observant) community (not at all important - extremely important).

Eligibility for *BRCA1/2* testing was determined using the demographic and breast cancer risk factor data provided in the survey. The Six-Point Scale (SPS), a validated family history screener, was used to determine eligibility for *BRCA1/2* genetic testing based on U.S. Preventive Services Task Force guidelines (USPSTF), namely having Ashkenazi Jewish background and a personal or first/second-degree family history of breast or ovarian cancer [22–24].

Analyses

Cross-sectional survey—We generated descriptive statistics for baseline variables such as demographics, breast cancer risk factors, genetic testing knowledge, stigma, perceived breast cancer risk, and breast cancer worry by prior *BRCA1/2* genetic testing uptake (yes/no) and community segment (Modern Orthodox/non-Modern Orthodox). Frequency distributions were calculated between categorical variables and compared using chi-squared

tests. The continuous variables of age, breast cancer worry, and stigma were compared using two-sample t-tests. To identify the independent predictors of genetic testing uptake, multivariable logistic regression models were used. Variables were included in multivariable model development if $p<0.15$ on univariate analysis. Backward selection was used to select variables for the final multivariable model. Variables were kept in the model if any parameter estimate changed greater than 10% after the variable in question was removed. Personal and family history of breast or ovarian cancer and blood relatives with a known *BRCA1/2* mutation determined eligibility for genetic testing; thus, individual elements of this construct were not evaluated for inclusion in the multivariable model. Statistical tests were two-tailed and a p-value less than 0.05 was considered statistically significant. All analyses were conducted using SAS version 9.3 (Cary, NC).

Focus groups—Qualitative analysis evaluated the depth of the major themes and the evolution of participants' thoughts regarding personal and family history, stigma, perception, knowledge, and intention of *BRCA1/2* genetic testing. Two investigators independently coded transcripts from the four focus groups. Independently, initial codes and coding templates were created and any resulting discrepancies in the codes were negotiated at weekly research meetings, after which the coding template was established and modified as the analysis progressed. We grouped the codes into general themes and discussed the themes among the entire team of investigators in order to select representative quotes. Atlas.ti 7.0 software was used to facilitate qualitative data management and analysis. All the transcripts were uploaded into the software to enable investigators to code, build the codebook, and group the codes into themes. A final comparison of coding across all focus groups yielded a Scott's pi inter-rater reliability ranging from 0.54 to 0.78.

Results

Cross-Sectional Survey

A total of 343 women completed the cross-sectional survey from the five towns included in this study (Figure 1). Three women who marked their origin as Sephardic only and nineteen women who did not answer the genetic testing intention question were excluded. The baseline characteristics of the remaining 321 participants are summarized in Table 1. The median age of the study sample was 47 years (range, 25–82). The majority were Modern Orthodox (55.8%), had a masters or doctoral degree (57.6%), and at least some post-secondary Jewish education (60.4%). Most of the women were married (84.1%), parous (86.3%), and premenopausal (58.9%). Twenty women (6.2%) previously had been diagnosed with breast cancer and 2 (0.62%) with ovarian cancer. Twenty-six women (8.1%) reported having a relative with a *BRCA1/2* mutation and 46.1% and 10.6% of women reported a family history of breast and ovarian cancer, respectively. Based upon USPSTF guidelines for *BRCA1/2* genetic counseling referral [23], 160 (49.8%) of the respondents were eligible for *BRCA1/2* genetic counseling.

Among the 321 Orthodox Jewish women, 64 (19.9%) reported having undergone *BRCA1/2* genetic testing. Of the women who had not been tested, their reported genetic testing intentions were: 52 (16.2%) who answered 'Yes, definitely', 88 (27.4%) 'Yes, probably', 37

(11.5%) 'No, probably not', 3 (0.9%) 'No, definitely not', and 77 (24.0%) 'Unsure.' The univariate analysis (Table 1) showed that genetic testing was significantly associated with the following demographic factors: older age (p=0.001), Modern Orthodox community segment (p=0.01), and Medicare health insurance coverage (p=0.0009). Breast cancer risk factors associated with genetic testing included: prior breast biopsy (p<0.0001), prior breast cancer diagnosis (p<0.0001), and family history of breast or ovarian cancer (p<0.0001). Having a relative who tested positive for a *BRCA1/2* mutation (p<0.0001) and meeting USPSTF criteria for *BRCA1/2* genetic counseling (p<0.0001) were associated with genetic testing. Genetic testing was also significantly associated with adequate genetic testing knowledge (p=0.04), higher perceived breast cancer risk (p<0.0001), and higher breast cancer worry (p=0.001).

Table 2 presents the variables included in the final multivariable logistic regression model. We found community segment (Modern Orthodox vs. non-Modern Orthodox), marital status (married vs. unmarried), prior breast biopsy, and eligibility for *BRCA1/2* genetic testing were significant independent predictors for genetic testing uptake (Table 2). Respondents identifying as Modern Orthodox had more than twice the odds of having received genetic testing (odds ratio [OR]=2.31; 95% confidence interval [CI]=1.03–5.17). Compared to unmarried women, married women were more likely to have undergone *BRCA1/2* genetic testing (OR=3.49; 95% CI=1.03–11.80). Compared to those who had not undergone a breast biopsy, those with a prior history of breast biopsy were more likely to have had genetic testing (OR=2.57; 95% CI=1.10–6.00). The strongest predictor of uptake was eligibility for *BRCA1/2* genetic counseling by the SPS family history screener (OR=9.74; 95% CI=3.62–26.18).

Given that community segment was a significant independent predictor for genetic testing uptake, we performed a comparison of the baseline characteristics between the Modern Orthodox and non-Modern Orthodox women (Supplementary Table 1). Univariate analysis of cultural and religious survey measures demonstrated that non-Modern Orthodox women were more likely to consult a rabbi when considering whether or not to undergo *BRCA1/2* genetic testing (p<0.0001) and when making a significant medical decision (p<0.0001). Compared to Modern Orthodox women, those who identified as non-Modern Orthodox were also more likely to ask a rabbi for guidance regarding *non-BRCA1/2* genetic testing (p<0.0001), as well as sharing of genetic test results (p<0.0001). Non-Modern Orthodox women were more likely to respond that it was very or extremely important to them that their genetic counselors (p=0.01) and their mental health professionals (p<0.0001) be "*frum*."

Focus Groups

Thirty-one women participated in the 4 focus groups. Their baseline characteristics are shown in Table 3. Three key factors impacting genetic testing decision-making emerged from discussions during the focus groups: impact on marriage and family, role of community, and religious considerations. Representative quotes of the themes can be found in Table 4.

The impact of genetic testing on marriage and family was an important factor in decision-making among both married and unmarried women. They expressed concern that their genetic test results could affect marriageability for themselves (single women) and for their siblings or children (both married and unmarried women).

The role of the community in contributing to the secrecy surrounding cancer and genetic testing was also discussed in the focus groups. All focus group participants agreed that these topics are not openly discussed, particularly in the Yeshivish and Chassidish communities. The stigma associated with carrying a *BRCA1/2* mutation was attributed to lack of open discussion about cancer and genetic testing. An absence of community support and education around *BRCA1/2* testing was thought to be a barrier to genetic testing uptake.

Most participants stressed the importance of consulting a rabbi when making major medical decisions or that rabbis could influence promotion of genetic testing in the community. Women from Yeshivish and Chassidish communities and married women were more open to input from a rabbi with regards to *BRCA1/2* genetic testing. Following the imperatives of Jewish law as well as the role of Divine Providence were discussed as factors in what was regarded as a responsible decision for genetic testing and cancer risk management.

Discussion

In this study, we examined factors associated with *BRCA1/2* genetic testing uptake among Orthodox Jewish women in NY/NJ in the United States. Of the survey respondents, nearly 20% had previously undergone *BRCA1/2* genetic testing. Predictors of genetic testing uptake included being Modern Orthodox, being married, having a prior breast biopsy, and meeting USPSTF eligibility for genetic testing. The focus groups supported the findings from the cross-sectional survey and illuminated concerns about the impact of genetic testing on marriage and family, the role of the community, and the religious considerations that affect decisions regarding *BRCA1/2* testing.

In a study of Canadian Jewish women with breast cancer, the decision to undergo *BRCA1/2* testing was influenced by a desire to contribute to research, potential benefits to family members, and curiosity. The survey respondents in this Canadian study were similar to the women in our study in that 17% expressed worry over the potential impact of test results on marriageability for themselves and family members. Additional concerns raised in the Canadian study included insurance discrimination (28%) and the overemphasis of genetic testing in the Jewish community (14%) [11]. Other factors in the literature influencing the decision of those of Ashkenazi Jewish ancestry to undergo genetic testing include a high perceived risk of being a mutation carrier, curiosity, and the value of information pertaining to personal and offspring's cancer risk [11–13,25]. However, it is important to note that those studies did not focus specifically on the Orthodox Jewish population as our study does. One study reported 5% of participants as Orthodox Jewish [11] and another reported 14% as "religious" (compared to 71% "nonreligious" and 14% "traditional") [25]. Our previous survey study of Orthodox Jewish women in Washington Heights, NY found that high decision self-efficacy, adequate genetic testing knowledge, and overestimation of risk were associated with genetic testing intention [15]. However, none of these associations were

found to be significant in the current study, in which the study population was older and comprised a smaller percentage of Modern Orthodox women. In addition, in the previous study we assessed *BRCA1/2* testing intention as the primary outcome, rather than prior genetic testing uptake.

We found that the strongest predictor of *BRCA1/2* testing uptake was meeting eligibility for genetic testing based on family history criteria. Nearly half of the survey participants were deemed to be eligible based on the SPS. In the focus group data, it was evident that those who had family members with a cancer diagnosis were more informed and aware about *BRCA1/2* genetic testing and thus may be more likely to undergo testing. The association of prior breast biopsy with increased genetic testing uptake may reflect the more intensive breast cancer screening among high-risk women with a positive family history of breast cancer.

Modern Orthodox women were over twice as likely to undergo *BRCA1/2* genetic testing compared to non-Modern Orthodox Jewish women, although the frequency of eligibility for genetic testing was comparable between the two groups. This difference may reflect limited knowledge about *BRCA1/2* testing among more insular Yeshivish and Chassidish populations with less access to secular outlets compared to Modern Orthodox Jews. Orthodox Jewish women from conservative, insular religious groups may rely more on rabbinic input for medical-decision making, including whether or not to receive *BRCA1/2* testing. Several studies have shown that Orthodox Jewish women's decision-making may be guided by faith and their views of God's plan [26–29]. Coleman-Bruckheimer *et al.* found that rabbis are an important resource for ultra-Orthodox breast cancer patients in the United Kingdom and, at times, have an active role in the decision-making process [28]. Additionally, the beliefs and recommendations with regards to *BRCA1/2* testing among religious leaders in Modern Orthodox community versus non-Modern Orthodox community also varies. Several Modern Orthodox leaders have endorsed *BRCA1/2* testing, while ultra-Orthodox leaders have cautioned against it [14,30].

Another key finding from our study is that married women from the Orthodox Jewish community are more than twice as likely to undergo *BRCA1/2* genetic testing compared to unmarried women. In the focus groups, many participants voiced concern about marriageability if one was found to be a mutation carrier. The perceived risk of genetic testing impacting marriage prospects for self and family members has been described in prior literature [11,31]. During the premarital phase in the Orthodox Jewish community, there is an emphasis on marriage at a young age, which is often done using a matchmaker and takes into account family status, and on having children that are healthy, which may require the disclosure of important personal medical information [32]. These findings provide insight into the reasons a married woman would be more likely to undergo genetic testing.

In the Orthodox Jewish community, the impact of genetics on marriage is not a foreign concept. The *Dor Yeshorim* program conducts genetic testing for autosomal recessive diseases in the Orthodox Jewish community and the results of this testing are used by couples considering marriage [14,33]. The acceptance of *Dor Yeshorim* is attributed to the

cloaking of each participant's respective results, which are never disclosed. Rather, couples are notified as to whether they are, as a pair, genetically compatible or not. This program has led to a dramatic decrease in the incidence of Tay-Sachs disease and other recessive disorders in the Orthodox community [34]. As *BRCA1/2* mutations are inherited in an autosomal dominant manner and female mutation carriers have a significantly increased risk of breast or ovarian cancer, an anonymized approach to testing is not a feasible option. Fear of social stigmatization of self and family was voiced as a barrier to *BRCA1/2* genetic testing before marriage. Although there are cancer risk management strategies available to mutation carriers, some of these strategies, such as RRSO before menopause, are in conflict with a culture in which great value is placed on the ability to produce healthy offspring [14,32].

Although we tried to capture the impact of stigma on genetic testing decision-making in the survey using a validated measure, our analyses did not reveal a significant association with prior *BRCA1/2* testing uptake. Conversely, during discussion in the focus groups, there were multiple mentions of "stigma," "branding," and "taboo" classification associated with positive *BRCA1/2* genetic testing results and the subsequent knowledge of being at increased risk of developing cancer. On this topic, the qualitative data revealed insights that were not identified in the quantitative data. Studies of healthcare behaviors and beliefs among the ultra-Orthodox suggest that illness, such as cancer, attracts stigma and may be seen as a punishment or a spiritual test [35,36]; this may lead to interpretations of some sicknesses as socially unacceptable. Although a few women from our focus groups spoke of being spiritually responsible and the need to avoid positioning themselves as a "sick person" if found to carry a genetic mutation, almost all wanted more information about risk management and attributed fear to lack of knowledge or expressed frustration at community silence on the topic. This suggests that the sharing of information and experiences may mitigate the social stigma surrounding genetic testing and breast cancer.

One limitation of the study is that it was conducted in NY and NJ in the United States and thus may not be generalizable to Orthodox Jewish persons living elsewhere, although Orthodox communities share strong commonalities. Additional limitations of our study include potential selection bias due to the low response rate to our online survey and the low representation among Chassidish women (2.8%), which may be due to a lack of internet access to complete the online survey. However, our quantitative findings were enhanced by the use of the focus groups which collected additional information that a survey is not able to capture. Other major strengths included the relatively large sample size, use of validated measures, and targeting of Orthodox Jewish communities, which were often under-represented in prior studies of genetic testing among Ashkenazi Jews.

Identifying actionable *BRCA1* and *BRCA2* mutations can inform health behaviors and, ultimately, decrease the morbidity and mortality associated with breast and ovarian cancer. There have been few empirical studies on the attitudes of Orthodox Jewish women toward genetic testing, and this study provides insights into the unique factors that play a role in the decision-making process within this community. These data provide a foundation for future exploration of some of the important factors affecting genetic testing uptake, including religious considerations and stigma. Women from more insular Orthodox Jewish

communities may need targeted education efforts that communicate breast cancer information, the risks and benefits of genetic testing, and the promotion of prevention strategies. Focusing efforts on testing married women or those who have completed child bearing, who may consider RRSO, may increase acceptability of *BRCA1/2* testing. Endorsement by key religious and community leaders from this population will be essential to adoption and to provide culturally sensitive healthcare delivery and risk management options that align with community values. By understanding the religious and cultural issues regarding genetic testing in the Orthodox Jewish community and engaging faith-based leaders, we can develop culturally sensitive interventions to enhance knowledge and informed choice about *BRCA1/2* genetic testing that may facilitate the implementation of population-based genetic screening at the appropriate time of life among Orthodox Jews. Furthermore, this research highlights the general importance of cultural factors in decision-making regarding genetic testing and demonstrates the need for the development of culturally sensitive approaches to promote genetic testing not only in the Orthodox Jewish community but also among other religious or ethnic groups at risk for high-penetrance genetic mutations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Kuchenbaecker KB, Hopper JL, Barnes DR, Phillips KA, Mooij TM, Roos-Blom MJ, Jervis S, van Leeuwen FE, Milne RL, Andrieu N, Goldgar DE, Terry MB, Rookus MA, Easton DF, Antoniou AC, Brca, Consortium BC, McGuffog L, Evans DG, Barrowdale D, Frost D, Adlard J, Ong KR, Izatt L, Tischkowitz M, Eeles R, Davidson R, Hodgson S, Ellis S, Nogues C, Lasset C, Stoppa-Lyonnet D, Fricker JP, Faivre L, Berthet P, Hooning MJ, van der Kolk LE, Kets CM, Adank MA, John EM, Chung WK, Andrulis IL, Southey M, Daly MB, Buys SS, Osorio A, Engel C, Kast K, Schmutzler RK, Caldes T, Jakubowska A, Simard J, Friedlander ML, McLachlan SA, Machackova E, Foretova L, Tan YY, Singer CF, Olah E, Gerdes AM, Arver B, Olsson H. Risks of Breast, Ovarian, and Contralateral Breast Cancer for BRCA1 and BRCA2 Mutation Carriers. Jama. 2017;317(23):2402–2416. [PubMed: 28632866]

2. Domchek SM, Friebel TM, Singer CF, Evans DG, Lynch HT, Isaacs C, Garber JE, Neuhausen SL, Matloff E, Eeles R, Pichert G, Van t'veer L, Tung N, Weitzel JN, Couch FJ, Rubinstein WS, Ganz PA, Daly MB, Olopade OI, Tomlinson G, Schildkraut J, Blum JL, Rebbeck TR. Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. Jama. 2010;304(9):967–975. [PubMed: 20810374]

3. Warner E, Hill K, Causer P, Plewes D, Jong R, Yaffe M, Foulkes WD, Ghadirian P, Lynch H, Couch F, Wong J, Wright F, Sun P, Narod SA. Prospective study of breast cancer incidence in women with a BRCA1 or BRCA2 mutation under surveillance with and without magnetic resonance imaging. J Clin Oncol. 2011;29(13):1664–1669. [PubMed: 21444874]

4. King MC, Wieand S, Hale K, Lee M, Walsh T, Owens K, Tait J, Ford L, Dunn BK, Costantino J, Wickerham L, Wolmark N, Fisher B, National Surgical Adjuvant B, Bowel P. Tamoxifen and breast cancer incidence among women with inherited mutations in BRCA1 and BRCA2: National Surgical

Adjuvant Breast and Bowel Project (NSABP-P1) Breast Cancer Prevention Trial. Jama. 2001;286(18):2251–2256. [PubMed: 11710890]

5. Metcalfe KA, Mian N, Enmore M, Poll A, Llacuachaqui M, Nanda S, Sun P, Hughes KS, Narod SA. Long-term follow-up of Jewish women with a BRCA1 and BRCA2 mutation who underwent population genetic screening. Breast cancer research and treatment. 2012;133(2):735–740. [PubMed: 22240989]
6. Manchanda R, Loggenberg K, Sanderson S, Burnell M, Wardle J, Gessler S, Side L, Balogun N, Desai R, Kumar A, Dorkins H, Wallis Y, Chapman C, Taylor R, Jacobs C, Tomlinson I, McGuire A, Beller U, Menon U, Jacobs I. Population testing for cancer predisposing BRCA1/BRCA2 mutations in the Ashkenazi-Jewish community: a randomized controlled trial. Journal of the National Cancer Institute. 2015;107(1):379. [PubMed: 25435541]
7. Lerman C, Narod S, Schulman K, Hughes C, Gomez-Caminero A, Bonney G, Gold K, Trock B, Main D, Lynch J, Fulmore C, Snyder C, Lemon SJ, Conway T, Tonin P, Lenoir G, Lynch H. BRCA1 testing in families with hereditary breast-ovarian cancer. A prospective study of patient decision making and outcomes. JAMA : the journal of the American Medical Association. 1996;275(24):1885–1892. [PubMed: 8648868]
8. Kelly K, Leventhal H, Marvin M, Toppmeyer D, Baran J, Schwalb M. Cancer genetics knowledge and beliefs and receipt of results in Ashkenazi Jewish individuals receiving counseling for BRCA1/2 mutations. Cancer Control. 2004;11(4):236–244. [PubMed: 15284715]
9. Struewing JP, Hartge P, Wacholder S, Baker SM, Berlin M, McAdams M, Timmerman MM, Brody LC, Tucker MA. The risk of cancer associated with specific mutations of BRCA1 and BRCA2 among Ashkenazi Jews. The New England journal of medicine. 1997;336(20):1401–1408. [PubMed: 9145676]
10. Manchanda R, Legood R, Burnell M, McGuire A, Raikou M, Loggenberg K, Wardle J, Sanderson S, Gessler S, Side L, Balogun N, Desai R, Kumar A, Dorkins H, Wallis Y, Chapman C, Taylor R, Jacobs C, Tomlinson I, Beller U, Menon U, Jacobs I. Cost-effectiveness of population screening for BRCA mutations in Ashkenazi jewish women compared with family history-based testing. Journal of the National Cancer Institute. 2015;107(1):380. [PubMed: 25435542]
11. Phillips KA, Warner E, Meschino WS, Hunter J, Abdolell M, Glendon G, Andrulis IL, Goodwin PJ. Perceptions of Ashkenazi Jewish breast cancer patients on genetic testing for mutations in BRCA1 and BRCA2. Clinical genetics. 2000;57(5):376–383. [PubMed: 10852372]
12. Lehmann LS, Weeks JC, Klar N, Garber JE. A population-based study of Ashkenazi Jewish women's attitudes toward genetic discrimination and BRCA1/2 testing. Genetics in medicine : official journal of the American College of Medical Genetics. 2002;4(5):346–352. [PubMed: 12394347]
13. Wiesman C, Rose E, Grant A, Zimilover A, Klugman S, Schreiber-Agus N. Experiences from a pilot program bringing BRCA1/2 genetic screening to theUS Ashkenazi Jewish population. Genetics in medicine : official journal of the American College of Medical Genetics. 2017;19(5): 529–536. [PubMed: 27735926]
14. Grazi RV, Wolowelsky JB. Cultural Concerns when Counseling Orthodox Jewish Couples for Genetic Screening and PGD. Journal of genetic counseling. 2015;24(6):878–881. [PubMed: 26174938]
15. Tang EY, Trivedi MS, Kukafka R, Chung WK, David R, Respler L, Leifer S, Schechter I, Crew KD. Population-Based Study of Attitudes toward BRCA Genetic Testing among Orthodox Jewish Women. The breast journal. 2016.
16. Tehranifar P, Reynolds D, Flom J, Fulton L, Liao Y, Kudadjie-Gyamfi E, Terry MB. Reproductive and menstrual factors and mammographic density in African American, Caribbean, and white women. Cancer causes & control: CCC. 2011;22(4):599–610. [PubMed: 21327938]
17. Wakefield CE, Meiser B, Homewood J, Peate M, Taylor A, Lobb E, Kirk J, Young MA, Williams R, Dudding T, Tucker K, Group AGC. A randomized controlled trial of a decision aid for women considering genetic testing for breast and ovarian cancer risk. Breast cancer research and treatment. 2008;107(2):289–301. [PubMed: 17333332]
18. Sussner KM, Edwards TA, Thompson HS, Jandorf L, Kwate NO, Forman A, Brown K, Kapil-Pair N, Bovbjerg DH, Schwartz MD, Valdimarsdottir HB. Ethnic, racial and cultural identity and perceived benefits and barriers related to genetic testing for breast cancer among at-risk women of

African descent in New York City. Public Health Genomics. 2011;14(6):356–370. [PubMed: 21540561]

19. Armstrong K, Micco E, Carney A, Stopfer J, Putt M. Racial differences in the use of BRCA1/2 testing among women with a family history of breast or ovarian cancer. Jama. 2005;293(14):1729–1736. [PubMed: 15827311]
20. Maly RC, Umezawa Y, Ratliff CT, Leake B. Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients. Cancer. 2006;106(4):957–965. [PubMed: 16402372]
21. Green MJ, Peterson SK, Baker MW, Harper GR, Friedman LC, Rubinstein WS, Mauger DT. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. Jama. 2004;292(4):442–452. [PubMed: 15280342]
22. Joseph G, Kaplan C, Luce J, Lee R, Stewart S, Guerra C, Pasick R. Efficient identification and referral of low-income women at high risk for hereditary breast cancer: a practice-based approach. Public Health Genomics. 2012;15(3–4):172–180. [PubMed: 22488460]
23. Moyer VA, Force USPST. Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: U.S. Preventive Services Task Force recommendation statement. Ann Intern Med. 2014;160(4):271–281. [PubMed: 24366376]
24. Stewart SL, Kaplan CP, Lee R, Joseph G, Karliner L, Livaudais-Toman J, Pasick RJ. Validation of an Efficient Screening Tool to Identify Low-Income Women at High Risk for Hereditary Breast Cancer. Public Health Genomics. 2016;19(6):342–351. [PubMed: 27788513]
25. Shkedi-Rafid S, Gabai-Kapara E, Grinshpun-Cohen J, Levy-Lahad E. BRCA genetic testing of individuals from families with low prevalence of cancer: experiences of carriers and implications for population screening. Genetics in medicine : official journal of the American College of Medical Genetics. 2012;14(7):688–694. [PubMed: 22481128]
26. Bressler T, Popp B. Orthodox Jewish Thought Leaders' Insights Regarding BRCA Mutations: A Descriptive Study. Journal of oncology practice / American Society of Clinical Oncology. 2017;13(4):e303–e309.
27. Freund A, Cohen M, Azaiza F. The doctor is just a messenger: beliefs of ultraorthodox Jewish women in regard to breast cancer and screening. J Relig Health. 2014;53(4):1075–1090. [PubMed: 23543095]
28. Coleman-Brueckheimer K, Spitzer J, Koffman J. Involvement of Rabbinic and communal authorities in decision-making by haredi Jews in the UK with breast cancer: an interpretative phenomenological analysis. Social science & medicine. 2009;68(2):323–333. [PubMed: 19019515]
29. Teman E, Ivry T, Bernhardt BA. Pregnancy as a proclamation of faith: Ultra-Orthodox Jewish women navigating the uncertainty of pregnancy and prenatal diagnosis. American journal of medical genetics Part A. 2011;155A(1):69–80. [PubMed: 21204212]
30. Eckstein J Genetic testing? Only when it will do no harm. AMI-LIVING 2016: 2.
31. Mor P, Oberle K. Ethical issues related to BRCA gene testing in orthodox Jewish women. Nurs Ethics. 2008;15(4):512–522. [PubMed: 18515440]
32. Rose E, Schreiber-Agus N, Bajaj K, Klugman S, Goldwaser T. Challenges of Pre- and Post-Test Counseling for Orthodox Jewish Individuals in the Premarital Phase. Journal of genetic counseling. 2016;25(1):18–24. [PubMed: 26354339]
33. Raz AE, Vizner Y. Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma. Soc Sci Med. 2008;67(9):1361–1369. [PubMed: 18701203]
34. Schneider A, Nakagawa S, Keep R, Dorsainville D, Charrow J, Aleck K, Hoffman J, Minkoff S, Finegold D, Sun W, Spencer A, Lebow J, Zhan J, Apfelroth S, Schreiber-Agus N, Gross S. Population-based Tay-Sachs screening among Ashkenazi Jewish young adults in the 21st century: Hexosaminidase A enzyme assay is essential for accurate testing. American journal of medical genetics Part A. 2009;149A(11):2444–2447. [PubMed: 19876898]

35. Coleman-Brueckheimer K, Dein S. Health care behaviours and beliefs in Hasidic Jewish populations: a systematic review of the literature. J Relig Health. 2011;50(2):422–436. [PubMed: 21249524]

36. Kate C, Jonathan K, Charles D. Why is this happening to me? Illness beliefs held by haredi Jewish breast cancer patients: an exploratory study. Spirituality and Health International. 2007;8(3):121–134.

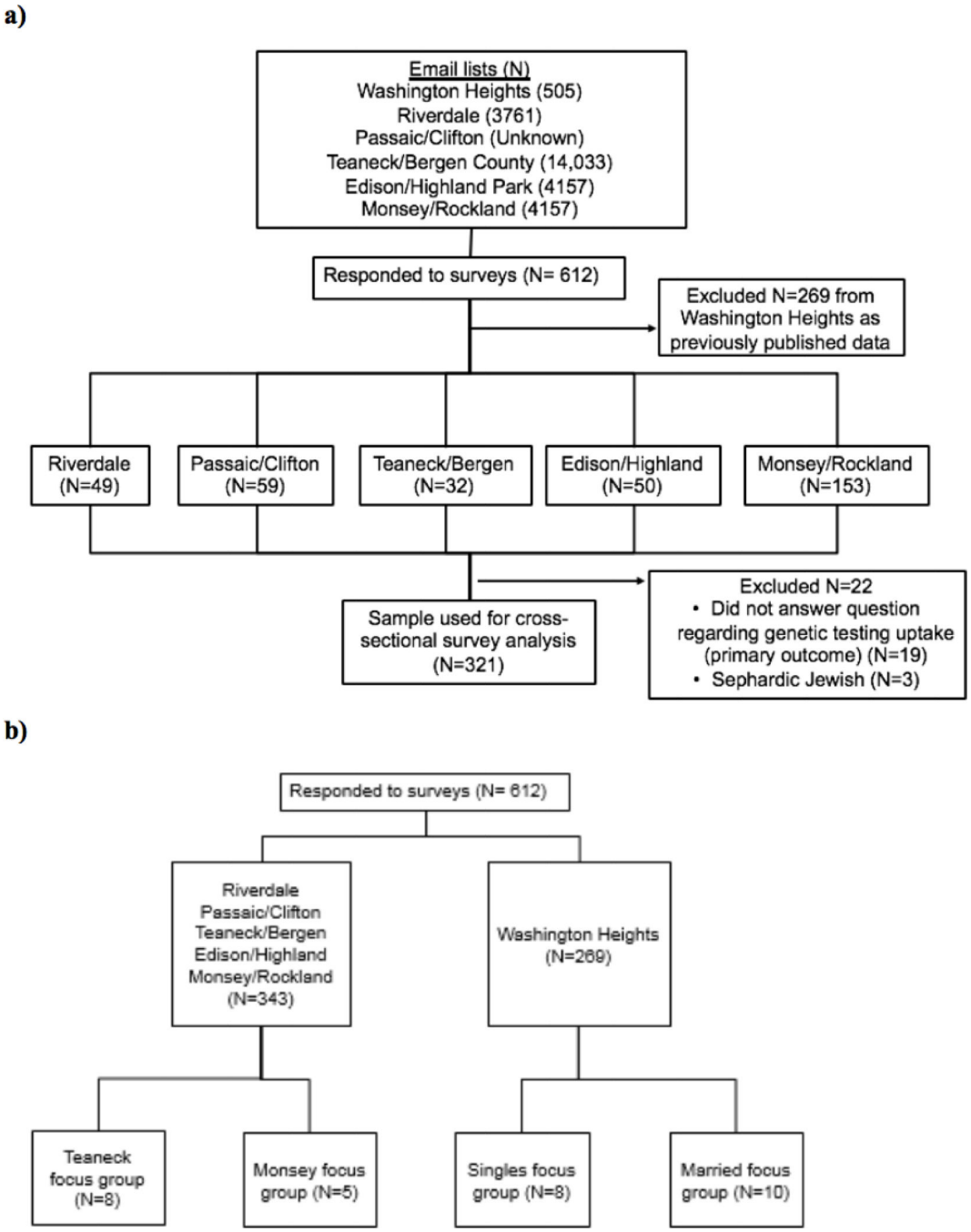

Figure 1.

CONSORT Diagram for a) Cross-sectional Survey and b) Focus groups conducted in Orthodox Jewish women from New York and New Jersey (2015–2017)

Table 1.

Baseline characteristics of study population of Orthodox Jewish women from New York and New Jersey, 2015–2017 (N=321).

		Total	Genetic Testing Uptake		p-value
		N= 321	YES N=64 (19.9%)	NO N=257 (80.1%)	
Demographics					
Age, median in years (range)		47 (25–82)	54 (25–82)	44 (25–77)	0.001
Jewish community segment, N (%)	Modern Orthodox	179 (55.8)	44 (69.8)	135 (52.5)	0.01
	Yeshivish/Chassidish/ Other	141 (43.9)	19 (30.2)	122 (47.5)	
Highest level of secular education, N (%)	Elementary/High School/ Vocational	18 (5.61)	2 (3.1)	16 (6.2)	0.46
	Some College/University Degree	118 (36.8)	21 (32.8)	97 (37.7)	
	Masters/Doctoral Degree	185 (57.6)	41 (64.1)	144 (56.0)	
Highest level of Jewish education, N (%)	None	39 (12.1)	9 (14.3)	30 (11.7)	0.19
	Elementary school/High School	86 (26.8)	23 (36.5)	63 (24.6)	
	Post-secondary	117 (36.4)	18 (28.6)	99 (38.7)	
	Collegiate or graduate	77 (24)	13 (20.6)	64 (25)	
Insurance Status, N (%)	Medicaid	18 (5.6)	1 (1.7)	17 (6.6)	0.0009
	Medicare	37 (11.5)	12 (18.8)	25 (9.7)	
	Private Insurance	259 (80.7)	50 (78.1)	209 (81.3)	
	Uninsured/Don’t know	7 (2.8)	1 (1.6)	6 (2.3)	
Marital status, N (%)	Married	270 (84.1)	58 (90.6)	212 (82.5)	0.11
	Unmarried	51 (15.9)	6 (9.38)	45 (17.51)	
Prior breast biopsy, N (%)	Yes	90 (28.0)	33 (51.6)	57 (22.3)	<0.0001
	No	230 (71.7)	31 (48.4)	199 (77.7)	
Prior breast cancer, N (%)	Yes	20 (6.2)	15 (23.4)	5 (1.95)	<0.0001
	No	301 (93.8)	49 (76.6)	252 (98.1)	
Breast and Ovarian Cancer History					
Personal history of breast cancer, N (%)	Yes	20 (6.2)	15 (23.4)	5 (1.95)	<0.0001
	No	301 (93.8)	49 (76.6)	252 (98.1)	
Personal history of ovarian cancer, N (%)	Yes	2 (0.62)	1 (1.6)	1 (0.4)	0.36
	No	314 (97.8)	63 (98.4)	251 (99.6)	
Family history of breast cancer, N (%)	Yes	148 (46.1)	48 (75)	100 (38.9)	<0.0001
	No	173 (53.9)	16 (25)	157 (61.1)	
Family history of ovarian cancer, N (%)	Yes	34 (10.6)	20 (31.3)	14 (5.5)	<0.0001
	No/Don’t know	287 (89.4)	44 (68.8)	243 (94.6)	
Relative tested positive for *BRCA1/2* mutation, N (%)	Yes	26 (8.1)	22 (34.4)	4 (1.6)	<0.0001

		Total	Genetic Testing Uptake		p-value
		N= 321	YES N=64 (19.9%)	NO N=257 (80.1%)	
	No/Don't know	295 (91.9)	42 (65.6)	253 (98.4)	
Eligible for *BRCA1/2* genetic testing based upon USPSTF guidelines, N (%)	Yes	160 (49.8)	56 (87.5)	104 (40.5)	<0.0001
	No	161 (50.2)	8 (12.5)	153 (59.5)	
Validated Measures					
Adequate genetic testing knowledge, N (%)	Yes	121 (37.7)	33 (51.6)	88 (34.2)	0.04
	No	137 (42.7)	21 (32.8)	116 (45.1)	
	Unknown	63 (19.6)	10 (15.6)	53 (20.6)	
Perceived Risk Compared to Average Woman of Same Age, N (%)	Lower	46 (14.3)	5 (7.8)	41 (16.0)	<0.0001
	Same	174 (54.2)	25 (39.1)	149 (58.0)	
	Higher	60 (18.7)	26 (40.6)	34 (13.2)	
	Unknown	41 (12.8)	8 (12.5)	33 (12.8)	
Breast cancer worry *	Mean (SD), range: 1 [none] - 7 [worry all of the time]	2.4 (1.2)	2.9 (1.5)	2.3 (1.1)	0.001
Stigma of carrying a gene mutation for cancer *	Average (SD), range: 1 [low stigma] – 5 [high stigma]	2.3 (1.1)	2.1 (1.0)	2.3 (1.1)	0.14

*More than 5% missing data. Percentages and p-values based on known values only.

Table 2.

Multivariable analysis of factors associated with *BRCA1/2* genetic testing uptake among Orthodox Jewish women from New York and New Jersey, 2015–2017 (N=253).

Predictors	Odds Ratio	95% Confidence Interval	p-value
Age	1.02	0.99–1.05	0.20
Community Segment (Modern Orthodox vs Non-Modern Orthodox)	2.31	1.03–5.17	0.04
Marital Status (Married vs Unmarried)	3.49	1.03–11.80	0.04
Prior Biopsy (YES vs NO)	2.57	1.10–6.00	0.03
USPSTF Eligible for Genetic Testing (YES vs NO)	9.74	3.62–26.18	<0.0001
Adequate Genetic Testing Knowledge (YES vs NO)	1.40	0.67–2.96	0.37
Breast Cancer Risk Perception[a]			
Same (referent)	1.00	-	-
Lower	1.09	0.34–3.57	0.88
Higher	2.06	0.87–4.90	0.10
Unknown	1.70	0.06–48.4	0.76
Breast Cancer Worry (1 [none] - 7 [worry all of the time])[b]	0.87	0.62–1.23	0.45

Final model: p<0.0001 when adjusted for all variables in the model. Participants with missing data were excluded from the model except in cases of dummy variable for an “unknown” category. Since menopausal status correlated with age, and family history of breast/ovarian cancer and relative with *BRCA1/2* mutation were associated with eligibility for *BRCA1/2* genetic testing, they were not included in the multivariable model.

[a] Breast cancer risk perception assessed comparative risk to the average woman, with responses including same risk as the average woman (reference category), lower risk than the average woman, or higher risk than the average woman.

[b] Breast cancer worry was analyzed as a continuous variable.

Table 3.

Baseline characteristics of focus group participants of Orthodox Jewish women from Teaneck, NJ, Monsey, NY, and Washington Heights, NY, 2015–2016 (N=31)

Characteristic	Teaneck (N=8)	Monsey (N=5)	Washington Heights – Single (N=8)	Washington Heights – Married (N=10)
Median age, years (range)	51 (42–69)	53 (28–60)	24 (22–36)	29 (23–77)
Jewish origin, N (%)				
Ashkenazi	8 (100)	5 (100)	7 (88)	9 (90)
Sephardi	0	0	0	0
Both	0	0	1 (13)	0
Jewish community, N (%)				
Modern Orthodox	4 (50)	0 (0)	5 (63)	8 (80)
Yeshivish	3 (38)	3 (60)	3 (38)	2 (20)
Chassidish/Lubavitch	0 (0)	2 (40)	0 (0)	0 (0)
Other	1 (13)	0 (0)	0 (0)	0 (0)
Highest level of secular education, N (%)				
High school	0 (0)	1 (20)	0 (0)	0 (0)
College/Some College	7 (88)	1 (20)	6 (75)	4 (40)
Masters/Doctoral degree	1 (13)	3 (60)	2 (25)	6 (60)
Highest level of Jewish education, N (%)				
None	1 (13)	1 (20)	0 (0)	1 (10)
Elementary/High school	2 (25)	1 (20)	0 (0)	1 (10)
Post-secondary/Higher	4 (50)	2 (40)	8(100)	8 (80)
Marital status, N (%)				
Single	1 (13)	0 (0)	8(100)	0 (0)
Married/Widowed	7 (88)	5 (100)	0 (0)	10 (100)

Table 4.

Themes and quotations from discussions about *BRCA1/2* genetic testing and breast cancer across four focus groups of Orthodox Jewish women from New York and New Jersey, 2015–2016 (N=31).

Themes	Examples
Impact on Marriage and Family	• "If you're dating, then suddenly that has to come up and suddenly they had someone in their family who struggled with it and died and it could be a very big deal breaker." • "The fear in our community is if someone is branded, so now who wants to marry them because they have a 50% chance of passing away early." • "There's money involved [in testing expenses] so I have to kind of follow a path that he's [my husband] gonna be comfortable with and he's gonna actually follow the advice that I'm given." • "They [husbands] may have a say in these kind of decisions. And then all of the decisions that follow. They're all financial as well as life decisions so if they don't have the [medical] knowledge, then that could be a problem."
Role of Community	• "You have to know your crowd but a lot of it does start at the Shabbos [Sabbath] table when you're with people and you start talking about things, and you make people aware, more open. If we continue to treat it as some taboo, then this information is not going to be shared." • "Going to the Chassidish community – I'm not talking about the modern Chassidish – but I'm talking about the ones who are you know really right-wing. There you're gonna have people who really don't have internet, they're not gonna benefit from anything that's internet based." • "I wanted to do whatever I could to help in this field because the amount of friends I have that when I told them [that I was diagnosed with breast cancer], said to me, 'I never had a mammogram' – was absolutely frightening to me. And I want to do whatever I can to help women protect themselves."
Religious Considerations	• "After the fact, when you're dealing with the repercussions of [genetic testing] – what are my medical decisions that I have to make now, and some of them have *halachic* implications – I think then I would consult a rabbi." • "I spoke to my rav [rabbi] about it [breast cancer diagnosis] and he did not want me to have my name out there for the general community for knowledge. His reason was not because of any of this fear thing, his was like a spiritual reason. That when you present yourself...Hashem [God] treats you as a sick person, so he wanted me to just let my more immediate friends, family know to be supportive but that I was like spiritually be positioning myself differently." • "I'm sure a lot of people are terrified and just absolutely think you're just gonna drop dead and they don't want to know, they don't want to know, or it's all in God's hands. Yeah, everything is in God's hands, but we are supposed to take care of ourselves and doctors do have the ability to heal and we don't know why, why this, why that."