UNDERSTANDING SOCIAL, CULTURAL, AND RELIGIOUS FACTORS INFLUENCING MEDICAL DECISION-MAKING ON BREAST CANCER GENETIC TESTING IN THE ORTHODOX JEWISH COMMUNITY

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Abstract

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Background. While the prevalence of a pathogenic variant in the *BRCA1* and *BRCA2* genes occurs in about 1:400 (0.25%) in the general population, the prevalence is as high as 1:40 (2.5%) among the Ashkenazi Jewish population. Despite cost-effective preventive measures for mutation carriers, Orthodox Jews constitute a cultural and religious group that presents challenges to *BRCA1* and *BRCA2* genetic testing. This study analyzed a dialogue of key stakeholders and community members to explore factors that influence decision-making about *BRCA1* and *BRCA2* genetic testing in the New York Orthodox Jewish community.

Methods. Qualitative research methods, based in Grounded Theory and Narrative Research, were utilized to analyze the narratives of key stakeholders and community members in an analysis of qualitative data collected from 49 stakeholders. A content analysis was conducted to identify themes; inter-rater reliability was 71%.

Results. Facilitators to genetic testing were prevention and education, while barriers to genetic testing included negative emotions, impact on family/romantic relationships, cost, and stigma. The role of religious figures and healthcare professionals in medical decision-making were viewed as controversial. Education, health, and community were discussed as influential factors. There were issues around disclosure, implementation, and information needs.

Conclusion. This study revealed the voices of the Orthodox Jewish women (*decision-makers*) and key stakeholders (*influencers*) who play a critical role in the medical decision-making process. The findings have broad implications for engaging community stakeholders within faith-based or culturally distinct groups to ensure better utilization of healthcare services for cancer screening and prevention designed to improve population health.

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Chapter I

INTRODUCTION

This chapter begins by providing a brief overview of this study and presenting the problem statement. Then, the purpose, specific aim, and significance of the study is discussed. Grounded Theory and Narrative Research, which are the guiding theoretical perspectives of this study, are explained in detail, followed by definition of key terms, delimitations of this study, and the implications for health education and behavioral intervention. The researcher's prior experience and relevance to the study are discussed in the last part of this chapter.

Breast cancer confers significant morbidity and mortality among women in the United States. To address this, Healthy People 2030 has set goals to reduce the female breast cancer death rate, increase the proportion of women with a family history of cancer who receive genetic counseling for hereditary breast and ovarian cancer (HBOC) and receive *BRCA1/2* genetic testing based on the most recent guidelines (U.S. Department of Health and Human Services, n.d.). Genetic determinants, such as germline pathogenic variants in the *BRCA1* and *BRCA2* genes, have an important impact on breast and ovarian cancer risk. An estimated 2-7% of breast cancers result from inherited mutations in *BRCA1* and *BRCA2* (Risch et al., 2006). Risk

management options now include enhanced breast cancer screening with annual mammography and breast MRI, risk-reducing surgeries (i.e., prophylactic mastectomy, bilateral salpingo-oophorectomy), and chemoprevention, all of which have been shown to improve early detection and reduce breast and ovarian cancer incidence and mortality (Domchek et al., 2010; King et al., 2001; Warner et al., 2011). Counseling, screening, and preventive measures associated with *BRCA1/2* genetic testing have also been shown to improve quality of life, reduce psychological distress about cancer, and increase accuracy of cancer risk perception and knowledge about genetics (Sivell et al., 2007).

While the prevalence of a *BRCA1/2* pathogenic variant is about 1 in 400 (0.25%) in the general population, the prevalence of founder mutations in the *BRCA1* (5382insC or 185delAG) and *BRCA2* (6174delT) is as high as 1 in 40 (2.5%) in the Ashkenazi (central and eastern European) Jewish population (Metcalfe et al., 2012; Struewing et al., 1997). Population-based *BRCA1/2* testing of unselected Ashkenazi Jews compared to family history-based screening identifies about 56% more mutation carriers (Manchanda, Loggenberg, et al., 2014). In addition, one study has shown that population-based screening among this population is highly cost-effective in Ashkenazi Jewish women 30 years or older (Manchanda, Legood, et al., 2014). Despite this, there are multiple patients, healthcare systems, and societal factors involved in the acceptance and implementation of population-based screening among Ashkenazi Jews. Studies examining attitudes and knowledge about *BRCA1/2* genetic testing 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 (Lehmann et al., 2002; Phillips et al., 2000; Wiesman et al., 2017).

This study is part of a community-based participatory research (CBPR) project in which a multi-disciplinary research group at an academic institution collaborated with a Jewish organization to better understand knowledge, attitudes, and perceptions of *BRCA1/2* genetic testing among the Orthodox Jewish community. Utilizing quantitative and qualitative data that have been collected and analyzed by this academic institution-community organization partnership, we conducted studies investigating attitudes, influential factors, intention, and uptake of *BRCA1/2* genetic testing among a population of Orthodox Jewish women (Tang et al., 2017, Trivedi et al., 2018, Yi et al., 2017, Yi et al., 2018). Previous studies collected data on women around *BRCA1/2* genetic testing.

We conducted this study to fill the gap in this understanding by revealing the voices of key stakeholders and community members to understand the social and cultural factors affecting medical decision-making around *BRCA1/2* genetic testing. Including women in the discussion would be inevitable because women are the ones making the medical decisions around *BRCA1/2* genetic testing. Many Jewish women may be unsure about their personal desire or religious obligation to disclose genetic test results with others (Phillips et al., 2000). We sought to develop a comprehensive understanding of the social, cultural, and religious factors that influence Orthodox Jewish women's medical decision-making.

Problem Statement

According to the U.S. Preventive Services Task Force guidelines, Ashkenazi Jewish women with any first or second-degree relatives with breast or ovarian cancer should be referred for *BRCA1/2* genetic counseling (Bellcross et al., 2013). Due to the availability of preventive measures for mutation carriers, some have advocated for population-based *BRCA1/2* genetic

testing in unselected Ashkenazi Jews (Metcalfe et al., 2013). However, Orthodox Jews are an understudied population with unique social, cultural, and religious issues that may present challenges to their participating in population-based genetic screening. As a result, before setting the stage for population-based screening, it is essential to first identify the unique issues, challenges, and barriers that may arise among the Orthodox Jewish population due, in part, to their adherence to *Halacha*, which is the Jewish law or code of ethics.

In a previous survey we conducted in Washington Heights in New York City, we found that Orthodox Jewish women tend to seek medical advice from rabbis, especially to find out the *halachic* implications (Yi et al., 2017). After analyzing the surveys and focus groups that were conducted in five towns in New York and New Jersey (including Riverdale, NY; Passaic/Clifton, NJ; Teaneck/Bergen, NJ; Edison/Highland, NJ; and Monsey, NY), we concluded that, in order to increase the uptake of *BRCA1/2* genetic testing among the Orthodox Jewish 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 (Trivedi et al., 2018). Therefore, in order to explore these factors in depth, this study analyzed the narratives of community members, including women, healthcare providers, genetic counselors, religious leaders, and other stakeholders, around *BRCA1/2* genetic testing. This study is unique and promises to make a significant contribution to the literature because it includes and focuses attention on the voices of not only the women (*decision-makers*), but also community members around them (*influencers*) that play a role in the decision-making process.

Purpose of the Study

The purpose of this study was to understand the social, cultural, and religious factors influencing medical decision-making on *BRCA1/2* genetic testing in the Orthodox Jewish community.

Specific Aim

The aim was to analyze a dialogue of key stakeholders and community members to explore factors that influence decision-making about *BRCA1/2* genetic testing in the Orthodox Jewish population. The stakeholder dialogue included healthcare providers, religious leaders, and community members to gain a comprehensive understanding of the social, cultural, and religious factors that influence Orthodox Jewish women's medical decision-making.

Significance of the Study

As a community-based participatory research study, an interdisciplinary research group at Columbia University Irving Medical Center partnered with the Institute for Applied Research and Community Collaboration (ARCC) to explore cultural beliefs about *BRCA1/2* genetic screening. ARCC's mission is to conduct and disseminate rigorous research on psycho-social issues in the Orthodox Jewish community. This collaboration allowed us to better understand the Orthodox Jewish community and culture throughout the research process, which has resulted in identifying religious aspects that affect medical decisions that are not yet studied. In addition, by understanding social, cultural, and religious factors, this study was designed to identify important barriers to *BRCA1/2* genetic testing among Orthodox Jewish women. Appropriate use of genetic

testing will improve breast cancer risk assessment and enhance uptake of risk-appropriate screening and prevention strategies.

The perceived benefits and risks of genetic testing vary by demographic, cultural, and religious backgrounds. Orthodox Jewish communities are growing world-wide due to their high birth rate and the fact that many remain within their communities (Greenberg & Witztum, 2001). Orthodox Jews often consult with rabbinic and communal authorities in medical decision-making, which is consistent with their religious values (Coleman-Brueckheimer et al., 2009). The Jewish community is already familiar with genetic testing due to successful testing programs for genetic disorders, such as Tay-Sachs, an autosomal recessive disease (Broide et al., 1993). However, there are unique challenges to testing for *BRCA1/2* genes in the Jewish population. In order to understand the social, cultural, and religious factors influencing medical decision-making on *BRCA1/2* genetic testing in detail and in depth, this study conducted a qualitative research study (Anderson, 2010).

Guiding Theoretical Perspectives

As part of the community-based research project, a population-based study investigated attitudes toward *BRCA1/2* genetic testing among Orthodox Jewish women. A cross-sectional survey assessed breast cancer risk, genetic testing knowledge, self-efficacy, perceived breast cancer risk and worry, and religious and cultural factors affecting medical decision-making among Orthodox Jewish women (Tang et al., 2017). However, the questions on religious and cultural factors were solely focused on the role of rabbis in the decision-making process. Following this research, another mixed-methods study examined the role of rabbis in medical decision-making and the results showed that not only rabbis, but also healthcare professionals

influence medical decisions about genetic testing in the Orthodox Jewish population (Yi et al., 2017). Therefore, in order to explore the social, cultural, and religious factors in depth, this study utilized the Grounded Theory method and Narrative Research to examine the *narratives* of stakeholders and community members, including healthcare providers, genetic counselors, religious leaders, and women around *BRCA1/2* genetic testing. As applied in this study, researchers are increasingly combining different methodologies while conducting qualitative research. A study from Lal et al. (2012) shows that integrating Grounded Theory and Narrative Research are theoretically commensurable and can complement each other within qualitative studies. In addition, integrating the two approaches allows deeper understanding of the phenomenon.

Grounded Theory

This study is based on Grounded Theory, which is a form of qualitative research developed by Glaser and Strauss (1967). The authors define Grounded Theory as "the discovery of theory from data" (p. 1). Grounded Theory is also known as "a systematic procedure used to generate a theory that broadly explains, at a conceptual level, a process, action, or interaction about a substantive topic" (Behar-Horenstein, 2018). Grounded Theory has unique features. First, the concepts out of which the theory is constructed are not defined prior to starting the research but are derived from data collected during the research phase (Creswell, 2013). Second, Grounded Theory is an accumulation and representation of all the cases rather than a collection of individual cases. Each case contributes to the development of the concepts, and the concepts drive the analysis. Third, research analysis and data collection are inter-related. Theoretical

sampling takes place, which is when the researcher analyzes the data and concepts derived from the analysis form the basis for the subsequent data collection.

In Grounded Theory, respondents are not the objects of analysis, since the purpose of Grounded Theory research is to identify, develop, and integrate concepts; rather, the concepts that respondents provide through the narrative data are the object of analysis. Thus, this is an interpretive process that involves defining concepts to stand for the meaning of the data. When constructing theory from data, the interplay between researcher and data is crucial so that the final theory is a construction of both data and researcher perspective (Corbin, 2017).

Grounded Theory and qualitative content analysis have similar aspects. Both identifies themes and patterns that is based on naturalistic inquiry and involves rigorous coding. In addition, Grounded Theory and qualitative content analysis both analyze and interpret qualitative data. However, the similarities and differences between them have not been clarified in literature (Priest et al., 2002). According to Cho & Lee (2014), Grounded Theory is considered as a research methodology and content analysis as a method. Also, Grounded Theory is treated as a theoretical framework and content analysis as a research method of textual data analysis. Qualitative content analysis is a strategy when analyzing qualitative descriptive studies (Sandelowski, 2000) and a technique of other research methods, such as ethnographic and grounded theory (Altheide, 1987). For this study, the research methodology and theoretical framework is Grounded Theory, and the research method of textual data analysis is content analysis.

Narrative Research

In the social sciences, narrative and life story have become increasingly noticeable in the theory, research, and application of various fields, including psychology, gender studies, education, anthropology, history, sociology, linguistics, law, and medicine. In these fields, narrative studies thrive by seeking to understand the narrator's lifestyle and culture. There are numerous studies that utilize narrative to investigate a research question. In psychology, education, and medicine, for example, researchers use narratives to diagnose psychological and medical problems or learning disabilities. In sociology and anthropology, narrative is used to present the lifestyle of certain subgroups in society (i.e., gender, race, religion). In cognitive sciences, narrative allows researchers to study memory, language development, and information processing. These studies demonstrate that narratives are a powerful means by which to understand meaning and can be used both in basic and applied research (Lieblich et al., 1998). In health communication research, narrative inquiry is enacted through study objectives and design, and how the data are extracted. According to Yamasaki et al. (2014), "Investigators with an *attitude* open to narrative sensibilities consider both the *acts* of making stories and the resulting textual *artifacts* as important areas of study." (p. 102). When "real-life problems" need to be investigated, narrative methods can be considered "real-world measures" (Bickman & Rog, 1998).

Qualitative researchers retain the data in their original and descriptive form and analyze these in ways that preserve their narrative meaning. Narrative analysis is the most widespread of qualitative data analysis that draws more from the humanities than the social sciences. Some of these approaches involve coding and thematic analysis (Maxwell, 2018). According to Lieblich et al. (1998), narrative research refers to any study that uses or analyzes narrative materials,

which can be the object of the study or a means for the study of another question. Mazur (2018) stated the following:

> Narrative research is driven by a desire to fill a gap in existing knowledge about a given topic. For that reason, an extensive literature review is usually among the first steps of any narrative research project. Such a review will help the researcher understand which parts of an idea or construct would benefit from being further investigated through narrative inquiry and will provide a foundation for how to approach the research puzzle. (p.3)

Narrative investigators collect narrative data from qualitative research (i.e., observation, interview, focus group, archival examination) like other researchers, but they focus on stories. For instance, an ethnographer analyzes the whole picture in the field, such as rituals, behavior, and discourse, while a narrative researcher focuses on the stories being told. Two basic principles are known to characterize narrative methodology: 1) treats the story as an object for analysis, and 2) follows the narrative ontology that emphasizes the story's holistic nature by adopting a multidimensional and interdisciplinary lens, treating the story as a whole unit, and paying attention to form and contexts (Spector-Mersel, 2010).

Conducting interviews with subjects is thus a common means by which narrative researchers collect data. During the interviews, the researchers focus on listening and supporting the storytelling, rather than talking. Then, an iterative process is used to analyze texts, which requires reading it over multiple times to understand how themes relate to each other and to a larger whole. This process allows the researcher to detect the voices that surface and continue this cycle until the researcher has gained an understanding of the meaning and nuances of the

text. In addition, some narrative researchers receive feedback about their work from others to improve their study (Mazur, 2018).

Definition of Key Terms

Ashkenazi Jewish. Descendants of Jews from France, Germany, and Eastern Europe (Tracey, n.d.-a).

Breast Cancer. A disease in which malignant (cancer) cells form in the tissues of the breast (National Breast Cancer Foundation, 2020).

BRCA1/2. Breast cancer susceptibility genes, *BRCA1* and *BRCA2*.

BRCA1/2 Genetic Testing. A blood test that uses DNA analysis to identify harmful changes (mutations) in either one of the two breast cancer susceptibility genes, *BRCA1* and *BRCA2* (Mayo Clinic, n.d.).

Dor Yeshorim. A genetic testing program for autosomal recessive diseases in the Orthodox Jewish community. The results of this testing are used by couples considering marriage (Grazi & Wolowelsky, 2015; Raz & Vizner, 2008).

Halacha/Halachic. Jewish law or code of ethics.

Kallah Teacher. Teaches women the basics of Jewish marital etiquette.

Medical Decision-Making. As a descriptive endeavor, it seeks to explain how physicians and patients routinely make decisions, and identifies both barriers to, and facilitators of, effective decision making (Schwartz & Bergus, 2008).

Orthodox Jewish. One of the major movements of Judaism, believing that Jewish law comes from God and cannot be changed (Tracey, n.d.-b).

Rebbetzin. Wife of rabbi.

Shadchan. A Jewish professional matchmaker.

Shidduch/Shidduchim. Matchmaking for a Jewish arranged marriage.

Yoetzet Halacha. A woman certified to serve as an advisor to women.

Delimitations

Because this was a qualitative study, the research is heavily dependent on the individual skills and perspective of the researcher and thus may be influenced by the researcher's personal biases. Also, the responses of participants can be affected by the researcher's presence during the data gathering phase. Second, the population of interest in this study comprises Orthodox Jews in New York; thus, the findings may not be generalizable to a larger population or Jewish communities in other areas. Third, the data for this analysis were collected in 2015. Therefore, while enduring aspects of the Jewish culture are generally known to remain stable across generations, there is nevertheless a possibility that the results may have been different had more recent data been collected and analyzed.

Implications for Health Education and Behavioral Intervention

This study anticipated that social, cultural, and religious factors play a significant role in medical decision-making among Orthodox Jewish woman. As shown in my previous study, rabbis and other religious leaders in the Jewish community affect medical decisions on *BRCA1/2* genetic testing (Yi et al., 2017). Therefore, providing education on *BRCA1/2* genetic testing not only to women, but also religious figures and community leaders, will be crucial. Furthermore, this study has broad implications for engaging community stakeholders within faith-based or

cultural minority groups to ensure better utilization of healthcare services for cancer screening and prevention programs that are designed to improve population health and prevent disease.

Application to Development of Culturally-Tailored Decision Aids

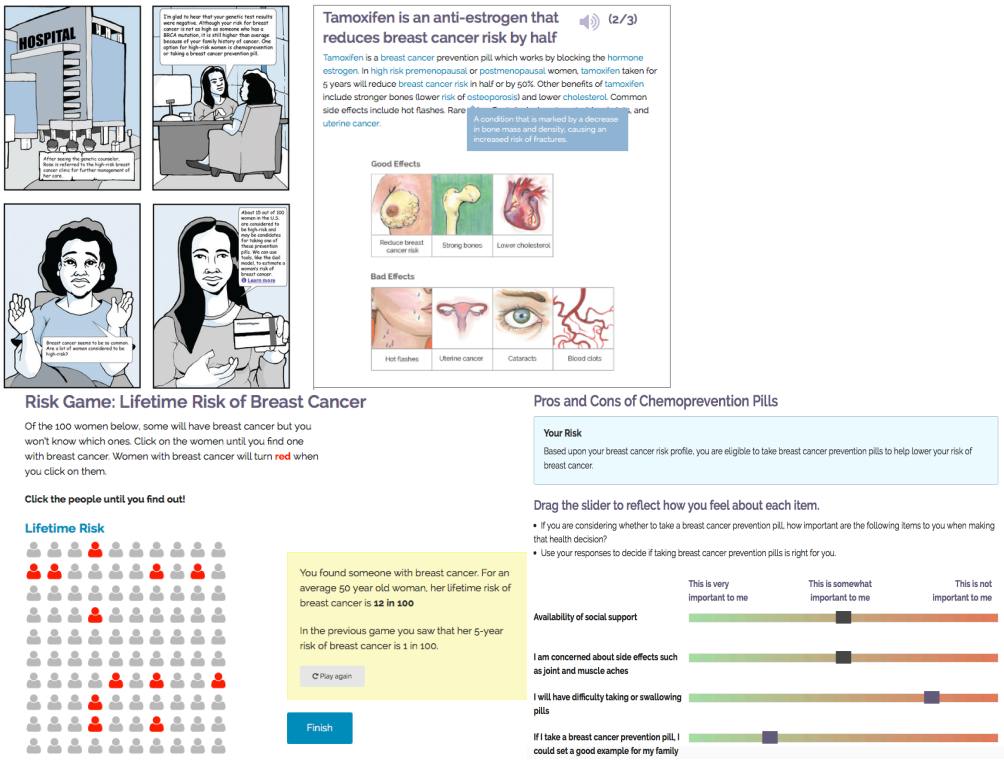
We anticipate that the results of this study could inform the development of a culturally-tailored and patient-centered decision aid for high-risk women (*RealRisks*) and a provider-facing breast cancer risk navigation tool (*BNAV*). I have been actively involved in developing, evaluating, and modifying these tools since its initial stage collaborating with developers and experts in breast cancer and biomedical informatics. By applying the results of this study, the use of these tools could be expanded from the clinic to the community setting.

RealRisks is a web-based patient-centered decision aid designed to improve: 1) accuracy of breast cancer risk perceptions; 2) chemoprevention knowledge, and 3) informed choice (Figure 1). The decision aid includes audio and Spanish translations, as well as the following modules: 1) breast cancer risk (breast cancer risk factors, calculation of personal breast cancer risk according to the Gail model, interactive games on risk communication); 2) chemoprevention (what is chemoprevention, risks and benefits of selective estrogen receptor modulators and aromatase inhibitors for chemoprevention, preference elicitation for chemoprevention). Through the *RealRisks* tool, the decision aid collects information on breast cancer risk factors (i.e., age, age at first period, age at the time of the birth of a first child, family history of breast cancer, number of past breast biopsies, number of breast biopsies showing atypical hyperplasia) to calculate their Gail risk score (also known as the Breast Cancer Risk Assessment Tool). It also collects factors that influenced decision-making about chemoprevention through the preference elicitation game. *RealRisks* generates an action plan for patients summarizing their personalized

breast cancer risk profile and preference elicitation for chemoprevention. The tool is designed for patients with varying levels of health literacy and numeracy. Using surveys, think-aloud protocols, and subject recordings, we identified several themes relating to the usability of *RealRisks*, specifically in the content, ease of use, and navigability of the application. By conducting studies in two languages with a diverse multi-ethnic population, we were able to implement interface changes to make *RealRisks* accessible to users with varying health literacy and acculturation (Coe et al., 2016).

Figure 1

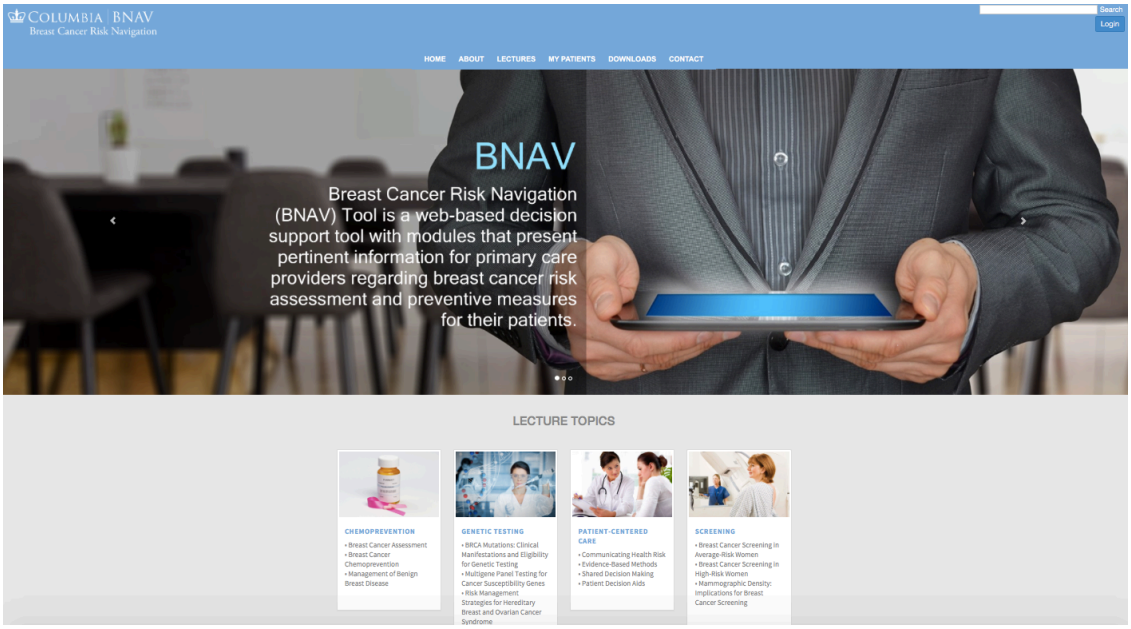
Screenshots of RealRisks



The breast cancer risk navigation tool (*BNAV*) uses a two-pronged approach to improve knowledge among healthcare providers about breast cancer risk assessment and chemoprevention (Figure 2). After patients complete *RealRisks*, a tailored action plan is generated for providers, who will also be invited to access the web-based *BNAV* toolbox. Modeled based on the Theory of Planned Behavior (Ajzen, 1991), the toolbox is a repository of information and resources that includes: 1) standard guidelines and a self-paced interactive educational guide with slide presentations and audio (attitudes); 2) case-based learning modules with quizzes (subjective norm); 3) a repository of their patients' breast cancer risk information, along with action plans based upon their patients' interactions with *RealRisks* (perceived behavioral control). *BNAV* provides information around chemoprevention (breast cancer assessment, breast cancer chemoprevention, management of benign breast disease), genetic testing (*BRCA1/2* mutations: clinical manifestations and eligibility for genetic testing, multigene panel testing for cancer susceptibility genes, risk management strategies for hereditary breast and ovarian cancer syndrome), patient-centered care (communicating health risk, evidence-based methods, shared decision making, patient decision aids), and screening (breast cancer screening in average-risk women/high-risk women, mammographic density: implications for breast cancer screening).

Figure 2

Screenshot of BNAV



Implementing a multi-level intervention for Orthodox Jewish women (*RealRisks*), their healthcare providers (*BNAV*), and faith-based community leaders will possibly increase uptake of *BRCA1/2* genetic testing and counseling. While there are countless decision aids available, there has been little consideration of culture, especially religion, when designing and implementing these tools. This study promises to contribute to inspiring new ways to develop culturally-tailored decision aids whose design and implementation to educate target populations at risk are grounded in practice-based evidence.

Community Dissemination Plan

At the conclusion of the analysis of the stakeholder dialogue, we plan to prepare a written report describing the study, the findings, and a set of recommendations based on those findings. The report will include qualitative and quantitative analysis along with illustrative quotes from

participants, as well as recommendations from the rabbis regarding relevant matters of Jewish law. The report will be made available to participants online and as printed copies. Upon completion of the stakeholder dialogue and issuance of the study report, we will meet with the Advisory Board to discuss the results and engage in dialogue about implementation strategies. The community dissemination plan includes: 1) sharing the results of the cross-sectional survey, focus groups, and stakeholder dialogue online in a communally accessible approach; 2) presenting the results of the final report in a community-wide session; 3) forwarding the report to multiple rabbinic organizations to disseminate to community rabbis outside target area. We believe that providing various sources of health information will be beneficial to the community.

Prior Experience and Relevance to the Study

I came to this study with prior experience that proved invaluable in conducting all aspects of the work. I am currently working as a qualitative researcher at the Laboratory of Informatics Approach to Precision Prevention & Health Promotion at the Columbia University Irving Medical Center. Previously I worked as the data manager and research assistant at the lab. Being part of an interdisciplinary group of researchers, I had the opportunity to conduct research on breast cancer risk and prevention. The research team developed a patient-centered decision aid (*RealRisks*) and a provider-facing breast cancer risk navigation tool (*BNAV*), which has been tailored to target diverse populations. While collecting and analyzing data, I became deeply interested in the cultural factors that influence the different populations and how they affect medical decision-making.

In my previous study, which was awarded a Meritorious Student Award from the Society of Behavioral Medicine, the key findings showed that rabbis and health professionals influence

medical decisions about genetic testing in the Orthodox Jewish population (Yi et al., 2017). I also presented a mixed-methods study identifying the consequences of *BRCA1/2* genetic testing in this religious community at the American Public Health Association annual meeting (Yi et al., 2018). I participated in studies that investigated factors associated with uptake of *BRCA1/2* genetic testing and evaluated a decision aid on *BRCA1/2* genetic testing in Orthodox Jewish women, which led to publication in Public Health Genomics and a conference presentation (Trivedi et al., 2018; Trivedi et al., 2019). This work led to my current research study, which focuses on the social, cultural, and religious factors of *BRCA1/2* genetic testing that influence medical decision-making in the Orthodox Jewish community.

Prior to undertaking this research, I have been conducting qualitative research since I was a master's degree student in Public Administration at Cornell University. I presented my thesis, a qualitative study that conducted a content analysis, at the Global Health & Innovation Conference at Yale University. Having experience in qualitative research methods, I was responsible for analyzing qualitative data and training other researchers to conduct content analysis using ATLAS.ti, a popular software for qualitative data analysis. This led to becoming a Certified ATLAS.ti Trainer and Consultant. The Grounded Theory approach I have been using for several years to collect and analyze qualitative data revealed new findings on culture and perspectives of diverse populations, and was used for this study as well. In addition, as I worked with diverse populations of interest, such as Hispanic and Jewish groups, I gained great interest in Narrative Research and believe that the narratives of people can provide unique perspectives when developing culturally-sensitive, tailored health-related programs and policies. Following is a list of my publications and selected conference presentations during my doctoral studies that led to my current study. Topics include patient-provider communication, developing and

evaluating decision support tools, culturally diverse population, *BRCA1/2* genetic testing, and medical decision-making.

Publications:

Coe, A. M., Ueng, W., Vargas, J. M., David, R., Vanegas, A., Infante, K., Trivedi, M., Yi, H., Dimond, J., Crew, K. D., & Kukafka, R. (2016). Usability testing of a web-based decision aid for breast cancer risk assessment among multi-ethnic women. *American Medical Informatics Association Annual Symposium Proceedings,* 411-420. [PMCID: 28269836]

Kukafka, R., Yi, H., Xiao, T., Thomas, P., Aguirre, A., Smalletz, C., David, R., Crew, K. (2015). Why breast cancer risk by the numbers is not enough: Evaluation of a decision aid in multi-ethnic low-numerate women. *Journal of Medical Internet Research, 17*, e165. [PMCID: PMC4526996]

McGuinness, J., Ueng, W., Trivedi, M. S., Yi, H., David, R., Vanegas, A., Vargas, J., Sandoval, R., Kukafka, R., & Crew, K. D. (2017). Factors associated with false positive results on screening mammography in a population of predominantly Hispanic women. *Cancer Epidemiology Biomarkers and Prevention, 27*, 446-453. [PMCID: PMC5884721]

Trivedi M. S., Colbeth, H., Yi, H., Stark, R., Diamond, R., Respler, L., Vanegas, A., Chung, W. K., Appelbaum, P., Kukafka, R., Schechter, I., & Crew, K. D. (2019). Understanding factors associated with uptake of *BRCA1/2* genetic testing among Orthodox Jewish women in the United States using a mixed methods approach. *Public Health Genomics, 21*(5-6), 186-196. [PMCID: PMC6687531]

Yi, H., Xiao, T., Thomas, P. S., Aguirre, A. N., Smalletz, C., Dimond, J., Finkelstein, J., Infante, K., Trivedi, M., David, R., Vargas, J., Crew, K. D., & Kukafka, R. (2015). Barriers and facilitators to patient-provider communication when discussing breast cancer risk to aid in the development of decision support tools. *American Medical Informatics Association Annual Symposium Proceedings*, 1352-1360 [PMCID: PMC4765687]

Selected Presentations:

Kukafka, R., Crew, K. D., Yi, H., Xiao, T., Sivasubramanian, P. S., Aguirre, A. N. (2014). Evaluation of an early prototype of a patient-centered decision aid to improve accuracy of breast cancer risk perception. *American Medical Informatics Association Annual Symposium Proceedings*, Washington, DC.

Telfort, J., Trivedi, M. S., Yi, H., Colbeth, H., Vanegas, A., Vargas, J., Sandoval, R., Wood, J., Dimond, J., Finkelstein, J., Kukafka, R., Crew, K. D. (2017). Implementing decision support for breast cancer chemoprevention in primary care. *Journal of Clinical Oncology, 35*, no. 15_suppl. [DOI: 10.1200/JCO.2017.35.15_suppl.e13038]

Trivedi, M. S., Colbeth, H., Yi, H., Vanegas, A., Starck, R., Chung, W. K., Appelbaum, P. S., Kukafka, R., Schechter, I., & Crew, K. D. (2017). Understanding factors associated with uptake of *BRCA* genetic testing among Orthodox Jewish women using a mixed-methods approach. *San Antonio Breast Cancer Symposium,* San Antonio, TX.

Trivedi, M. S., Manley, H., Yi, H., Silverman, T., Chung, W. K., Appelbaum, P. S., Starck, R., Schechter, I., Kukafka, R., & Crew, K. D. (2019). Evaluation of a decision aid on *BRCA1/2* genetic testing in Orthodox Jewish women. *San Antonio Breast Cancer Symposium,* San Antonio, TX.

Trivedi, M. S., Yi, H., Chung, W., Dimond, J., David, R., Respler, L., Stark, R., Schechter, I., Kukafka, R., & Crew, K. D. (2016). Development of a culturally-tailored decision aid on *BRCA* genetic testing for Orthodox Jews. *Basser Annual Scientific Symposium*, Philadelphia, PA.

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Chapter II

REVIEW OF THE LITERATURE

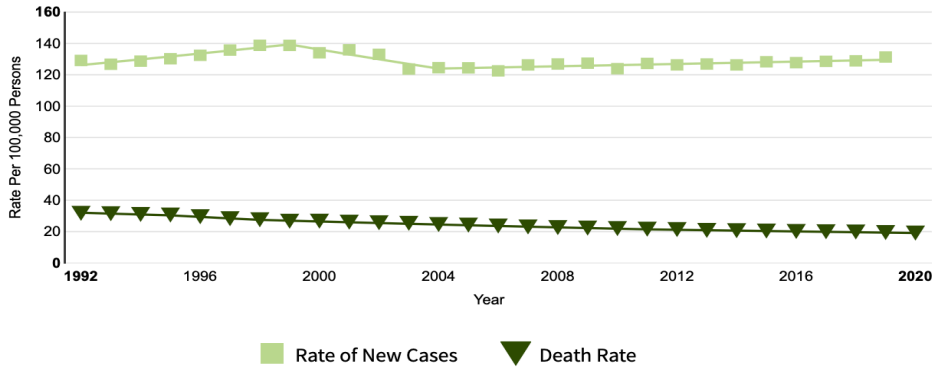
This chapter will explore breast cancer, breast cancer genetic testing, and medical decision-making around genetic testing in the Jewish population. Then, previous efforts to promote genetic testing will be studied. There is a genetic testing program in the Orthodox Jewish community called *Dor Yeshorim*, which conducts genetic testing for autosomal recessive diseases in the Orthodox Jewish community. This program has led to a dramatic decrease in the incidence of Tay-Sachs disease. In addition, marriages in the Orthodox Jewish community are facilitated by a system of matchmaking (*shidduchim*) and the results of genetic testing are used in this process. Therefore, the last two sections of this chapter will discuss the social and community context of Orthodox Jews and Tay-Sachs in the Jewish community.

Breast Cancer and Breast Cancer Genetic Testing

Breast cancer confers significant morbidity and mortality among women in the U.S. Figure 3 shows the rate of new cases and death rate from 1992 to 2020. In 2022, there are 287,850 estimated new cases of breast cancer, which is 15% of all new cancer cases. 43,250 estimated deaths occurred due to breast cancer in 2022, which is 7.1% of all cancer deaths. Based on 2012-2018 data, the 5-year relative survival rate (survives 5 years of more after being diagnosed with female breast cancer) for breast cancer is 90.6% (National Cancer Institute, 2022b). Data show that not only 1 in 8 women in the U.S. will develop breast cancer in her lifetime, but also every 2 minutes a woman is diagnosed with breast cancer on average in the U.S. (National Breast Cancer Foundation, 2020). As shown in Figure 4, women aged 65-74 are most frequently diagnosed with female breast cancer (26.5%), and the median age at diagnosis is 63. Women aged 65-74 also has the highest percentage of female breast cancer deaths (24.4%) and the median age at death is 70 (Figure 5). Table 1 shows that non-Hispanic White and non-Hispanic Black race/ethnicity groups have higher death rates than death rates of all races (National Cancer Institute, 2022b).

Figure 3

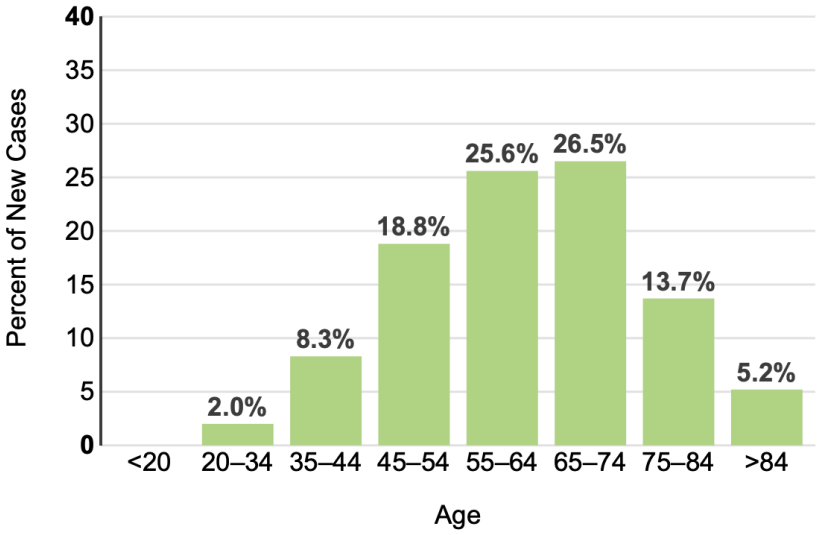
New Cases and Deaths of Female Breast Cancer



Note. From *Cancer Stat Facts: Female Breast Cancer,* by National Cancer Institute, 2022b (https://seer.cancer.gov/statfacts/html/breast.html). Copyright 2022 by SEER.

Figure 4

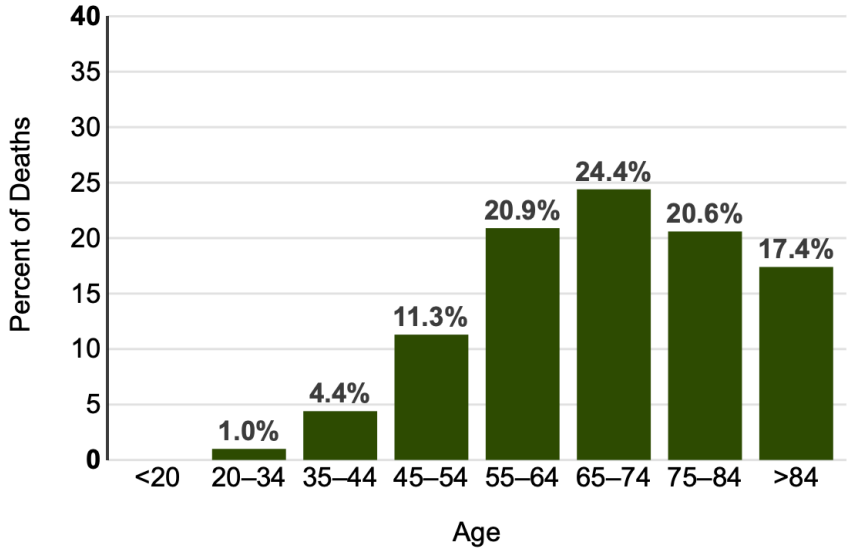
Percent of New Cases by Age Group: Female Breast Cancer



Note. From *Cancer Stat Facts: Female Breast Cancer,* by National Cancer Institute, 2022b (https://seer.cancer.gov/statfacts/html/breast.html). Copyright 2022 by SEER.

Figure 5

Percent of Death by Age Group: Female Breast Cancer



Note. From *Cancer Stat Facts: Female Breast Cancer,* by National Cancer Institute, 2022b (https://seer.cancer.gov/statfacts/html/breast.html). Copyright 2022 by SEER.

Table 1

Death Rate per 100,000 Persons by Race/Ethnicity: Female Breast Cancer

All Races	19.6
Non-Hispanic White	19.7
Non-Hispanic Black	27.6
Non-Hispanic Asian/Pacific Islander	11.7
Non-Hispanic American Indian/Alaska Native	17.6
Hispanic	13.7

Note. From *Cancer Stat Facts: Female Breast Cancer,* by National Cancer Institute, 2022b (https://seer.cancer.gov/statfacts/html/breast.html). Copyright 2022 by SEER.

Breast cancer is a disease in which malignant (cancer) cells form in the tissues of the breast (National Breast Cancer Foundation, 2020). According to the National Cancer Institute (2022a), risk factors (factors that increase one's chance of getting a disease) for breast cancer include the following: personal history of invasive breast cancer, ductal carcinoma in situ (DCIS), or lobular carcinoma in situ (LCIS); personal history of benign (noncancer) breast disease; family history of breast cancer in a first-degree relative (mother, daughter, or sister); inherited changes in the *BRCA1* or *BRCA2* genes or in other genes that increase the risk of breast cancer; breast tissue that is dense on a mammogram; exposure of breast tissue to estrogen made by the body that may be caused by menstruating at an early age, older age at first birth or never having given birth, or starting menopause at a later age; taking hormones such as estrogen combined with progestin for symptoms of menopause; treatment with radiation with progestin for symptoms of menopause; treatment with radiation therapy to the breast/chest; drinking alcohol; and obesity. The main risk factor for most cancers is age. As you get older, the chance

of getting cancer increases. Inherited gene mutations may also cause breast cancer. Women who have certain gene mutations (i.e., *BRCA1* or *BRCA2* mutation) have a higher risk of breast cancer. Men who have a mutated gene related to breast cancer also have an increased risk of breast cancer. An estimated 2-7% of breast cancers and 10-15% of ovarian cancers result from inherited mutations in *BRCA1* and *BRCA2* (Risch et al., 2006). For those who are concerned of having a harmful variant in the BRCA1 or BRCA2 gene are recommended to consult with a healthcare provider or genetic counselor (National Cancer Institute, 2020).

Utilizing multi-gene panels, the parallel testing of multiple genes allowed cancer predisposing genes to be simultaneously and rapidly analyzed to represent a further detailed picture of the molecular foundation of family-related breast cancers and precisely identify individuals that are high risk (Catana et al., 2019; D'Argenio et al., 2015; Fountzilas & Kaklamani, 2018; Nunziato et al., 2019). In 2019, the National Comprehensive Cancer Network (NCCN) guidelines for hereditary breast cancer presented additional 18 different genes that can be tested beyond *BRCA1* and *BRCA2*. Specifically, each of these genes are categorized as exhibiting a very strong, strong, or partial evidence for a higher risk of breast, ovarian, and other cancers (McAlarnen et al., 2021). Among affected patients, around 11% of pathogenic germline variants in Caucasian patients and about 9% in Asians affect genes other than *BRCA1/2* (da Costa E Silva Carvalho et al., 2020). In breast and ovarian cancers, identifying germline cancer-predisposing DNA variants in early stages is crucial to 1) manage the affected patients by providing proper surgical and pharmacological approaches and 2) implement prevention programs for family members that are at risk (Nunziato et al., 2022).

Protective factors (factors that decrease the chance of getting a disease) for breast cancer include the following: taking estrogen-only hormone therapy after a hysterectomy, selective

estrogen receptor modulators (SERMs), or aromatase inhibitors; less exposure of breast tissue to estrogen made by the body, which can be a result of early pregnancy or breastfeeding; getting enough exercise; and having mastectomy/oophorectomy to reduce the risk of cancer or ovarian ablation. Tests and procedures that are used to diagnose breast cancer are physical exam and health history, clinical breast exam, mammogram, ultrasound exam, MRI (magnetic resonance imaging), blood chemistry studies, and biopsy. Once cancer is found, tests are conducted to study the cancer cells. Decisions about the best treatment are based on the results of an estrogen and progesterone receptor test, a human epidermal growth factor type 2 receptor (HER2/neu) test, or multigene tests (National Cancer Institute, 2022a).

This study focuses on *BRCA1/2* genetic testing in the Jewish population. *BRCA1/2* genetic testing is a blood test that uses DNA analysis to identify harmful changes (mutations) in either one of the two breast cancer susceptibility genes, *BRCA1* and *BRCA2* (Mayo Clinic, n.d.). While the prevalence of a *BRCA1/2* pathogenic variant is about 1 in 400 (0.25%) in the general population, the prevalence of founder mutations in the *BRCA1* (5382insC or 185delAG) and *BRCA2* (6174delT) is as high as 1 in 40 (2.5%) in the Ashkenazi (central and eastern European) Jewish population (Metcalfe et al., 2012; Struewing et al., 1997). Ashkenazi Jewish descents have a higher risk for a *BRCA1/2* gene mutation. Specifically, women who have 1) any first-degree relative (mother, daughter, or sister) has been diagnosed with breast or ovarian cancer or 2) two second-degree relatives (grandmother, aunt, or niece) on the same family (mother's or father's side) have been diagnosed with breast or ovarian cancer are at increased risk, should consider genetic counseling (Centers for Disease Control and Prevention, 2021).

Due to the availability of preventive measures for mutation carriers, some have advocated for population-based *BRCA1/2* genetic testing in unselected Ashkenazi Jews. A study shows that

population-based *BRCA1/2* testing of unselected Ashkenazi Jews compared to family history-based screening identifies about 56% more mutation carriers. In addition, population-based screening among this population is highly cost-effective in Ashkenazi Jewish women 30 years or older (Manchanda, Loggenberg, et al., 2014; Manchanda, Legood, et al., 2014). Despite this, there are various factors involved in implementing population-based screening of Ashkenazi Jewish women. For instance, genetic discrimination, accuracy and interpretation of results, cancer risk/prevention, and the potential impact on other family members were shown to be factors that influence the decision to undergo testing among Ashkenazi Jewish women (Lehmann et al., 2002; Phillips et al., 2000; Wiesman et al., 2017).

Medical Decision-Making on Breast Cancer Genetic Testing

Medical decision-making research seeks to explain how physicians and patients routinely make decisions and identifies both barriers and facilitators to effective decision-making (Schwartz & Bergus, 2008). Good medical decisions are hard to make when uncertainty exists, making it difficult to reach a consensus on the right or best choice. This is a common dilemma in healthcare. While the field emphasizes evidence-based medicine, patients and providers must make complex decisions when adequate evidence or consensus among experts is insufficient to guide the selection of available options based on the best available information (Hamilton et al., 2017). According to the Ottawa Decision Support Framework (O'Conner et al., 1998), the quality of a decision is determined by having a good decision process and outcome that includes shared decision-making. This framework assumes that decision-making is a multi-dimensional process that is affected by specific characteristics of the decision, decisional conflict, knowledge and expectations of the health situation and treatment options and outcomes, personal values and preferences, support and resources needed to implement the decision at multiple levels of influence, personal characteristics, and clinical characteristics. Many decision support interventions, including decision aids, utilized this framework to develop interventions that increase patient participation in medical decisions and improve decision outcomes.

Studies show that physicians make decisions based on their preferences rather than focusing on the patient's values possibly because the physicians do not have the time to understand the patient (Pope, 2017). This may lead to negative assumptions, mistreatment, or treatment that do not align with the patient's preferences. In addition, because physicians often rotate and they each have different thoughts of proper treatment, patients may experience a lack of consistent care and arbitrariness when making decisions around treatment (Ozar, 2019). To

support these patients and their healthcare providers, moral guidance is necessary. While traditional Jewish law does not offer unlimited autonomy of decision-making to patients, their personal goals and preferences could be considered when deciding appropriate interventions (Weiner, 2021).

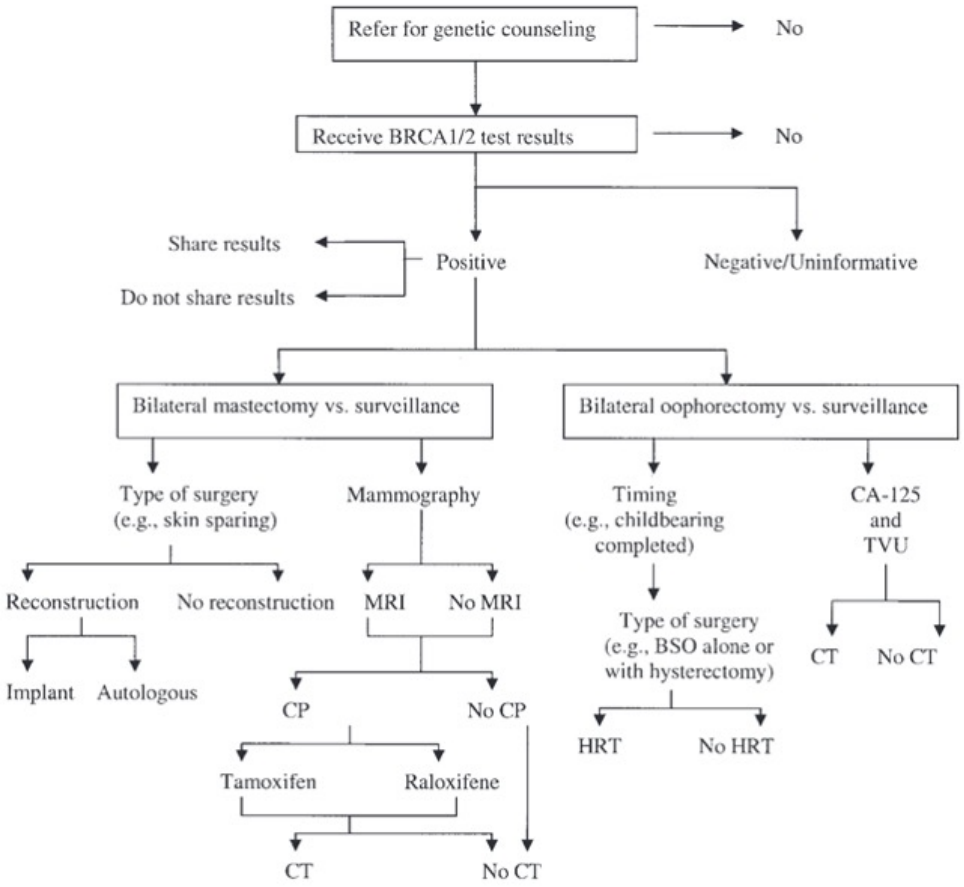
To provide guidelines around medical decision-making, Weiner (2021) presents two of the most fundamental and crucial Jewish values: "Love your neighbor as yourself (Leviticus 19:18)" and "This is the book of the generations of Adam (Genesis 5:1)". The latter phrase stating that everyone is created in the image of God broadens the obligation to all humanity. The author suggests that these core values can be applied to healthcare by emphasizing that healthcare providers should focus on interactions with patients and be aware that they have inherent duties to take care of every individual. This Jewish approach puts more weight on providers' obligations, and less on patients' rights, which can significantly influence how and why decisions are made (Freedman, 1999). Being created in the image of God confers human dignity and imply that the lives of individuals belong to God, and therefore, the primary value is not autonomy (Brewer et al., 2017). Weiner (2021) argues that because this duty-based perspective strives to ensure that proper care is provided in the right way, basing medical decisions on these Biblical values can result in treating each patient with dignity.

Genetic counseling is the core in the decision-making process in *BRCA1/2* mutation testing. Generally, two sessions take place in cancer genetic counseling. Information is gathered in a *pretest session* and test results are shared in a *disclosure session*. Below is a simplified version of the process of medical decisions that stem from a patient's decision to pursue genetic counseling (Figure 6). As shown in the figure, each of the decisions made by the participants

presents its own pros and cons. Whether patients are capable of considering the pros and cons when making decisions is a key question (Schwartz, Peshkin, et al., 2005).

Figure 6

Flow of Patient Decisions Following Genetic Counseling



Note. MRI = magnetic resonance imaging; CP = chemoprevention; CT = clinical trial; BSO = bilateral (salpingo) oophorectomy; HRT = hormone replacement therapy; CA-125 = cancer antigen 125 (serum blood test); TVU = transvaginal ultrasound. From *"*Decision Making and Decision Support for Hereditary Breast-Ovarian Cancer Susceptibility"*,* by M. D. Schwartz, B. N. Peshkin, K. P. Tercyak, and H. Valdimarsdottir, 2005, *Health Psychology, 24*(Suppl 4), p. S79. Copyright 2005 by the American Psychological Association.

Table 2 shows the pros and cons of *BRCA1/2* mutation testing. Several studies revealed that those who perceive their risk for cancer to be high and who think genetic testing is beneficial are more willing to undertake *BRCA1/2* testing. Since the information in genetic counseling is complex, researchers have developed decision aids to assist decision making related to *BRCA1/2* testing (Schwartz, Peshkin, et al., 2005). Uptake of *BRCA1/2* mutation testing will lead to providing information to the patient and family members, improving breast and ovarian cancer risk management, relieving distress, and allowing informed lifestyle decisions. However, it may also cause psychological distress or loss of privacy.

Table 2

Potential Pros and Cons of BRCA1/2 Mutation Testing

Pros	Cons
• Information for patient • Improved breast and ovarian cancer risk management • Relief from uncertainty/distress • More informed lifestyle decisions • Information for family members	• Possibility of uninformative test results • Loss of privacy, insurance, employment discrimination • Psychological distress • Unproven efficacy of management options • Results provide a probability of developing cancer – not a certainty

Note. From "Decision Making and Decision Support for Hereditary Breast-Ovarian Cancer Susceptibility", by M. D. Schwartz, B. N. Peshkin, K. P. Tercyak, and H. Valdimarsdottir, 2005, *Health Psychology, 24*(Suppl 4), p. S80. Copyright 2005 by the American Psychological Association.

Patient's treatment choices and experiences can be influenced by clinical decision-making aids to support individualized treatment (Lipkus et al., 2010). Physician recommendation was also shown be a strong independent predictor of testing (Schwartz, Lerman, et al., 2005). A survey that analyzed the relationship between trust and patient involvement shows that women with high trust are more involved in medical decision-making compared to men with high trust (Pokhilenko et al., 2021). On the other hand, younger patients and ethnic minorities were found to have fewer positive experiences when involved in decision making from a recent study with over 40,000 participants that have cancer (El Turabi et al., 2013).

Several studies explored influential factors of medical decision-making around *BRCA1/2* genetic testing in the Jewish population. A population-based survey of 200 Jewish women found that 40% were interested in *BRCA1/2* genetic testing, mainly due to a desire to obtain information about their children's risk. A few women expressed concern or discomfort with targeting of Jews for genetic testing (17%). Most women (71%) thought there were scientific reasons for testing Jews (Lehmann et al., 2002). In a survey of over 100 breast cancer patients of Ashkenazi Jewish descent who were offered *BRCA1/2* genetic testing as part of a research study, the most common motivating factors to undergo testing were a desire to contribute to research that may help the Jewish community and potential benefit to other family members (Phillips et al., 2000). In a recent study from our research group, stigma and effect on marriageability were shown to be crucial factors that affect women's medical decisions on genetic testing uptake (Trivedi et al., 2018).

Other studies investigated the uptake of *BRCA1/2* genetic testing in the Jewish population. In Ontario, Canada, 6179 Jewish women received *BRCA1/2* genetic testing through a population-based screening program and 93 (1.5%) tested positive, including 92 (99%) who were

unaffected with cancer (Metcalfe et al., 2013). Among mutation carriers, 11.1% had prophylactic mastectomy and 89.5% had risk-reducing oophorectomy within 2 years of receiving their genetic test results (Metcalfe et al., 2012). Cancer-related distress decreased among those women who underwent risk-reducing surgeries; 98.2% expressed satisfaction with the testing process and would recommend testing to other Jewish women. These studies included Jews for whom unique issues may arise surrounding *BRCA1/2* genetic testing due to their obligations under Jewish law or code of ethics (Mor & Oberle, 2008; Phillips et al., 2000).

Previous Efforts to Promote Genetic Testing

Genetic testing for cancer susceptibility has been studied in various fields and utilized in clinical settings because it can lead to assessing and reducing cancer risk by providing prevention guidelines and treatment. Innovative technology and declining costs have also enabled genetic testing to become a crucial part of cancer care (Katz et al., 2015). Cancer risks are associated with many genes and standards provide screening and prevention procedures for pathogenic variants in more than 40 genes (Couch et al., 2017; Daly et al., 2020; Gupta et al., 2017).

While there have been many studies on patient experience and outcomes of germline genetic testing for inherited cancer susceptibility genes, access to genetic services in research and practice is mainly focused on well-insured, Caucasian individuals that can easily access genetic counseling and testing (Underhill et al., 2017). On the other hand, research on some communities is understudied. Underserved communities include those with financial struggles and low-socioeconomic status. They may also be racial or ethnic minorities that have difficulty accessing genetic testing services. Health insurance coverage is also a barrier to undertake genetic testing. The Genetic Information for Treatment Surveillance and Support (GIFTSS) program was established by the Cancer Resource Foundation (CRF) in 2009 to assist the out-of-pocket fees for cancer genetic testing targeting high-risk individuals that has limited financial means and insurance coverage.

A study by Underhill et al. (2017) presents genetic findings of at-risk participants with low-socioeconomic status. The findings in this study show that genetic testing can provide valuable information in the community. Reducing barriers to accessing genetic testing need to be discussed to provide equitable genetics care. The results can be used to describe genetic testing outcomes in a high-risk underserved community. Studies also report that individuals with limited

resources are less likely to access genetic testing. Therefore, genetic counselors and clinicians should utilize various approaches to enhance access to genetic testing and make it convenient to reach underserved communities. The results of genetic testing can lead to treatment or diagnostic/prevention recommendations. To enhance the quality of genetic testing and improve the appropriate use of genetic tests in healthcare, the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS) have been collaborating with other organizations since 1997 (Chen & Greene, 2010).

Cancer survivors and their families can benefit from biomedical advances in cancer prevention, early detection, treatment, and survivorship when the persons at increased risk for breast cancer is identified. To achieve reductions in cancer morbidity, mortality, and health disparities at population levels, national guidelines for cancer genetic risk assessment need to be widely disseminated and adopted. A key national priority in the United States is to identify individuals with inherited cancer predisposition. While numerous organizations recommended genetic counseling to enhance understanding, informed consent, preventive behaviors, and individualized care (Robson et al., 2015), among those women with breast or ovarian cancer who meet family history criteria for referral for cancer genetic risk assessment, less than half of them receive genetic counseling or testing (Childers et al., 2017; Katz et al., 2018; Kurian et al., 2017). Only 10% of unaffected carriers of *BRCA1/2* pathogenic variants are aware of their status (Drohan et al., 2012). In previous studies, 80% of participants responded that they are somewhat or very interested in testing for colon cancer susceptibility (Croyle & Lerman, 1993) and 69% showed interest in testing for breast cancer susceptibility (Tambor et al., 1997).

A recent study that included 187,535 patients with breast cancer and 14,689 patients with ovarian cancer examined trends in germline testing over 7 years among women in Georgia and

California (Kurian et al., 2021). The results show that there were no sociodemographic differences in testing trends, a small increase in pathogenic variants, and a significant increase in variants of uncertain significance (VUS)-only rates. The findings suggest that the clinical validity and utility of genetic testing for women with breast or ovarian cancer can be improved with a more delimited panel composition. For instance, since most pathogenic variants were found in 20 genes among patients with breast or ovarian cancer, genetic testing uptake for only these genes could increase the yield of pathogenic variants while decreasing the results of variants of uncertain significance (VUS). A variant of uncertain significance (VUS) is a result of genetic testing that discovers a change in *BRCA1* or *BRCA2* that has not been linked to cancer and is rare in the general population. It is not evident if this specific genetic change is harmful (National Cancer Institute, 2020).

There are also studies around genetic testing in the Jewish population. Considering factors from relevant studies could contribute to promoting genetic testing in this population. Remennick (2006) conducted a study of Israeli women. The results showed that educated and middle-class women were more likely to accept genetic testing considering testing is part of "good motherhood". Another study asked Orthodox Jews their uptake of genetic testing or genetic counseling before they started dating or got married (Pollak, 2011). Among the responses, 61% answered that they did not get testing prior to dating or marriage and 39% answered that they did. In addition, the possibility of genetic testing or counseling increased as birth order approached the oldest sibling, which means the youngest children had the least chance of getting tested or counseled.

To effectively promote genetic testing to Jews, understanding the views of community leaders are important. A qualitative study analyzed the perspectives of Orthodox Jewish leaders

regarding genetic testing and counseling (Bressler & Popp, 2017). The themes that were identified were concern about cancer, shifting community norms, rabbinic role in medical decisions, and tampering God's plan (balance between determinism and individual responsibility for safeguarding one's health). This study suggests that social networks and faith-based leaders influence medical decisions, including *BRCA1/2* genetic testing. Genetic testing has become common practice for young adults after rabbinic leadership became involved (Sutton, 2002).

However, genetic testing has not been standard medical practice in Jewish tradition. Testing may indicate a lack of reliance on God's oversight, and therefore, Orthodox Jews may be reluctant to genetic testing. The assumed benefits of genetic testing or counseling are debatable considering the Orthodox Jewish sociocultural system. Being informed of the genetic testing results has advantages, but it is uncertain whether it is worth it because of the conflicts with religious values (Pollak, 2011).

While the Orthodox Jewish community is commonly targeted in genetic research, genetic testing and counseling is limited in this population (Raz, 2009). This may result from many Orthodox Jews shying away from most genetic services due to Jewish law. In addition, encounters between genetic counselors and Orthodox Jews have gaps: lack of referrals of Orthodox Jewish patients to genetic counseling services, fear of stigmatization, struggle establishing rapport, and the inconvenience for counselors of having to bring the rabbi into the conversation (Mittman et al. 2007). However, a healthy clinical relationship built on rapport and empathy could be possible if genetic counselors learn the norms of the religious group (Raz, 2009).

Previous efforts to promote genetic testing in the Orthodox Jewish population will be further discussed in a separate section.

Social and Community Context of Orthodox Jews

Social and community context refers to the social settings where people live and act, which includes social relationships and the social, religious, cultural, and occupational institutions with which they interact (Barnett & Casper, 2001). Considering the social and community context of Jewish women is important because Orthodox Jews often live in tightly-knit communities and are culturally distinct due to their insularity and traditional observance of Jewish law or *Halacha*. In secular ethics, autonomy is considered a highly valued feature of healthcare, whereas *Halacha* is based upon religiously mandated legal, spiritual, and ethical codes and obligations in a given situation. For Orthodox Jews, *Halacha* regulates nearly every aspect of behavior, including observance of the Sabbath (a day of religious observance), dietary laws, modesty in behavior and dress, gender separation in public domains, limited exposure to general culture, as well as medical and health decisions (Coleman-Brueckheimer et al., 2009). Judaism, which incorporates religion, culture, national identity, community, and individual, seeks to understand the connection between taking care of the soul and body. For over 3,500 years, Jewish culture around health and healing has been discussing illness and wellness and their relationship with body, mind, and spirit (Levin & Prince, 2011).

Based on different levels of observance of *Halacha* and access to secular outlets, a spectrum from Modern Orthodox to Yeshivish and Chassidish (Hasidic) communities exists within the Orthodox Jewish community (Grazi & Wolowelsky, 2015). Although there is a wide range of adherence, the most typical categorizations of Orthodox Judaism are Modern and Yeshiva Orthodox (emphasizes rabbinic authority and leadership with stringent interpretation of Jewish law), and Hasidic (emphasizes cultural insularity and minimization of exposure to secular information outlets). Rabbinic authorities are typically consulted across the three Orthodox

denominations to answer *shailohs*, questions related to the determination of a point of Jewish law, including medical decisions (Coleman-Brueckheimer et al., 2009).

A relatively unique feature of the Orthodox Jewish community is the existence of multiple organizations of medical navigators or culture brokers, who are not medical professionals, which may bridge the gap between Orthodox Jewish individuals and medical services provided by the secular community (Greenberg & Witztum, 2001). Given the centrality of these figures, who may have limited knowledge or access to accurate information, it is important to understand the roles of rabbis and communal figures in medical decision-making for the Orthodox Jewish community and their potential ability to disseminate standards of care (i.e., genetic testing).

In addition to religious considerations, many practical and sociocultural concerns exist about genetic testing, such as adverse psychological impact on the individual and their family members, reproductive consequences, discrimination in insurance and employment, and uncertainty about the accuracy and interpretability of results. Given that marriages in the Orthodox Jewish community occur at younger ages and are often facilitated by a system of matchmaking (*shidduchim*), some families may decline testing because of fear of reducing desirability to prospective mates for them, as well as other children and siblings. Also, many Jewish women may be unsure about their personal desire or religious obligation to disclose genetic test results with family members (Phillips et al., 2000).

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 (Grazi & Wolowelsky, 2015; Raz & Vizner, 2008). The acceptance of *Dor Yeshorim* is attributed to the concealing 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 (Schneider et al., 2009).

Dor Yeshorim allows carrier screening and matching for genetic diseases that occur in the Ashkenazi Jewish population for several reasons (i.e., religious objection to abortion). After extending the traditional norm of pre-arranged matchmaking, the uptake is over 95% and hardly any children affected with Tay-Sachs have been born to couples who married in this community (Ekstein & Katzenstein 2001). However, there are also concerns around *Dor Yeshorim*. While *Dor Yeshorim* and other similar community-based programs may reduce the prevalence of genetic diseases, utilizing carrier screening by community members could also maintain or increase the stigma of identified carriers (Raz, 2009). These are unintended consequences of *Dor Yeshorim* when carrier screening is conducted in the community. To address issues that may occur, Raz (2009) claims that healthcare providers should collaborate with community leaders. Cultural identity and religious practices should be discussed openly at the initiation of the medical encounters. In addition, the Jewish Genetic Disease Consortium, an organization that oversees various Jewish genetic disease community support groups, emphasizes that patients should be fully educated about genetic testing so that informed consent is meaningful (Pletcher et al. 2008). It would be critical for patients to understand possible consequences of genetic testing beforehand.

Orthodox Jews during the Pandemic

The social and community context of Orthodox Jews changed during the pandemic. The Orthodox Jewish community was greatly affected in the early COVID-19 pandemic: ‘patient-

zero' being an Orthodox Jew (Gold & Ferre-Sadurni, 2020); early rapid spread that significantly affected the ultra-Orthodox Jewish community (Zyskind et al., 2021); painful losses of prominent leaders (Stack, 2020). Public health enforcement and the Jewish community experienced tensions related to adherence to COVID-19 guidelines (The Yeshiva World, 2020). When the pandemic started, a majority of the ultra-Orthodox Jewish population followed health guidelines. However, some resisted to follow public health rules and cases increased in predominately Orthodox areas as more cases of 'non-compliance' were reported (Stack & Goldstein, 2020).

A recent study explored the sociocultural and religious views toward the COVID-19 pandemic in the Orthodox Jewish community (Berger Lipsky & Gabbay, 2023). Community members in the Orthodox Jewish population generally rely more on information disseminated within the community than in public health officials, possibly because they have restricted access to the internet due to religious reasons. These social factors (i.e., limited access to health information) may result in medical misinformation and mistrust. In addition, other socioeconomic factors (i.e., large family sizes in small living spaces) could magnify the spread of the virus and the difficulties caused by quarantining in place. This study suggests that consistent and transparent communication between health officials and Orthodox Jewish community leaders can utilize the communal structure to increase adherence of health guidelines. Since medical misinformation is common in this population, maintaining close connections and ensuring that public safety is priority will allow community members to feel respected. On the other hand, if these are not considered, community members may become more reluctant to medical information and feel as though they are unfairly targeted. Therefore, recognizing the

religious and social factors that influence the Jewish community is important to strengthen the relationship between the Jewish and medical communities.

A typical daily life of an Orthodox Jew is guided by *Halacha* (Jewish law), which is based on customs, passages in the Torah, and interpretations by rabbis over centuries. Activities include daily morning and evening prayers with at least ten other males, study groups discussing religious topics, and weddings/funerals with large groups. Since Orthodox Jews are communally centered, the pandemic that required social distancing affected religious observances (Trencher, 2021). While the Jewish community experienced social distancing in past pandemics, the use of technology became a new topic. The body of rabbinic literature explaining why halachic changes occurred, how to use technology, and how to balance community values and safety with religious obligations has grown (Klapper, 2020).

A study by Trencher (2020) revealed that "feelings of Jewishness" were affected during the pandemic (Table 3). While 3% of Orthodox Jews replied that their feelings of Jewishness had weakened, a higher percentage replied that their feeling had strengthened (22% of Modern Orthodox, 38% of Haredi).

Table 3

Pandemic Experiences Effect on How People Feel "Jewishly"

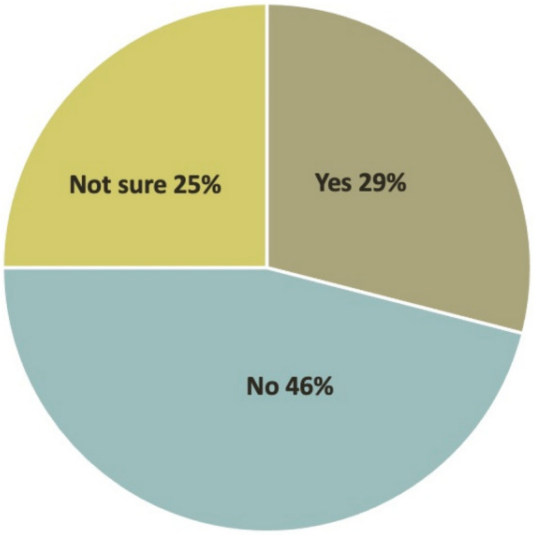
My "Jewish feelings" overall …	Orthodox total (%)	Modern Orthodox (%)	Haredi (%)
Have become strengthened	32	22	38
Have become weakened	3	5	1
Are mixed; in some ways strengthened, but in some ways weakened	16	18	15
No real change	49	55	46

Note. From *"*The Orthodox Jewish Community and the Coronavirus: Halacha Grapples with the Pandemic"*,* by M. L. Trencher, 2021, *Contemporary Jewry, 41*(1), p. 135. Copyright 2021 by Springer Nature.

The pandemic affected the community by increasing the use of technology in various settings, including online prayer and halachic flexibilities because of health risks. A survey asked if rabbis should consider adopting more halachic flexibility in areas of technology to Modern Orthodox Jews. Among the respondents, 29% replied that rabbis should allow more flexibility, 46% did not agree, and 25% were not sure (Figure 7). The Orthodox Jewish community is now minimally affected, and synagogues have re-opened with some restrictions. However, Orthodox Jews are questioning the uncertain future and where the community is heading (Trencher, 2021).

Figure 7

Modern Orthodox Desire for Future Halachic Flexibility



Note. From "The Orthodox Jewish Community and the Coronavirus: Halacha Grapples with the Pandemic", by M. L. Trencher, 2021, *Contemporary Jewry, 41*(1), p. 137. Copyright 2021 by Springer Nature.

During the pandemic, another study surveyed nearly 5,000 adults in the U.S. who identify as Jewish from 2019 to 2020. The participants were drawn from a national stratified random sampling, which included addresses from all 50 states and the District of Columbia (Pew

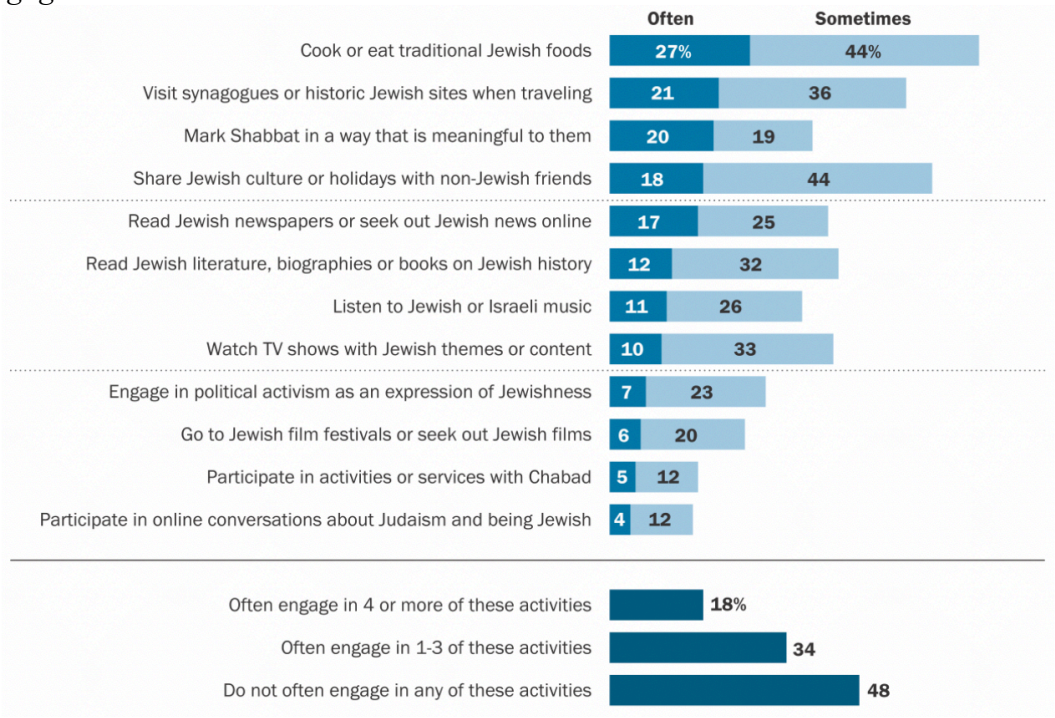
Research Center, 2021). The results show that 66% of American Jews identify as Ashkenazi (Figure 8). In addition, Jewish Americans engage in traditional forms of religious observance (i.e., attending a synagogue). They also take part in cultural Jewish activities including cooking or eating traditional Jewish foods, visiting historic Jewish sites, reading Jewish literature, and listening to Jewish or Israeli music (Figure 9).

Figure 8

Jewish Identification

Figure 9

Engagement in Jewish Activities

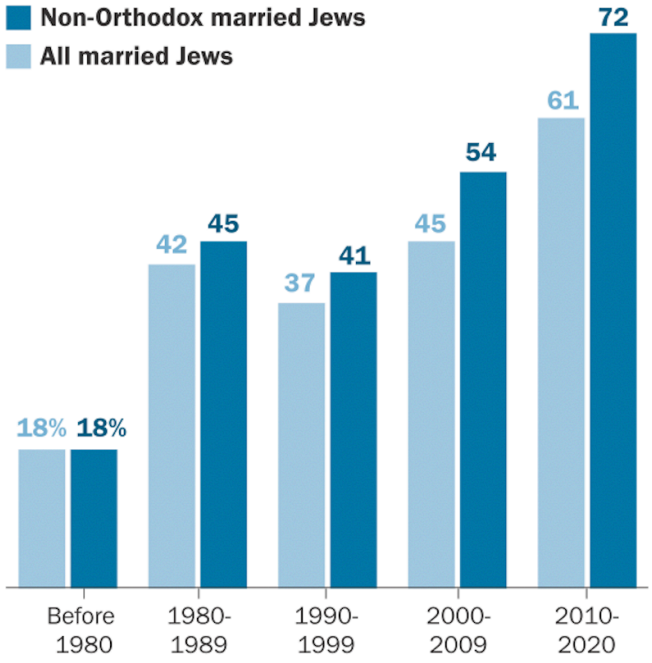


Note. From *Jewish Americans in 2020,* by Pew Research Center, 2021 (https://www.pewresearch.org/religion/2021/05/11/jewish-americans-in-2020/). Copyright 2023 by Pew Research Center.

In the Orthodox Jewish community, intermarriage is very rare. Only 2% of married Orthodox Jews replied that their spouse is not Jewish. On the other hand, among married Jews who are not in the Orthodox Jewish community, 47% said that their spouse is not Jewish. 72% of non-Orthodox Jews who got married between 2010 and 2020 responded that they are intermarried (Figure 10).

Figure 10

Intermarriage Rate



Note. From *Jewish Americans in 2020,* by Pew Research Center, 2021 (https://www.pewresearch.org/religion/2021/05/11/jewish-americans-in-2020/). Copyright 2023 by Pew Research Center.

The results of the report (Pew Research Center, 2021) also show that many American Jews consider being Jewish as a combination of religion, ancestry, and culture, and most of them do not think being Jewish is solely about religion. Half of the respondents replied that continuing

family traditions is a crucial part of their Jewish identity. Around 30% of respondents replied that all or most of their close friends are Jewish, while 88% of Orthodox Jews said that all or most of their close friends share their Jewish identity. In addition, Orthodox Jews have an average of 3.3 children and non-Orthodox Jews have an average of 1.4 children, which shows that fertility in the Orthodox Jewish population is higher than non-Orthodox Jews.

A recent study conducted in the Jewish community revealed interesting findings (Nishma Research, 2023). A majority of Orthodox Jews consider their lives religiously satisfying (93% strongly or somewhat agree). 60% of respondents went through family planning and almost half of the families reduced the number of children. The cost of Jewish education and dealing with those who commit abuse (physical, mental, sexual) were the top priority in the community. 82% cited that dealing with others that abuse Jews is a crucial issue that the Jewish community must address in the next decade. 90% stated that they have a primary shul that they attend, feel welcomed, and receive halachic guidance.

Tay-Sachs and the Jewish Community

Tay-Sachs disease (TSD) is defined as a progressive disease that destroys the function of the brain. Treatment is limited to supportive care and no known cure is around. It is difficult to estimate the numbers of children in the United States that are affected per year, since there is no official disease registry for TSD. However, based on the best data of the National Tay-Sachs and Allied Diseases Association (NTSAD), it is estimated that there are 12-15 new infantile diagnoses of TSD a year and less then 50 children in the United States are currently living with Tay-Sachs (includes cases of Sandoff disease, which is a clinically similar disorder). The estimates are the most accurate that can be found, since NTSAD is the primary support community for families affected by Tay-Sachs (Colaianni et al., 2010).

Recommendations from the American College of Obstetricians and Gynecologists (ACOG) and American College of Medical Genetics (ACMG) help establish the standard of care for screening for Tay-Sachs in the United States. The ACOG organized a committee opinion restating and recommending that people of Ashkenazi Jewish descent should be offered screening for Tay-Sachs and eight other diseases that are relevant to this population (American College of Obstetricians and Gynecologists, 2004). Cost-effectiveness or cost-benefit analysis studies of DNA-based testing for TSD has not been found. The reason why it is difficult to find studies that address the economics of DNA-based TSD test may be because Tay-Sachs is considered to be a devastating and incurable disease, and therefore, whatever the screening costs, they are willing to pay for it (Colaianni et al., 2010). NTSAD offers service to send help in a letter form to the health plan for other insurance companies that do not cover genetic testing for people of Ashkenazi Jewish descent (National Tay-Sachs and Allied Diseases Association, 2018).

TSD is a genetic disorder that results in progressive neurological disorder. When both parents carry the defective gene, each child has a 25% chance of having the disease. Carriers of this gene can be detected by a blood test. While there is no cure that has been found, strategies to manage life with Tay-Sachs exist. While 1 in every 250 people in the general population is a carrier, 1 in every 27 Jews in the U.S. is a carrier. Specifically, Ashkenazi Jews from European descent have a higher chance to be carriers (National Tay-Sachs and Allied Diseases Association, 2020). Orthodox Jews are familiar with genetic counseling and mandatory screening takes place for arranged marriages. Matchmakers conduct confidential testing to examine the suitability of prospective couples. The results of the genetic test can bring dramatic life changes to the parent and child. Prior to testing or receiving the results, decisions (i.e., whether to sustain the pregnancy, adoption, and selective embryo implantation) should be developed and genetic counseling can be beneficial in this process.

Judaism is a culture and biological heritage, which is more than a religion or race. This biogenetic heritage also carries risk for genetic diseases, such as Tay-Sachs (Clayton, 2017). While defining the diverse philosophical, historical, legal, and ethical aspects of Judaism is complicated, several important factors point out that there is an accountability to vulnerable populations (i.e., children with genetic diseases like Tay-Sachs) and everyone should equally have access to healthcare (Levin, 2012). It would be possible to prevent parents suffering from the pain of having a child born with Tay-Sachs and the child experiencing the painful symptoms by knowing whether they carry the recessive gene for Tay-Sachs. Genetic counseling for potential parents that are linked to Ashkenazi Jews can receive support from the American College of Medical Genetics and Genomics (Ferreira et al., 2014).

Several genetic experts believe in genetic exceptionalism. They claim that the confidentiality of the results of genetic testing should be dealt different from other medical records. Since genetic disorders affect current and future family members, family members should also receive the results regardless of written consent of the patient. Genetic testing provides information that is needed to make informed decisions for the Jewish community. Since genetic testing is a sensitive and ethical topic, couples should receive extensive consultation from the medical and religious communities when making the decision (Clayton, 2017).

Due to successful anonymization and institutionalization of the testing program, pre-marital genetic testing for Tay-Sachs is common practice in the *shiduch* (matchmaking) process of the Orthodox community (Broide et al., 1993). However, there are unique challenges in testing for *BRCA1/2* genes, which are influenced by the culture and community. Furthermore, there is very limited discussion and knowledge about this emerging new topic in Jewish law. Learning from the case of TSD, genetic testing for *BRCA1/2* mutations can become more acceptable with specialized attention, policies, and *Halacha* (Jewish law) decisions.

Conclusion

While population-based *BRCA1/2* genetic testing in the Ashkenazi Jewish population is highly cost-effective and can detect more mutation carriers than family history-based screening, barriers exist for undergoing genetic testing, including religious considerations and practical/sociocultural concerns about genetic testing. Furthermore, little is known and nothing has been systematically studied and reported based on the voices of community members about the social and cultural aspects that are affecting medical decision-making around *BRCA1/2* genetic testing. Since Tay-Sachs has been successfully implemented population-wise and the incidence rate of Tay-Sachs has significantly decreased, it would be meaningful to carefully examine the social, cultural, and religious factors that are affecting medical decision-making, which could eventually lead to population-based *BRCA1/2* genetic testing and lowering the risk of breast cancer among Ashkenazi Jews. In addition, since Orthodox Jews live in tightly-knitted communities, including narratives of stakeholders and community members would be crucial to understand barriers and effectively implement population-based *BRCA1/2* genetic screening.

Chapter III

METHODS

This study utilized qualitative research methods to analyze the narratives of key stakeholders and community members to understand the social, cultural, and religious factors influencing medical decision-making on *BRCA1/2* genetic testing in the Orthodox Jewish community. Qualitative research is useful in early stages of research when little is known or understood about the important variables of interest. Since evidence around social, cultural, and religious factors influencing medical decisions of the Orthodox Jewish community are limited, this study undertook a content analysis of qualitative data by focusing on the narratives of key stakeholders and community members. This study sought to develop a comprehensive understanding of the social, cultural, and religious factors that influence Orthodox Jewish women's medical decision-making.

Study Setting and Population

There are over 1.5 million Jews across the eight-county New York area (Table 4), including the counties of the Bronx, Brooklyn, Manhattan, Queens, Staten Island, Nassau, Suffolk, and Westchester (Figure 11). This area continues to be home to the greatest concentration of Jewish people of any metropolitan area in the United States, with nearly half a million Jewish people living in Orthodox households (Table 5). In addition, the 144% increase since 2002 in the number of people in Jewish households in the Washington Heights neighborhood of New York City represents the greatest rate of growth among all profiled Jewish areas. Another distinctive feature of the Washington Heights neighborhood is its high proportion of people who identify as Orthodox (21%), the highest of all Manhattan areas (Beck et al., 2013). Therefore, this study sought the participation of Jews in the Orthodox Jewish communities in the New York area, including Washington Heights.

Table 4

Jews by County, Eight-County New York Area

County	Number of Jews	Percent of Jews in Eight-County Area
Bronx	54,000	4%
Brooklyn	561,000	36%
Manhattan	240,000	16%
Queens	198,000	13%
Staten Island	34,000	2%
Subtotal, New York City	**1,086,000**	**71%**
Nassau	230,000	15%
Suffolk	86,000	6%
Westchester	136,000	9%
Subtotal, Suburban Counties	**452,000**	**29%**
Total, Eight-County Area	**1,538,000**	**100%**

Note. From *Jewish Community Study of New York: 2011 Geographic Profile,* by P. Beck, C. M. Cohen, J. B. Ukeles, and R. Miller, 2013 (https://www.jewishdatabank.org/api/download/?studyId=597&mediaId=JCSNY-2011-Geographic-Profile-Report-All+SectionsCombined-Rev-10-13.pdf). Copyright 2013 by the Berman Jewish DataBank.

Figure 11

Jews by County, Eight-county New York Area

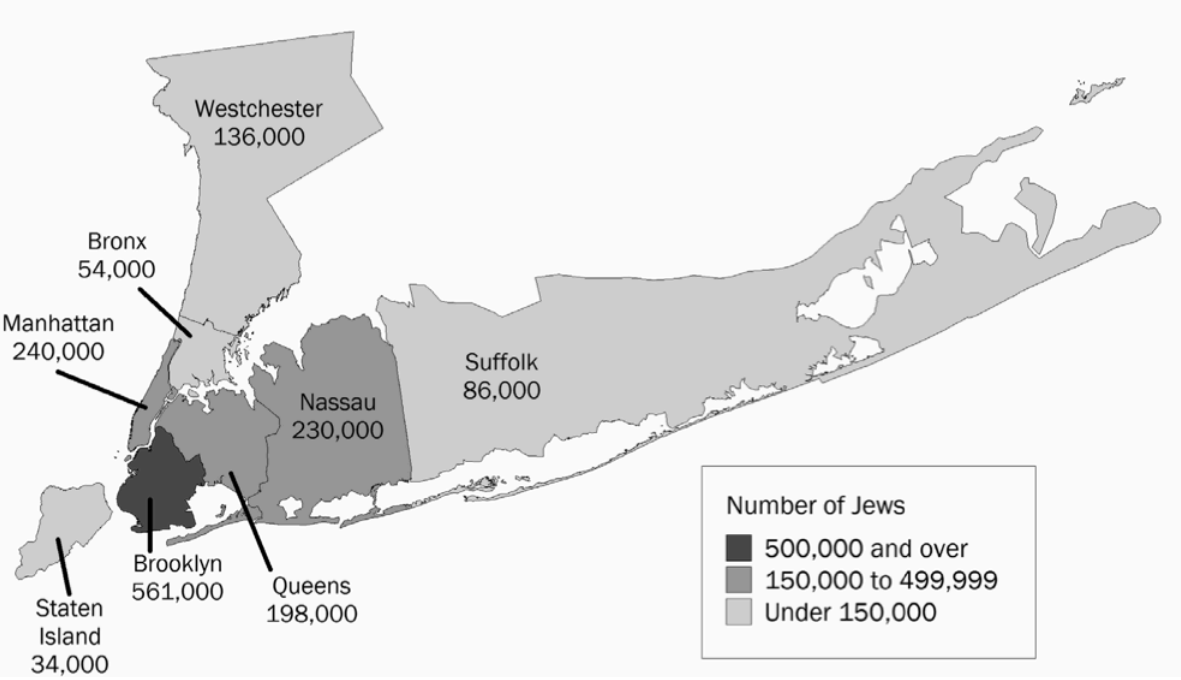


Table 5

Number of Households and Jews by Orthodox Type

	Number of Households	Percent of All Jewish Households, Eight-County New York Area	Number of Jews	Percent of All Jews, Eight-County New York Area
Hasidic	50,000	7%	239,000	16%
Yeshivish	23,000	3%	97,000	6%
Modern Orthodox	55,000	8%	157,000	10%
Subtotal — Orthodox	**129,000**	**19%**	**493,000**	**32%**
Non-Orthodox	565,000	81%	1,045,000	68%
Total	694,000	100%	1,538,000	100%

Note. From *Jewish Community Study of New York: 2011 Comprehensive Report,* by C. M. Cohen, J. B. Ukeles, and R. Miller, 2012 (https://www.jewishdatabank.org/api/download/?studyId=597&mediaId=C-NY-New_York-2011-Main_Report.pdf). Copyright 2012 by the Berman Jewish DataBank.

Data Source

This study is part of a community-based participatory research (CBPR) project in which a multi-disciplinary research group at an academic institution collaborated with a Jewish organization to better understand knowledge, attitudes, and perceptions of *BRCA1/2* genetic testing among the Orthodox Jewish community. Utilizing quantitative and qualitative data that have been collected and analyzed by this academic institution-community organization partnership, we conducted studies investigating attitudes, influential factors, intention, and uptake of *BRCA1/2* genetic testing among a population of Orthodox Jewish women (Tang et al., 2017; Trivedi et al., 2018; Yi et al., 2017; Yi et al., 2018). This publication was supported by the National Center for Advancing Translational Sciences, National Institutes of Health (grant No. 5KL2TR001874, UL1 TR000040, and P30 CA013696), the American Cancer Society Research grant (No. RSG-17-103-01), and the Susan G. Komen Foundation (grant No. PDF16378127). A stakeholder dialogue was utilized for analysis. This study received IRB approval from Teachers College at Columbia University (21-180) and Columbia University Irving Medical Center (AAAO1760).

Study Procedures

The research team identified key stakeholders and invited them to participate (Appendix A). The participants included physicians (medical and surgical oncologists), nurse practitioners, breast cancer experts (director of breast cancer prevention, hematology/oncology fellow), genetic counselors, medical advocates (bridge the gap between Orthodox Jewish individuals and medical services provided by the secular community), rabbis, rebbetzins (wives of rabbis/female advisors to women in the community), kallah teachers (teaches women the basics of Jewish marital

etiquette), shadchans (Jewish professional matchmaker) and community organizers. Five of the participants were women from the Orthodox Jewish community who were drawn from focus groups we previously conducted in Washington Heights (Trivedi et al., 2018) and who were identified as representing the full range of perspectives that were present in the focus groups. All participants provided informed consent (Appendix B).

The stakeholder dialogue, which was conducted in June 2015 at Columbia University Irving Medical Center in Washington Heights, included 49 participants and lasted about 6 hours. The goal of the meeting was to stimulate discussion among stakeholders on the medical and social issues surrounding *BRCA1/2* genetic testing and develop practical action plans for implementation in the community setting. As presented in Table 6, the agenda of the stakeholder dialogue was divided into two parts: 1) where we are (medical overview, halachic considerations, sociocultural considerations, attitudes, and behaviors); and 2) where we need to go (brainstorming community policies, actions, and next steps). The first part outlined the parameters of the medical, cultural, and communal reality. Suggested policies by sub-population, emerging policies, and sustainability and action plan towards implementation and evaluation were discussed in the second part. Steps included: 1) a presentation of the focus group findings among Orthodox Jewish women (Trivedi et al., 2018); and 2) a plenary discussion to present different perspectives from the medical, legal, ethical, sociocultural, and religious stakeholders, with the goals of exploring influential factors and identifying key challenges and opportunities moving forward and creating action plans with respect to *BRCA1/2* genetic testing among Orthodox Jews. The stakeholder dialogue was audio recorded and transcribed.

Table 6

Agenda of Stakeholder Dialogue Meeting

Time (estimate)	Focus
11:00 – 11:10	Intro & Goals
	PART I: WHERE WE ARE
11:10 – 11:40	Medical Overview & Discussion
11:40 – 12:10	Halachic Considerations & Discussion
12:10 – 12:40	Sociocultural Considerations, Attitudes and Behaviors & Discussion
12:40 – 12:55	Lunch Break
	PART II: WHERE WE NEED TO GO Brainstorming Community Policies, Actions, and Next Steps
12:55 – 1:40	Round I Dialogue: Suggested Policies by Sub-population
1:45 – 2:35	Round II Dialogue: Emerging Policies – Comments and Consensus
2:35 – 3:00	Round III: Sustainability & Action Plan – Towards Implementation and Evaluation
3:00	Wrap-Up.

Data Analysis

Transcripts of the stakeholder discussions were coded and analyzed using Grounded Theory and Narrative Research. Grounded Theory is a form of qualitative research developed by Glaser and Strauss (1967). The authors define Grounded Theory as "the discovery of theory from data" (p. 1). When constructing theory from data, the interplay between researcher and data is crucial so that the final theory is a construction of both data and researcher perspective (Corbin, 2017). Narrative research refers to any study that uses or analyzes narrative materials, which can be the object of the study or a means for the study of another question (Lieblich et al., 1998). As

applied in this study, researchers are increasingly combining different methodologies while conducting qualitative research. A study shows that integrating grounded theory and narrative research are theoretically commensurable and can complement each other within qualitative studies (Lal et al., 2012). In addition, integrating the two approaches allows deeper understanding of the phenomenon.

Using multiple coders is a widely advocated approach to provide external validation of an analysis. Having multiple independent coders and checking inter-rater reliability is suitable for studies that heavily depend on codes in which the meanings of the codes have to be discussed and agreed (Blandford et al., 2016). To analyze the qualitative data (80 pages, 28,257 words), two coders [HY and MT] met to develop a code book and conducted a content analysis. This study defines content analysis as "seeking to demonstrate the meaning of written sources by systematically allocating their content to pre-determined, detailed categories, and then interpreting the outcomes," which was adapted from the definition by Payne & Payne (2004). A unit of analysis can be a sentence, paragraph, message, or thematic phrase (Garrison et al., 2006). The unit of analysis was a thematic phrase in this study.

All the transcripts were uploaded into the ATLAS.ti software to enable investigators to code, build the code book, and group the codes into themes. The coders met regularly to agree on the definitions of codes, modify the code book, and eventually create a finalized version (Table 7). The goal was to establish a common understanding of the codes. The discrepancies between the two coders were discussed and the coding of each transcript was compared consecutively (Burla et al., 2008). After the final codes were defined, the two coders independently coded the transcripts. An Orthodox Jewish researcher [RS] familiar with qualitative analysis conducted an independent audit by reviewing the transcripts and analysis.

Table 7

Code Book for Stakeholder Dialogue

Codes	Code Names	Definitions
CI	Cultural Influences	Used to point out the role that Orthodox Jewish culture plays on the issue of breast cancer and testing.
GTC	Genetic Testing Consequences	Whenever the consequences of genetic testing/not testing were mentioned.
GTK	Genetic Testing Knowledge	For comments indicating how much someone knows or understands (or doesn't) about the process and technicalities of genetic testing.
IRR	Impact on Romantic Relationships	i.e, *Shidduchim*
IF	Influential Factors	This is a general category used when none of the more specific categories apply (i.e., mentions of other people or media that affected someone's thinking, decision-making or behaviors).
IN	Information Needs	For instances when the participant stated that more info is needed, or not enough is known about something (i.e., about genetics in general, how to understand statistics).
MC	Misconception	For instances when a behavior is predicated on a misconception.
PR	Perceived Risk	Used whenever one's perceived risk of contracting breast or ovarian cancer, or of carrying the *BRCA1/2* gene, was discussed.
RH	References to Healthcare	Whenever reference to medical care/doctors was made.
RO	Religious Obligations	Used whenever religious obligation was mentioned (i.e., when speaking of the religious obligation to test).

RF	Risk Factors	Used whenever the risk factors for *BRCA1/2* or breast/ovarian cancer were mentioned.
RM	Risk Management	Whenever ways of managing one's risks of breast cancer were brought up (i.e., interventions for those at high risk, being mindful of risks, reducing risks, and screening when one is at risk).
RC	Role of Community	The role that the community plays in regard to breast cancer and testing (i.e., helping to reduce stigma and getting rid of misconceptions). This was generally used regarding the role that the community should play in the future regarding these issues.

Rigor is essential to confirm the consistency of the methods, which leads to establishing trust and confidence in the findings of the research (Thomas & Magilvy, 2011). Therefore, at the end of this iterative process, the inter-rater reliability was calculated. The coders used the Scott's Pi measure, which is an index of inter-coder agreement that calculates reliability of content analysis (Scott, 1955). A final comparison of the code book using the Scott's Pi measure was 0.7091, or 71% agreement between the coders. While there is no single value or cutoff point where intercoder reliability is achieved, according to the general set of benchmarks for Scott's Pi (Table 8), the strength of agreement between the two coders shows to be substantial (Wombacher, 2017).

Table 8

General Set of Benchmarks for Scott's Pi

Scott's Pi	Strength of Agreement
< 0.00	Poor
0.0 - 0.20	Slight
0.21 - 0.40	Fair
0.41 - 0.60	Moderate
0.61 - 0.80	Substantial
0.81 - 1.00	Almost Perfect

Note. From *"*Intercoder Reliability Techniques: Scott's Pi"*,* by K. Wombacher, 2017, *The SAGE Encyclopedia of Communication Research Methods*, pp. 754. Copyright 2017 by SAGE Publications, Inc.

Chapter IV

RESULTS

This chapter begins by presenting the basic characteristics of the key stakeholders and community members. Then, the codes utilized for content analysis is shown. Finally, themes and sub-themes that emerged from the dialogue related to social, cultural, religious factors that impact medical decision-making in the Orthodox Jewish population are discussed by analyzing narratives of the stakeholders and community members.

Participant Characteristics

As shown in Table 9, among the 49 participants, 17 were employed in healthcare, 18 were in Jewish education, 9 were in academia and 5 were women from the Jewish community. Specifically, participants of the stakeholder dialogue included the following occupations: genetic counselors (n=4), medical advocates (n=2), nurse practitioner (n=1), physicians (n=10), rabbis (n=9), rebbetzins (n=3), shadchans (n=2), kallah teachers (n=3), principal (n=1), professors (n=8), and project manager (n=1).

Table 9

Basic Characteristics of Stakeholder Dialogue Participants

Healthcare professionals	Genetic Counselor	4	17
	Medical Advocate	2	
	Nurse Practitioner	1	
	Physician	10	
Religious figures	Rabbi	9	18
	Rebbetzin	3	
	Shadchan	2	
	Kallah Teacher	3	
	Principal	1	
Academia	Professor	8	9
	Project Manager	1	
Community members	Women from focus groups	5	5

Themes

Number of quotations of codes that were utilized for the analysis are presented in Table 10. The themes that emerged from the stakeholder dialogue around medical decision-making are summarized below.

Table 10

Code Book and Number of Quotations (Stakeholder Dialogue)

Code Names	Number of Quotations
Cultural Influences	23
Genetic Testing Consequences	47
Genetic Testing Knowledge	37
Impact on Romantic Relationships	19
Influential Factors	11
Information Needs	7
Misconception	2
Perceived Risk	6
References to Healthcare	16
Religious Obligations	15
Risk Factors	1
Risk Management	7
Role of Community	4
Total	195

Facilitators and Barriers to Genetic Testing

Education/Prevention were heavily discussed as facilitators to genetic testing. Participants said that "educating the Jewish community that genetic testing will save lives" would be essential. Identifying women with *BRCA1/2* pathogenic variants would not only prevent them from dying but would also have a huge impact on other family members ("I think the focus needs to be because if women are identified with a *BRCA1* mutation, then there is a huge

opportunity to not only prevent them from being diagnosed with breast cancer but to also prevent them from dying of breast cancer, which has a huge impact on the other members of the family.").

However, there were also barriers to genetic testing, such as negative emotions, impact on family/romantic relationships, and cost. According to the discussions, negative emotions would be an obstacle. A participant stated that "education would not help because emotions are stronger than the mind." Also, a woman dealing with depression and obsessive-compulsive disorder (OCD) said that she decided not to get tested because of her mental health diagnosis and for her marriage. The impact on family and stigma were crucial topics that were brought up in the dialogue. They said that "stigma and fear of marrying into families" with *BRCA1/2* pathogenic variants interfere with the uptake of genetic testing ("It contributes to this stigma and fear of marrying into families where someone has a *BRCA1/2* mutation, and it keeps women from coming in to being tested in the first place. It would be extraordinarily important to talk about the steps that can be taken to manage risk, to prevent it being passed on to your children."). Some participants were concerned that *BRCA1/2* carriers may not be able to do a *shidduch* (a Jewish arranged marriage) and that this will break entire families ("They are afraid they will not be able to do a *shidduch* with those healthy children. I can tell you from my experience this is going to break entire families."). Therefore, education on the consequences of being a carrier, steps to manage risk, and prevention to reduce the risk of passing it on to your children was discussed as important information for the Jewish community ("With regard to the educational aspect, everyone seems to agree that it's a first step, it strikes me that it would be extraordinarily important to talk not just about the consequences of being a carrier, but what comes next, that is the steps that can be taken to manage risk, to prevent it being passed on to your children, to

reduce risk."). The impact on romantic relationships was another barrier to genetic testing. Knowing that one has a *BRCA1/2* pathogenic variant was considered a weight that needed to be disclosed to a potential spouse, who now would have to make a big decision ("Just knowing I have a breast cancer gene is just going to be another weight like I have to tell a boy and he's going to have to make a big decision and what's it going to help anyway?"). Insurance not covering the cost of *BRCA1/2* genetic testing or consulting a genetic counselor was another barrier ("I was in the process of deciding whether to get breast cancer testing after my insurance had denied it, I was being asked to pay out of pocket.").

Table 11

Facilitators/Barriers to Genetic Testing

Themes	Subthemes	Selected Quotations
Facilitators to genetic testing	Education/Prevention	"We have to educate the Jewish community that this is going to save lives. I don't think that that message comes out clear enough." "I think the focus needs to be because if women are identified with a *BRCA1* mutation, then there is a huge opportunity to not only prevent them from being diagnosed with breast cancer but to also prevent them from dying of breast cancer, which has a huge impact on the other members of the family." "If it's positive, okay then you can do many things, even if your time is running out." "Of course, many of those terrible situations we would avoid in the first place by genetic testing before they get married. And I have been involved those difficult situations where they don't avail themselves of *Dor Yeshorim* and they don't test until well into the relationship."

Barriers to genetic testing	Negative emotions	"Education doesn't help, I can tell you. Because the emotions are a lot stronger than your mind." "The fact that for my situation [dealing with depression and OCD] and for my marriage, I decided not to get tested."
	Impact on family	"It contributes to this stigma and fear of marrying into families where someone has a breast cancer mutation and it keeps women, I suspect, from coming in to being tested in the first place. So, with regard to the educational aspect, everyone seems to agree that it's a first step, it strikes me that it would be extraordinarily important to talk not just about the consequences of being a carrier, but what comes next, that is the steps that can be taken to manage risk, to prevent it being passed on to your children, to reduce risk." "The first thing they are talking about, they are afraid they will not be able to do a *shidduch* with those healthy children. And what I'm worried is that this household should not get ruined. Because that's the biggest biggest worry, that the entire family should not get ruined. And therefore, I ask please everybody to consider this, that doing that it's a lot easier to break than to build. And I can tell you from my experience this is going to break entire families. They will not be able to do a *shidduch*, finally they will do *shidduchim* to breast cancer carriers. That will be the outcome of that because they will not find other *shidduchim*."
	Impact on romantic relationships	"Just knowing I have a breast cancer gene is just going to be another weight like I have to tell a boy and he's going to have to make a big decision and what's it going to help anyway?"
	Cost	"I was in the process of deciding whether to get breast cancer testing after my insurance had denied it, I was being asked to pay out of pocket." "I did not [meet with my genetic counselor because] I was told my insurance wouldn't cover it."
	Stigma	"There are so many people who are between the ages of like 25 and 35 and single, and a lot of them are meeting their spouses through, you know, the

		community. So you don't just hear about whether or not they have all these diseases before you get to know them as a person, so that kind of takes away a little bit of, I think, the stigma."

Role of Religious Figures in Medical Decision-Making

Participants supported the role of religious figures by claiming that "the rabbonim have to be educated" to educate patients. Rabbonims encouraging genetic testing was suggested if there is a family history ("If there's a family history it should be encouraged, maybe by the rabbonim themselves who know about these things, to try to get additional testing."). However, some said that "there's no standard protocol from the frum [religious] community."

Role of Healthcare Professionals in Medical Decision-Making

The role of healthcare professionals in medical decision-making was discussed among stakeholders. Prevention/Education was the main reason why they supported the role of healthcare professionals. For instance, they talked about coming up with a realistic solution so that women who are at high risk for breast cancer can have effective screening/prevention options and can be counseled the right way ("I'm so grateful that we have this meeting today so we can figure out strategies, to come up with a realistic solution so that women who really are at high risk of breast cancer can have effective screening and effective treating and can be counseled the right way, so this is an enormous opportunity."). Education about counselling was brought up to empower high risk women when making medical decisions ("Those should be educated that it's a good thing to go into counselling so that they get a more deep, more detailed information so that they're empowered to make the decisions."). They believe that prevention will be possible when women follow recommendations from experts in the medical field ("If we

want to help people, we have to make sure they make mammograms, ultrasounds, MRIs, or whatever is recommended by the medical to do prevention. This way you don't do harm.").

On the other hand, some participants were less enthusiastic about the role of medical professionals when making medical decisions in this population. A genetic counselor and doctor were considered as those who suggest procedures that are against the Torah, known as the first five books of the Hebrew Bible ("There are a lot of offerings the genetic counselor does which is totally against the Torah."). Participants stated that these medical professionals do not consider mental health or problems and do not respect people who choose not to get tested ("I was ridiculed by my doctor for this [decided not to get tested]. I think we need to focus on training doctors for this, for proper informed consent and to respect people who chose not to."). Not having enough genetic counselors was another concern ("There aren't enough genetic counselors around to be able to counsel every single person.").

Influential Factors

The influential factors were knowledge, health, and community. A participant said that women could change their decisions if they had the knowledge that getting tested could help prevent cancer ("Maybe women who said no I'm not going to get tested, if they would have known that a test result could help prevent cancer then that could completely change their decision."). In addition, they discussed that people might decide not to get tested due to their physiological, physical, and mental health ("I think there are legitimate reasons why people decide not to get tested whether physiological, physical, mental health."). Community leaders, medical community (including genetic counseling), and misperceptions from the community were factors that could influence uptake of genetic testing ("Misperceptions, and perhaps

misconceptions from the general community, and what responsibility do we have towards that factor and to affect that factor."). The role of men in the Orthodox Jewish community was also discussed ("The men in the community need to understand what the issues are for their wives and daughters and sisters.").

Table 12

Role of Religious Figures/Healthcare Professionals in Medical Decision-Making & Influential Factors

Themes	Subthemes	Selected Quotations
Role of religious figures in medical decision-making	Support	"I think the rabbonim have to be educated." "If there's a family history it should be encouraged, maybe by the rabbonim themselves who know about these things, to try to get additional testing." "When you don't have history, medical history, family history, for sure, better not to test. But if you do have, then you have to go to a real daas torah [rabbinic authority] who understands medicine."
	Against	"There's no standard protocol from the frum community."
Role of healthcare professionals in medical decision-making	Support	*Prevention/Education* "Had we known that she had a *BRCA1* mutation she would have had a different treatment, she wouldn't have died. So huge impact, so... for this I'm so grateful that we have this meeting today so we can figure out with strategies, to come up with a realistic solution so that women who really are at high risk of breast cancer can have effective screening and effective treating and can be counseled the right way, so this is an enormous opportunity." "I think that in terms of actual counseling, obviously one has to define the high risk. And those should be educated that it's a good thing to go into counselling so that they get a more deep, more detailed information so that they're empowered to make the decisions."

		"If we want to help people, we have to make sure they make mammograms, ultrasounds, MRIs, or whatever is recommended by the medical to do prevention. This way you don't do harm." "Educating physicians to educate their patients"
	Against	"There are a lot of offerings the genetic counsel does which is totally against the Torah, and there are always exceptions, but to go open up a Pandora's box and then go ask sheilas (a girl or young woman)?" "This is the medical community. They don't even think about somebody's psychologies and somebody's problems." "I was actually ridiculed by my doctor for this [decided not to get tested]. I think he need to focus on training doctors for this, for proper informed consent and to respect people who chose not to." "Probably the healthcare system isn't gonna have enough resources, genetic counselors to be able to take on that huge influx. We also have to think about ways of further disseminating this to a broader community." "There aren't enough genetic counselors around to be able to counsel every single person."
Influential factors	Education	"Maybe women who said no I'm not going to get tested, if they would have known that a test result could help prevent cancer then that could completely change their decision."
	Health	"I think there are legitimate reasons why people decide not to get tested whether physiological, physical, mental health."
	Community	"Communal leaders" "It's the medical community, it's also access to genetic counseling." "Misperceptions, and perhaps misconceptions from the general community, and what responsibility do we have towards that factor and to affect that factor." "The men in the community need to understand what the issues are for their wives and daughters and sisters as well."

Disclosure

Disclosure was discussed among various stakeholders. While some believed that everything should be disclosed ("I'm a big believer in disclosure that everything should be disclosed, that you know about."), some advocated that obligations to disclose information related to genetic testing may be subjective ("Some factors are more universal or considered to be more universal, the assumption is that anyone would want to know about certain things, so therefore an automatic obligation to disclose such information, other elements are more subjective, so where exactly does any of this fit in? Is something that is clear obligation even if one is not asked?"). Also, whether there is an "obligation to disclose the results with the person you are considering marrying" was brought up during the discussion ("Is that fooling the husband by not disclosing the possibility? Yes."). They said that "community education about disclosing information about potential matches" is needed.

Implementation

There was a discussion about where and how to implement genetic testing. Kallah teachers (who teach women the basics of Jewish marital etiquette) were considered to be a nice fit for the role ("A good place to start is with the kallah class teachers. Because these are a lot of young women, who are about to get married, before they're pregnant, but at the same time, they really want to undergo testing prior to the marriage."). Since genetic counselors might not be able to deal with the huge influx, stakeholders suggested "thinking about ways to further disseminate it to a broader community" ("Probably the healthcare system isn't going to have enough resources, genetic counselors to be able to take on that huge influx.").

Cultural considerations and age were the two sub-themes that emerged around implementation. For cultural reasons, the language will be crucial because 'breast cancer' will not be able to be written or spoken in the community ("The subject of language is going to be important in some of the communities because even the phrase 'breast cancer' is not going to make it into print or spoken language, and how do you deal with something that you can't say?"). Since marriage is crucial in the Jewish culture, targeting women in their thirties (married) rather than 17-20 (single) was proposed to deal with stigma ("This is something which our community are very concerned, the stigma of getting married, how this will impact, maybe we should be targeting a group, a different age, let's say thirty years old as opposed to the 17-20 years old."). There was a discussion about getting testing at a younger or older age. They said that testing at a younger age would "prevent the next generation from inheriting the gene," while testing at an older age would "implement more aggressive treatment to save lives".

Information Needs

Various participants addressed information needs: advantages/disadvantages of genetic testing ("What is the damage you are doing when test everybody and what is the gain?"), "to what extent one is obligated to disclose results," whether one has the responsibility to test before seeking a potential spouse ("Is there a responsibility on someone who at the present time is ignorant of the fact that whether she has the breast cancer [gene] or not have the breast cancer [gene] to test before they start going out for a marriage partner?"), whether there is "an obligation to get genetic testing under Jewish law," and steps to reduce risk ("The question is to address the individuals who have such a diagnosis, so what steps should they take, what steps can they take, are they obligated then to take steps, proactive steps in order to reduce the risk?").

Table 13

Disclosure, Implementation, and Information Needs

Themes	Selected Quotations
Disclosure	"What must be disclosed? I'm a big believer in disclosure that everything should be disclosed, that you know about." "We need more community education about lashon hara (derogatory speech about a person) and disclosing medical information about potential matches." "Is there an obligation to disclose this diagnosis with the person who you are considering marrying?" "Some factors are more universal or considered to be more universal, the assumption is that anyone would want to know about certain things, so therefore an automatic obligation to disclose such information, other elements are more subjective, so where exactly does any of this fit in? Is something that is clear obligation even if one is not asked? Is this an item that one would disclose only if one is asked, is there a difference in timing?" "Is that fooling the husband by not disclosing the possibility? Yes."
Implementation	"A good place to start is with the kallah class teachers. Right? Because these are a lot of young women, who are about to get married, before they're pregnant, but at the same time, they really want to undergo testing prior to the marriage." "I think that that can be a real role for kallah teachers throughout the marriage relationship." "Probably the healthcare system isn't going to have enough resources, genetic counselors to be able to take on that huge influx. We also have to think about ways of further disseminating this to a broader community." *Cultural considerations* "The subject of language is going to be important in some of the communities because even the phrase 'breast cancer' is not going to make it into print or spoken language, and how do you deal with something that you can't say?" "This is something which our community are very concerned, the stigma of getting married, how this will impact, maybe we should be targeting a group, a different age, let's say thirty years old as opposed to the 17-20 years old."

	Age "What the rabbi was saying that we should start at a later age, I thought that was very appropriate because after 25 you're saying we should start screening after 25 which would really help us out when we get a kallah into our room, she has so much to deal with at that time, that to bring in a subject like this would be like very very overwhelming, on the other hand, like the doctors said, we don't want to ignore such an issue that could save lives, but perhaps if we started at a later age, when they were married 5 years, 6 years, or whatever it is, at that time to introduce it to them, at that time to suggest that they go, then we would save them the anguish of having to deal with these even these kind of decisions at a time in their lives that they're so overwhelmed with everything that's going on." "One is testing early has to do with preventing the next generation from inheriting the gene which is one issue. The second issue is testing to implement more aggressive treatment, regimen to save lives and I think when we discuss this we're sort of back, and that's what your idea what you're fighting is some people are saying test early because the goal is to prevent the inheritance of the next generation. The other is saying test older, test 35 test 70 because we can do better medical management."
Information needs	"So, you can die even without breast cancer. And the risk, the exact risk. What is the damage you are doing when test everybody and what is the gain?" "One of the major elements that come up once testing has taken place is a very complex question, is the question of disclosure, to what extent is one obligated to disclose one's results to a third part, its most relevant to for one who is considering getting married, marrying someone specific, marrying someone in general." "Is there a responsibility on someone who at the present time is ignorant of the fact that whether she has the breast cancer [gene] or not have the breast cancer [gene] to test before they start going out for a marriage partner? Sometimes that question is decided by the mother who doesn't tell the child that even she the mother carries breast cancer." "Is there an obligation under the realm Jewish law, to undergo genetic testing of any specific type?" "Are there any reasons not to from a moral, *halachic* perspective and that's a question which includes philosophical as well as legal issues?" "Then the question is to address the individuals who have such a diagnosis, so what steps should they take, what steps can they take, are they obligated then to take steps, proactive steps in order to reduce the risk?"

The following statements from the stakeholder dialogue emphasize that education is important in the medical decision-making process and stress that *BRCA1/2* genetic testing should be communicated through multiple channels: doctor (healthcare professionals), rabbi (religious figures), and community education program (community).

> "I think first of all education is where it all starts. Empowering people to understand what the issues are and to make their own decisions. But I think that the education piece has to be very sensitive to different communities. I don't think it can be a uniform education. I think we have to realize that different communities are going to need a different level of education or different context of the information."
>
> "I think we need to be looking at multiple ways …, it's not just through the doctor, and it's not just through the rabbi, it's not just through the community education program, but we need to be really creative in thinking about different ways to be approaching the community from different aspects of the community, to be spreading this message of awareness."

Chapter V

DISCUSSION, CONCLUSION, AND RECOMMENDATIONS

The purpose of this study was to understand the social, cultural, and religious factors influencing medical decision-making on *BRCA1/2* genetic testing in the Orthodox Jewish community by analyzing narratives of key stakeholders and community members. The first section of this chapter comprises a discussion of the results of the stakeholder dialogue. This section also ties the results to the Orthodox Jewish culture and literature. After delivering the strengths and limitations of the study, the conclusion is discussed. The last section of this chapter provides recommendations for future research.

Discussion

This study aimed to understand the social, cultural, and religious factors influencing medical decision-making on *BRCA1/2* genetic testing in the Orthodox Jewish community. Facilitators to genetic testing were prevention and education, while barriers to genetic testing were negative emotions, impact on family/romantic relationships, cost, and stigma. The role of religious and healthcare professionals in medical decision-making were controversial. Education, health, and community were discussed as influential factors. There were issues around disclosure, implementation, and information needs.

Some previous studies have sought to understand issues around *BRCA1/2* genetic testing. A population-based survey of 200 Jewish women found that 40% were interested in *BRCA1/2* genetic testing, mainly due to a desire to obtain information about their children's risk. A few women expressed concern or discomfort with targeting of Jews for genetic testing (17%). Most women (71%) thought there were scientific reasons for testing Jews (Lehmann et al., 2002). In a survey of over 100 breast cancer patients of Ashkenazi Jewish descent who were offered *BRCA1/2* genetic testing as part of a research study, the most common motivating factors to undergo testing were a desire to contribute to research that may help the Jewish community and potential benefit to other family members (Phillips et al., 2000). In Ontario, Canada, 6179 Jewish women received *BRCA1/2* genetic testing through a population-based screening program and 93 (1.5%) tested positive, including 92 (99%) who were unaffected with cancer (Metcalfe et al., 2013). Among mutation carriers, 11.1% had prophylactic mastectomy and 89.5% had risk-reducing oophorectomy within 2 years of receiving their genetic test results (Metcalfe et al., 2012). Cancer-related distress decreased among those women who underwent risk-reducing surgeries; 98.2% expressed satisfaction with the testing process and would recommend testing to

other Jewish women. These studies included Jews for whom unique issues may arise surrounding *BRCA1/2* genetic testing due to their obligations under Jewish law or code of ethics (Mor & Oberle, 2008; Phillips et al., 2000).

While these studies have collected data from *women* on the issue of *BRCA1/2* genetic testing, the social, cultural, and religious factors that influence medical decision-making in the *social and community context* have yet to be deeply explored. Social and community context refers to the social settings where people live and act, which includes social relationships and the social, religious, cultural, and occupational institutions with which they interact (Barnett & Casper, 2001). Considering the social and community context of Jewish women is important because Orthodox Jews often live in tightly-knit communities and are culturally distinct due to their insularity and traditional observance of Jewish law or *Halacha*. In secular ethics, autonomy is considered a highly valued feature of healthcare, whereas *Halacha* is based upon religiously mandated legal, spiritual, and ethical codes and obligations in a given situation. For Orthodox Jews, *Halacha* regulates nearly every aspect of behavior, including observance of the Sabbath (a day of religious observance), dietary laws, modesty in behavior and dress, gender separation in public domains, limited exposure to general culture, as well as medical and health decisions (Coleman-Brueckheimer et al., 2009).

Based on different levels of observance of *Halacha* and access to secular outlets, a spectrum from Modern Orthodox to Yeshivish and Chassidish communities exists within the Orthodox Jewish community (Grazi & Wolowelsky, 2015). Although there is a wide range of adherence, the most typical categorizations of Orthodox Judaism are Modern and Yeshiva Orthodox (emphasizes rabbinic authority and leadership with stringent interpretation of Jewish law), and Hasidic (emphasizes cultural insularity and minimization of exposure to secular

information outlets). Rabbinic authorities are typically consulted across the three Orthodox denominations to answer *shailohs*, questions related to the determination of a point of Jewish law, including medical decisions (Coleman-Brueckheimer et al., 2009).

A relatively unique feature of the Orthodox Jewish community is the existence of multiple organizations of medical navigators or culture brokers, who are not medical professionals, which may bridge the gap between Orthodox Jewish individuals and medical services provided by the secular community (Greenberg & Witztum, 2001). Given the centrality of these figures, who may have limited knowledge or access to accurate information, it is important to understand the roles of rabbis and communal figures in medical decision-making for the Orthodox Jewish community and their potential ability to disseminate standards of care (i.e., genetic testing).

Medical decision-making research seeks to explain how physicians and patients routinely make decisions and identifies both barriers and facilitators to effective decision-making (Schwartz & Bergus, 2008). Good medical decisions are hard to make when uncertainty exists, making it difficult to reach a consensus on the right or best choice. This is a common dilemma in healthcare. While the field emphasizes evidence-based medicine, patients and providers must make complex decisions when adequate evidence or consensus among experts is insufficient to guide the selection of available options based on the best available information (Hamilton et al., 2017). According to the Ottawa Decision Support Framework (O'Conner et al., 1998 the quality of a decision is determined by having a good decision process and outcome that includes shared decision-making. This framework assumes that decision-making is a multi-dimensional process that is affected by specific characteristics of the decision, decisional conflict, knowledge and expectations of the health situation and treatment options and outcomes, personal values and

preferences, support and resources needed to implement the decision at multiple levels of influence, personal characteristics, and clinical characteristics. Medical decision-making in the Orthodox Jewish population also requires a multi-dimensional process that incorporates unique sociocultural and religious considerations.

Various factors that influence medical decision-making around *BRCA1/2* genetic testing were explored in this study. The results show education/prevention as facilitators, and negative emotions and cost as barriers to genetic testing, which is similar to another study that presents the pros and cons of *BRCA1/2* mutation testing. *BRCA1/2* testing leads to providing information to the patient and family members and improving breast and ovarian cancer risk management. However, it may also cause psychological distress or loss of privacy (Schwartz, Peshkin, et al., 2005). Health insurance coverage can also be a barrier to undertake genetic testing. The Genetic Information for Treatment Surveillance and Support (GIFTSS) program was established by the Cancer Resource Foundation (CRF) in 2009 to assist the out-of-pocket fees for cancer genetic testing targeting high-risk individuals that have limited financial means and insurance coverage (Underhill et al., 2017). Acknowledging the concerns of Orthodox Jews about ways to cover the cost could result in removing a possible barrier to *BRCA1/2* testing.

Studies also report that individuals with limited resources are less likely to obtain access to genetic testing (Chen & Greene, 2010). Therefore, genetic counselors and clinicians should utilize various approaches to enhance access to genetic testing and make it convenient to reach underserved communities. The results of genetic testing can lead to treatment or diagnostic/prevention recommendations. To enhance the quality of genetic testing and improve the appropriate use of genetic tests in healthcare, the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS) have been collaborating with

other organizations since 1997 (Chen & Greene, 2010). Since some Orthodox Jewish communities tend to be insular, it would be beneficial to increase access to genetic testing through various means (i.e., collaboration with healthcare facilities or religious organizations), which will lead to prevention or treatment.

Impact on family/romantic relationships and stigma were other barriers to genetic testing. Many practical and sociocultural concerns exist about genetic testing, such as adverse psychological impact on the individual and their family members, reproductive consequences, discrimination in insurance and employment, and uncertainty about the accuracy and interpretability of results. Given that marriages in the Orthodox Jewish community occur at younger ages and are often facilitated by a system of matchmaking (*shidduchim*), some families may decline testing because of fear of reducing desirability to prospective mates for them, as well as other children and siblings (Phillips et al., 2000).

One study showed that the Jewish community is, generally, already familiar with genetic testing because of the success of testing programs for genetic disorders, such as Tay-Sachs, an autosomal recessive disease (Broide et al., 1993). 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 (Grazi & Wolowelsky, 2015; Raz & Vizner, 2008). The acceptance of *Dor Yeshorim* is attributed to the concealing 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 (Schneider et al., 2009). Due to successful anonymization and institutionalization of the testing program, pre-marital genetic testing for Tay-Sachs is common practice in the *shiduch*

(matchmaking) process of the Orthodox community (Broide et al., 1993). Learning from the case of Tay-Sachs disease, genetic testing for *BRCA1/2* mutations can become more acceptable with specialized attention, policies, and *Halacha* (Jewish law) decisions.

However, *BRCA1/2* genetic testing is different from *Dor Yeshorim*. While *Dor Yeshorim* offers anonymous screening for recessive disorders (Broide et al., 1993), *BRCA1/2* pathogenic variants are inherited in an autosomal dominant fashion, therefore, if female carriers are identified as having an increased risk of breast and ovarian cancer, they can take action to reduce the risk. If tested positive, an individual may be obligated to disclose the results to family members and potential spouses, which is another potential burden. Carrying a pathogenic variant in *BRCA1/2* is not an absolute that an individual will develop cancer. Women who inherit *BRCA1/2* pathogenic variant may never develop cancer. In addition, women who have inherited a *BRCA1/2* pathogenic variant can reduce their risk of cancer by enhanced screening, risk-reducing surgery, and chemoprevention (National Breast Cancer Foundation, 2020).

Community members in the stakeholder dialogue discussed information needs around genetic testing. Since the information in genetic counseling is complex, researchers have developed decision aids to assist with decision-making related to *BRCA1/2* testing. Several studies revealed that those who perceive their risk for cancer to be high and who think genetic testing is beneficial are more willing to undertake *BRCA1/2* testing (Schwartz, Peshkin, et al., 2005). A key national priority in the United States is to identify individuals with inherited cancer predisposition. While numerous organizations recommended genetic counseling to enhance understanding, informed consent, preventive behaviors, and individualized care (Robson et al., 2015), among those women with breast or ovarian cancer who meet family history criteria for referral for cancer genetic risk assessment, less than half of them receive genetic counseling or

testing (Childers et al., 2017; Katz et al., 2018; Kurian et al., 2017). Only 10% of unaffected carriers of *BRCA1/2* pathogenic variants are aware of their status (Drohan et al., 2012).

Decision support tools that increase patient participation in medical decision-making and improve decision outcomes will be beneficial. These tools can be modified based on the needs and relevance to the audience. For instance, it will be possible to engage and educate the Orthodox Jewish population by utilizing: 1) patient-centered decision aids culturally tailored to Orthodox Jewish women, community members, and religious leaders (modified for educational purposes and introduced at synagogue) and 2) educational tools for healthcare professionals and religious leaders. Since this is a religious population where adherence to Jewish Law is crucial, discussing breast cancer risk with other community members and rabbinic leadership during the medical decision-making process will be critical to establish a common understanding that is socially agreeable. Results from previous studies also support the significance of stigma from the religious community and the role of religious leaders in medical decision-making (Trivedi et al., 2018; Yi et al., 2017).

Statements from the stakeholder dialogue indicate that tailored education that involves healthcare professionals, religious leaders, and community members will be critical in the initial stages of *BRCA1/2* genetic testing in the Orthodox Jewish population. As shown in several themes that emerged in this study, it is possible that these *influencers* will affect the *decision-makers* (Orthodox Jewish women) in the medical decision-making process around *BRCA1/2* genetic testing. Therefore, educating key stakeholders and community members about *BRCA1/2* testing will be essential to overcome barriers to testing, such as stigma. In addition, providing tailored education to Orthodox Jewish women depending on marital status (married and single)

would be a way to effectively inform them, since the impact on family and romantic relationships influence medical decisions in this population.

This study has some limitations. Because this is a qualitative study, the research is dependent on the individual skills of the researcher and may be influenced by researcher bias. Also, the responses of participants can be affected by the researcher's presence during the data gathering phase. Second, the population of interest for this study was Orthodox Jews in New York and, therefore, the findings may not be generalizable to Jewish communities in other geographic areas that are more insular and harder to reach. Third, the data for this analysis were collected in 2015. Although the Orthodox Jewish culture is generally known to be stable across generations, it is possible that the results may have differed if the data had been collected at another point in time. Recently, genetic testing has become more complex with multigene panel testing. More comprehensive multigene panel testing is used more commonly and can yield more indeterminate results or variants of uncertain significance (VUS).

Despite these limitations, the study has several notable strengths. Orthodox Jews are an understudied population; thus, this study provides an in-depth exploration of the social, cultural, and religious issues around *BRCA1/2* genetic testing in this unique population. Specifically, this study considered the *halachic* implications (Jewish law and code of ethics) and carefully identified the challenges and barriers. To provide external validation of the qualitative analysis and confirm the consistency of the methods, multiple coders met regularly to establish a common understanding of the codes. Utilizing the Grounded Theory approach, this study captured the narratives of Orthodox Jewish community members and key stakeholders, including women, healthcare providers, genetic counselors, and religious leaders around *BRCA1/2* genetic testing.

Conclusion

In conclusion, this study revealed the voices of the Orthodox Jewish women (*decision-makers*) and religious figures, healthcare professionals, and community members around them (*influencers*) who play a critical role in determining the decision-making process. The results provide a unique and significant contribution to the literature by advancing our understanding of the medical decision-making process in this distinct population. Finally, this study has broad implications for engaging community stakeholders within faith-based or culturally distinct communities to ensure better utilization of healthcare services for cancer screening and prevention to improve population health. Further research on the *influencers* (religious leaders, healthcare professionals, and community members) around *BRCA1/2* genetic testing will be essential to gain a better understanding of the Orthodox Jewish community to overcome the barriers to *BRCA1/2* testing. Population-based screening of Ashkenazi Jews is highly cost effective and results in identifying more mutation carriers than family history-based screening (Manchanda, Legood, et al., 2014; Manchanda, Loggenberg, et al., 2014). In this religious and cultural group, population-based *BRCA1/2* genetic testing will be enhanced when the *decision-makers* and *influencers* both consider *BRCA1/2* genetic testing as a socially and religiously acceptable practice in the Orthodox Jewish community.

Recommendations for Future Research

There are unique challenges in testing for *BRCA1/2* genes among the Orthodox Jews, which are influenced by the culture and community. Furthermore, there is very limited discussion and knowledge about this emerging new topic in Jewish law. However, genetic

testing has become standard practice in this population due to successful anonymization and institutionalization of genetic testing programs.

Utilizing relevant codes from the code book, I analyzed qualitative data from focus groups of married and single Orthodox Jewish women (n=18) to understand the sociocultural and religious factors affecting medical decision-making (Appendix C). After analyzing 360 quotations, ten themes emerged: barriers/facilitators to genetic testing, the role of religious figures/healthcare professionals in medical decision-making, influential factors, familiarity with genetic testing, implementation, information needs, impact on family, and disclosure. A following study can provide a rich and comprehensive understanding of the Orthodox Jewish population by combining the results from the stakeholder dialogue and focus groups, which includes narratives of religious leaders, healthcare professionals, breast cancer experts, community members, and women (n=67). This could possibly reveal similar or different perspectives around *BRCA1/2* genetic testing among *decision-makers* (Orthodox Jewish women, n=23) and *influencers* (key stakeholders and community members, n=44).

Further research on the *influencers* (healthcare professionals, religious leaders, and community members) around *BRCA1/2* genetic testing will be essential to gain a better understanding of the Orthodox Jewish community. For the next step, utilizing qualitative research will be helpful to collect narratives from each group to delve deeper into themes that emerged from this study (i.e., facilitators/barriers to genetic testing). In this religious and cultural group, population-based *BRCA1/2* genetic testing will be mostly acceptable when the *decision-makers* and *influencers* both consider *BRCA1/2* genetic testing as a social norm and is considered standard practice in the Orthodox Jewish culture. The stakeholder dialogue included 49 people with various backgrounds, so it was difficult to distinguish responses among

participants. Therefore, it would be beneficial to have separate focus groups to identify unique perspectives in each sector (i.e., groups of healthcare professionals, religious leaders, and community members).

In detail, stakeholders supported the role of religious leaders in medical decision-making. This emphasizes that Jewish law is important to the *decision-makers* (Orthodox Jewish women) and religious figures will have an impact on uptake of *BRCA1/2* genetic testing among Orthodox Jewish women. Therefore, future studies can conduct interviews or focus groups by discussing *BRCA1/2* genetic testing in depth with religious leaders (i.e., rabbis, rebbetzins, kallah teachers, shadchans). This would be essential to further explore underlying religious concerns, implementation strategies, and effective ways to broaden *BRCA1/2* genetic testing in this insular community.

Narratives of the stakeholder dialogue show that healthcare professionals can influence medical decisions of Orthodox Jewish women. Therefore, a mixed methods study can further explore the decision-making process that occurs during the medical encounter. Quantitative data can be collected by creating surveys that are based on relevant results from this study. After medical encounters, interviews of Orthodox Jewish women discussing the medical decision-making process can be conducted to obtain qualitative data (i.e., Did you discuss your religious concerns with your healthcare professional?).

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Appendix A

Email Script

Dear _____,

We would like to invite you to participate in a stakeholder dialogue on increasing knowledge and access to BRCA genetic testing in the Orthodox Jewish community. This is part of a funded research project involving Columbia University Medical Center and the Institute for Applied Research & Community Collaboration (ARCC), a community-based research organization which helps guide and inform policy- making within the Orthodox Jewish community.

We know that genetic mutations in the BRCA1 and BRCA2 genes are associated with an increased risk of breast and ovarian cancer, as well as other cancers. About 1 in 40 individuals of Ashkenazi Jewish descent carry a BRCA1 or BRCA2 mutation and may be candidates for increased cancer screening and prevention strategies. We have already conducted a survey of over 500 Orthodox Jewish women from the local community to understand social, cultural, and religious factors influencing BRCA genetic testing.

The goal of this dialogue is to hear different perspectives on BRCA genetic testing and how best to implement this testing in the Orthodox Jewish community. We will be inviting members of the medical and research community, including geneticists, cancer specialists, and ethicists, and key stakeholders and leaders of the Orthodox Jewish community. The session will be held on Sunday afternoon, June 7th, 2015 in Upper Manhattan (exact location and time, to be determined). The session will be audio- recorded and each participant will be given a $150 honorarium.

We welcome your input on this very important health issue. Please contact us if you would like to participate and are available on that date. We will then send further details.

Sincerely,

Katherine Crew, MD MS
Director, Clinical Breast Cancer Prevention Program Columbia University Medical Center

Yitzchak Schechter, PsyD
Executive Director
Institute for Applied Research & Community Collaboration

Appendix B

Consent and HIPAA Authorization Form

Study Protocol Number: IRB-AAAO1760
Principal Investigators: Dr. Katherine Crew, Dr. Isaac Schechter
IRB Protocol Title: *BRCA* genetic testing among Orthodox Jews

Participation Duration: 4.5 hours
Anticipated Number of Participants: 35

Research purpose
This is a research study aimed at obtaining insight into knowledge, attitudes, and decision-making preferences about *BRCA* genetic testing among Orthodox Jewish women. Our goals are twofold. First, we intend to use the insight gained from this session to inform the development of a community approach and "policy" towards BRCA genetic testing, and together with other data, this will be used to guide a "stakeholders meeting" of leading geneticists, medical experts, Rabbis, lay leaders and other community representatives. Second, we aim to develop written and electronic information that can assist women in interpreting breast cancer risk and genetic information and making informed personal decisions about risk management. The purpose of this stakeholder dialogue is to create a "community policy" statement on this topic.

Information on research
The stakeholder dialogue will take about 4.5 hours to complete. For the first 10 minutes, we will have introductions. Then for 30 minutes, we will have a medical overview about genetic testing from the clinical experts. Another 30 minutes will be for discussion of Halacha. The first half of the dialogue will close with a presentation and discussion about Orthodox Jewish culture, community and social issues. After a 20-minute break, the second half of the dialogue will consist of an open forum to discuss obstacles and opportunities (40 minutes), potential policies and systems (40 minutes), and implementation and dissemination (40 minutes).

Audio Recording
We will audio record the sessions. These recording(s) will be used for analysis by the research team. The recording(s) will not include any identifying information. If you mention any identifying details (names, addresses, etc.) they will be removed from the recording before the analysis begins. The recording(s) will be stored in a locked file cabinet, separately from other forms and data collected. The recordings will not be linked to your identity. We will retain the recording(s) for the duration of the study. We will destroy them upon completion of the study procedures.

Risks
There is a risk that you may feel uncomfortable because of the questions being asked or the topics being discussed. If you are uncomfortable with a question or topic, you can choose to stop participating in answering questions or discussion at any time and without presenting any reason. There is a risk for a breach in confidentiality. However, the research team will make great efforts to protect your data.

Compensation
In appreciation of your time, we will give you a gift card in the amount of $150 for participating in the stakeholder dialogue.

Benefits
We do not expect any direct benefits to any of the stakeholders. We expect, however, that the study will benefit other individuals from your community who may learn more about breast cancer, breast cancer risk, help them to decide about breast cancer genetic testing and make optimal informed personal decisions about breast cancer in the future.

Confidentiality
The results of the interviews, including recordings, will not be linked in any way to participant identifiers. The audiotapes of the interviews will be kept in a locked cabinet in the offices of the study Principal Investigators. In addition, once our research is finished, we will erase the recordings, so that no one will be able to identify you, personally, as the one who provided these specific answers.

Also, according to the rules governing research procedures at Columbia, by agreeing to participate in the study, you grant permission for information about you obtained during the study to be made available to:
- The investigators, study staff and other medical professionals who may be evaluating the study
- Authorities from Columbia University and New York Presbyterian Hospital, including the Institutional Review Board (IRB) (An Institutional Review Board is a committee organized to protect the rights and welfare of human subjects involved in research.)
- The Federal Office of Human Research Protections ('OHRP') and other government agencies that oversee the safety of human subjects.

Please note that you may change your mind and revoke "take back" this authorization at any time for any reason. To revoke this authorization you must contact the Principal Investigator, Dr. Katherine Crew at 212.305.0356. However, even if you revoke this authorization, the researchers may continue to use and disclose the information already collected, however new information will not be collected for this research purpose.

Use of this information / your HIPAA authorization will expire at the end of this research.

Voluntary
Whether you want to participate is completely up to you. You are free to say no to the study or to quit after you have started.

Contact information
If you have any questions now or later about this study, please contact Dr. Katherine Crew or Raven David at 212.305.0356 or email rd2501@cumc.columbia.edu or Dr. Isaac Schechter or Leah Respler at 845.445.7631 or email info@arccinstitute.org. If you have comments or concerns about your rights / welfare as a research subject, you may contact the IRB at (212-305-5883) or visit the website at http://www.cumc.columbia.edu/dept/irb/info.html.

I have read the consent form and talked about this research study, including the purpose, procedures, risks, benefits, and alternatives with the researcher. Any questions I had were answered to my satisfaction. I am aware that by signing below, I am agreeing to take part in this research study and that I can stop being in the study at any time. I am not waiving (giving up) any legal rights by signing this consent form. I will be given a copy of this consent form to keep for my records.

Your name: _____ Date: _____

Your signature: _____

Name of person obtaining consent: _____

Signature of person obtaining consent: _____

Appendix C

Focus Groups Study

Specific Aim

The aim was to analyze transcripts of focus group discussions of Orthodox Jewish women to a) identify social, cultural, and religious factors that influence their medical decisions and b) examine whether perceptions of *BRCA1/2* genetic testing differ depending on marital status.

Study Procedures

This study recruited 18 women to the focus groups who had participated in a previous survey and agreed to be re-contacted for future studies (Tang, 2017). Purposive sampling was used for the qualitative data to enhance sample coverage (Barbour, 2001). The study included a range of ages (≥ 18 years), with a slight over-representation of women at those ages when *BRCA1/2* genetic testing is most relevant (25-40 years). Researchers also ensured that the sample represents a range of experiences with cancer (i.e., women with a personal or family history of breast or ovarian cancer, unaffected women with a range of risk profiles).

Focus groups consisted of two 2-hour facilitated sessions, which took place at a local synagogue in Washington Heights in April 2015. The focus groups were divided into single (n=8) and married (n=10) groups to see whether discussions differed depending on marital status. Participants were provided incentives to attend, as well as food and refreshments during the session. The sessions were audio recorded to ensure accurate transcription. Initial orientation included the purpose and nature of the focus group, use of the results, ground-rules for the session, introduction of the issue and some basic facts about it. A workbook was developed for

these sessions designed around 2-4 distinct scenarios, which reflected distinct value sets held by the target population. The researchers consulted with an Advisory Board on the development of the scenarios, considering cultural and religious issues. Next, participants first worked in small groups of 4-5 people to discuss the likely good and bad results that would occur if each choice were adopted and constructed a vision of the future they would prefer to see. Then all participants came together in a plenary session in which each group reported its conclusions and the plenary as a whole worked to map out common ground. Finally, each participant gave concluding comments on how their views have changed and why. The focus group was led by a professional facilitator, who moderated the plenary session and circulated and intervened as necessary during the self-moderated small groups.

Data Analysis

Refer to data analysis for stakeholder dialogue (p. 56).

Results

Table 14 presents basic characteristics of the participants of the focus groups. 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. Eighteen women were included in the focus groups. Among them, 8 women were single and 10 women were married. The median age of the singles group was 24 and the married group was 29. A majority of women in both groups self-identified as Ashkenazi Jewish (Singles: 88%, Married: 90%) and Modern Orthodox (Singles: 63%, Married: 80%). All

of them had at least some college education. Many had seminary/post-seminary level of Jewish education (Singles: 100%, Married: 80%).

Table 14

Basic Characteristics of Focus Groups Participants

Focus Groups (n=18)		Singles (n=8)	Married (n=10)
Median age, years (range)		24 (22-36)	29 (23-77)
Jewish origin, N (%)	Ashkenazi	7 (88)	9 (90)
	Ashkenazi/Sephardi	1 (13)	0 (0)
Jewish community, N (%)	Modern Orthodox	5 (63)	8 (80)
	Yeshivish	3 (38)	1 (20)
Highest level of secular education, N (%)	High School	0 (0)	0 (0)
	College/Some college	6 (75)	4 (40)
	Masters/Doctoral degree	2 (25)	6 (60)
Highest level of Jewish education, N (%)	None	0 (0)	1 (10)
	Elementary/High school	0 (0)	1 (10)
	Seminary/Post-seminary	8 (100)	8 (80)

Codes that were analyzed for the focus groups are the following: Cultural Influences, Genetic Testing Consequences, Impact on Romantic Relationships, and Influential Factors. Table 15 shows the number of quotations for each code in the singles and married focus groups.

Table 15

Code Book and Number of Quotations (Focus Groups)

Code Names	Number of Quotations	
	Singles	Married
Cultural Influences	78	66
Genetic Testing Consequences	46	42
Impact on Romantic Relationships	22	N/A
Influential Factors	51	55
Total	197	163
	360	

By conducting content analysis of the codes, the themes that emerged from the focus groups were the following: facilitators to genetic testing, barriers to genetic testing, role of religious figures in medical decision-making, role of healthcare professionals in medical decision-making, influential factors, familiarity with genetic testing, implementation, information needs, impact on family, and disclosure.

As shown in Table 16, the sub-themes of facilitators to genetic testing were prevention, social norms, and information needs. Women said that they should know about the *BRCA1/2* gene because they can do something about it. Also, they discussed preventive measures and taking control over it. Comparing a genetic testing as a wakeup call, they said that they would do something if they knew that they were at risk. Single women were willing to undertake *BRCA1/2* genetic testing because of social norms and information needs. For instance, if it becomes a cultural or medical norm and everyone tests for *BRCA1/2* genes, then it will not be a big deal.

Women in the singles group stated that they want to know whether they have the genes for themselves because that's what is most important.

On the other hand, negative emotions, impact on family, stigma, impact on romantic relationships, medical procedures, and disclosure were sub-themes that emerged related to barriers to genetic testing. Women talked about anxiety, panic, fear, and being terrified that comes along with genetic testing. Impact on family/romantic relationships and stigma interfered with their decision to undertake genetic testing. Fear of passing the *BRCA1/2* gene to their children, being treated as a patient, and stigma/taboo were also brought up in the dialogue. Particularly, women in the singles focus group discussed the impact on romantic relationships saying that *BRCA1/2* genes can be a very big deal breaker in the dating phase. Medical procedures and disclosure were sub-themes in the barriers to genetic testing theme that only came up among single women. For instance, they considered double mastectomy a big deal that changes the consequences of genetic testing. In addition, they stated that they never want to get tested so that they do not have to deal with it. The weight to process the information and share it with others, which may also become a stigma towards them, was a responsibility they did not want to carry.

Table 16

Facilitators/Barriers to Genetic Testing

Themes	Subthemes	Selected Quotations
Facilitators to genetic testing	Prevention	"You should know about breast cancer. *Dor Yeshorim* is testing for only things that are fatal, but you can't do anything about it. The breast cancer gene, you should know about because you can do something about that." "If I did know, I would take care of it. In that case the guy would know most likely that now that I've taken care of it [so] I'll be

		okay versus he hears my mom had breast cancer and I didn't do anything about it then he might be scared. I don't know what they actually think." "If I had a breast cancer gene and I had the money, I can't say for sure now, but I think I would also get a double mastectomy with plastic surgery, but I wouldn't want to limit myself from ever having children because that would be like, too much." "When I am married and have kids or something, ideally I think I would want the knowledge both for myself and for my children." "I would, if I was positive, take more preventive measures, and to be more on top of it" "This would be the wakeup call to like, Oh, you know, I'm at risk. I need to do something."
	Social norms*	"It all depends on how you're introducing it to the public and how you present it to the community. If it is something that everyone does then it won't be a big deal if you have it." "In my community *Dor Yeshorim* testing is a norm and if they did breast cancer testing like that then you know many other people have it then it leads to a sense of community or understanding or more." "I assume if it became a medical thing that everyone gets tested, I would have. If it was a cultural norm but even within our smaller community."
	Information needs*	"I actually want to know for myself what I have. Cause the people I date now I would want both of us to know. And it wouldn't be such an issue because I don't do the *shidduch* scene, I meet people, so I want to be informed." "I would just want to know for myself, cause that's first and foremost."
Barriers to genetic testing	Negative emotions	"Though if I meet an Ashkenazi guy and we get serious I would do *Dor Yeshorim* but I won't know what I have so I won't be worried about it, I won't feel bad about it. Just things won't go further. I'd want to do that in a way I think, so I don't want to know." "Knowing that you don't have the gene would be a relief on some level but you're still not out of the woods and knowing that you have it would be terrifying. Like what are you going to do?" "It could trigger a lot of anxiety and panic."

		"Well, it's not just about taking the test, it's about understanding all the consequences, understanding how you handle it, anxiety and everything else, along with the mouthful of information coming from the doctor about it, these are the risks." "I think all it does might be is to increase the fear factor."
	Impact on family	"If I had the gene then suddenly my younger sister would have to worry. In the really yeshivish *shidduch* scene it could be a really big deal. It would be a really big issue for her and it's not something I'd want to deal with at the moment." "A particular type of fear, the fear of passing it on to your children."
	Stigma	"My mom died of breast cancer and I have an aunt now who has it. So, you know, once isn't, twice is a coincidence sort-of-a-thing so I know dealing with the social factors is kind-of a big deal. I know my mom was worried about what people would think." "If there wasn't the stigma or the family planning, where they wouldn't have to worry about their family or anything, then, for sure, I want to know everything." "I just think it goes back to one of the roots of the issue, and not just with breast cancer but with a lot of stuff, is that there's a huge stigma. You have to know your crowd but a lot of it does start at the Shabbos (Judaism's day of rest) 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." "I was afraid of viewing myself as a patient even before anything was actually proven to be a problem. And even if I didn't feel that way, I was afraid maybe my family members might, and try to treat me as a patient, like someone who is infirm."
	Impact on romantic relationships*	"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."
	Medical procedures*	"If you have the breast cancer gene, it might be a huge deal in *shidduchim* and getting set up and I felt, maybe I was wrong, that people were saying oh no, it's not a big deal, no one will ask about it, you don't have to reveal, but then when you were saying that when she found out about the breast cancer gene suddenly she was getting a double mastectomy and like tying her

		tubes and whatever, suddenly it seems like a bigger deal and the stakes change."
	Disclosure*	"This is the reason I never went to get tested, that if you have the gene you have to deal with it, and if you don't, you don't have to deal with it. But if I'm a carrier, suddenly I'm responsible to carry that information and share it with people and that's not something I'd want to have to do. I would have to tell certain people and then it would become like a stigma on me." "I would be concerned about the responsibility. I would have to tell certain people and then it would become like a stigma on me."

*Singles focus group only

As shown in Table 17, the role of religious figures in medical decision-making were discussed in both the married and singles group. Several women said that they would consult rabbis or other religious leaders for medical decisions related to *BRCA1/2* genetic testing. On the other hand, some women said that they wouldn't talk to their rabbi or leaders in their community for different reasons ("There is nothing religiously wrong with getting tested because they get tested for many things. They do not think health concerns are a religious issue.").

While the role of healthcare professionals in medical decision-making were discussed in both married and singles group, whether they supported or were against their role differed. The singles focus group participants were supportive of *BRCA1/2* genetic testing saying that if there was a link between Ashkenazi Jews and *BRCA1/2* genes, they would want it to be considered in the medical world. However, women in the married group were against the role saying that medical professionals may not have the larger view of how *BRCA1/2* genes affect their lives.

Table 17

Role of Religious Figures/Healthcare Professionals in Medical Decision-Making

Themes	Subthemes	Selected Quotations
Role of religious figures in medical decision-making	Support	"If rabbis were like yes, we found out that this is an Ashkenazi woman Jewish thing, then I would be more prone to doing it rather than the world was worried about this." "Rabbinic advice is warranted I guess." "The rabbis could have a role promoting getting tested." "I think if I was in a situation where I had a mutation and was considering doing some prophylactic surgery, perhaps I'd consult a rabbi or a *yoetzet* (a woman certified to serve as an advisor to women) just to find out what the *halachic* implications are." "After the fact, when you're dealing with the repercussions of this, 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." "Well, I'd like to see where the rabbis are going. And that would very much color how I ask, if I ask, and who I ask."
	Against	"If I was a carrier though, I wouldn't tell my rabbi. Something like this wouldn't come up." "There's nothing *halachically* wrong with getting tested. I mean, we get tested for things all the time. So, I wouldn't consult the rabbi when I say, do I want to get tested." "I wouldn't have gone to my rabbi or rebbetzin (wife of rabbi)." "I don't want to be disrespectful. But I just think that my health concerns and my health decisions are not a religious issue."

Role of healthcare professionals in medical decision-making	Support*	"If it came out that there was a link between the breast cancer gene and an Ashkenazi Jew, I'd want that to be taken into consideration in the medical world."
	Against**	"I'm just worried that perhaps they're [gynecologists] so focused on this medical aspect of it that they may not have the larger view of how this affects your life."

* Singles focus group only

** Married focus group only

Table 18 presents the sub-themes from the influential factors: social norms, cost, family history, family members, emotions, personal values, and healthcare professionals. Quotations related to social norms show that community norms/awareness/vigilance, friends, and relationships affect women's decision on genetic testing. Women tended to make medical decisions on *BRCA1/2* genetic testing depending on family history. While social norms and family history were discussed in both singles and married groups, cost, emotions, personal values were only evident in the singles focus group. Single women said that time and monetary aspects, such as expense and cost, have a role in their decision. When examining the emotions discussed among the participants, the results showed that personal stories that are emotional could have a positive impact. However, unnecessary anxiety that comes along with the testing may have a negative impact. Women in the singles group said that whether they are able to handle the information and think it will be helpful and worthy will influence their medical decisions. On the other hand, family members and healthcare professionals were influential factors that only emerged in the married focus group. Family members (i.e., mother, father, husband, aunt, sister) had an impact on married women's decision-making. In addition, healthcare professionals, such

as gynecologists, doctors, genetic counselors were brought up when discussing influential factors.

Table 18

Influential Factors

Themes	Subthemes	Selected Quotations
Influential Factors	Social norms	"Relation. Like whom do you know that's had it and how close it is to you." "If your friends have done it or not." "How the community would react." "Community norms" "Community awareness, community vigilance." "I want my insurance company to be like, this is now the standard: people get breast cancer tested. If you don't do it that's fine but we suggest you do it, then I would most definitely do it." "What would other people do?"
	Cost*	"If I knew that there wasn't a big copay then I would do it." "Time. Expense. Cost." "Monetary. Usually these things are expensive."
	Family history	"If I knew that maybe my grandmother who did have breast cancer, had the breast cancer gene then maybe it would make me more inclined to get the testing." "My family history." "The fact that I think I don't have a family history, [I] never had to really seriously consider testing."
	Family members**	"My grandmother is a breast cancer survivor, and then I think about two years ago my mom had an abnormal mammogram and she went to a high-risk breast center and then she was talking about getting it, and then ultimately she decided not to have the testing done. So, that made me think about, should I have it done if she's not going to have

		it done." "My father suggested it to me when I was in college and he was learning about it, that it was a thing you might want to get tested for." "Husband" "Mother" "My aunt" "Sister"
	Emotions*	"I would say that if there was a speaker event and personal stories that would trigger an emotional and I'm like okay I'll get this done." "Unnecessary anxiety"
	Personal values*	"Just if you feel like you can handle whatever information you do get." "If I thought it would actually be helpful." "If you believe there's anything worth it."
	Healthcare professionals**	"My gynecologist." "My doctor, when we had the initial appointment with family history, she didn't mention it but when I had the scare, that's the point where she said you want to get tested for it." "Probably genetic counselor."

* Singles focus group only

** Married focus group only

Women in both groups talked about familiarity with genetic testing, implementation, and information needs (Table 19). Genetic testing was considered a huge thing, a norm (*Dor Yeshorim*), and a rabbinically acceptable thing to do. They brought up Tay Sachs and the million videos that informed the community which did not turn into a stigma. When discussing implementation, majority of the women talked about Jewish organizations. Specifically, implementing *BRCA1/2* genetic testing to *Dor Yeshorim* (genetic testing program) was discussed

among the participants, saying this would make it possible to get it all done at the same time, one genetic counseling. The reasons were: reduce visits to get tested, minimal price, and confidentiality. Women suggested implementing *BRCA1/2* genetic testing before the kallah classes (teaches women the basics of Jewish marital etiquette) or mikvah (a bath used for the purpose of ritual immersion in Judaism to achieve ritual purity) so that it takes place before it is too late. Women said that religious leaders/figures could have a role in increasing uptake of *BRCA1/2* genetic testing. Rabbonim (rabbi), *yoetzet halacha* (a woman certified to serve as an advisor to women), and social workers in the frum (Jewish religious devotion) were brought up as examples among the participants.

Participants discussed their information needs. Women talked about responsibility after having the testing results. They were concerned about next steps, such as what to do with the information, what the responsible thing to do would be, and how life would be like afterwards. They were also interested in *BRCA1/2* genetic testing, but said they have no idea and nothing is really talked about it. There were misconceptions around breast cancer genetic testing as well ("If they do not have the gene, then they are free and clear. It does reduce the risk, almost to zero, but what other risks does it bring up?").

Table 19

Familiarity with Genetic Testing, Implementation, and Information Needs

Themes	Selected Quotations
Familiarity with genetic testing	"I just feel like in the community that I'm from, genetic testing is like this huge thing." "I think it all depends on how people are informed of it. Now breast cancer is one of the elephants in the room but if it was one of those things that people talk about the same way, I've seen a million videos on Tay Sachs disease and I'm informed on it and I don't know, I guess

	the community I'm from a lot more people have it, I guess they intermarry a lot more. I don't come from the modern orthodox community at all. In my community *Dor Yeshorim* testing is a norm and if they did breast cancer testing like that then you know many other people have it then it leads to a sense of community or understanding or more." "Genetic testing is something that's been discussed continuously and that's where *Dor Yeshorim* has come through. I mean, it's something that's rabbinically acceptable to do." "How many people outside the Jewish community know what Tay Sachs is and that hasn't turned into a stigma?"
Implementation	*Jewish organizations* "*Dor Yeshorim*. Get it all done at the same time. One genetic counseling." "So why not attach it to *Dor Yeshorim* testing, even if it is not confidential it can just be part of the *Dor Yeshorim* testing. Cause it's annoying to go and get it twice. If you can get it at the same time for a minimal price everyone would do it." "I think it makes sense to just slap on the breast cancer gene to *Dor Yeshorim*. It's confidential." "I also would say rabbonim (rabbi) if it became a norm. As in if rabbonim would start mentioning it." "Honestly, with the conjunction of if this is what the medical world is saying, I'm saying if that's okay, and then the rabbonim should get it. I guess it should go hand in hand." "With all discussion about confidentiality and *shidduchim*, I think, obviously with the advice of medical professionals that should be a decision of rabbonim to decide whether it is before or after marriage and to do the messaging as per that." "Goes back to what we were saying before about whether it's affecting family planning, right? Cause if it is then you want to get tested before the kallah classes (teaches women the basics of Jewish marital etiquette) and before the mikvah (a bath used for the purpose of ritual immersion in Judaism to achieve ritual purity), cause by the time you got to that point it would be kind of too late if it's going to affect what you are doing." "*Yoetzet halacha"* "Having these things available at the mikvah, I think that's a good resource." "Social workers in the frum community who work with people who, not

	children, who are older, twenties and up." *Other* "People who have had testing and survivors." "I've also seen in some shuls inside bathrooms they'll have signs in the stalls, like I've seen them for abuse prevention, so they could do the same thing here just general awareness."
Information needs	"I think it's also like the responsibility thing, like if you do find that you have it what do you do with that information. Now what? What's the responsible thing to do?" "My main concern with it was how would I deal with it once I had the information?" "What life would be like afterwards?" "The whole topic of breast cancer testing is interesting to me as well as issues that pertain to the Orthodox community." "I think what you are saying is that it [breast cancer] is the most talked about, yet nothing is really talked about." "I feel like I have no idea." *Misconceptions* "A lot of people think that if they don't have the gene, then they are free and clear." "So, my concern about how we talk about medical treatments, is, it does reduce the risk, almost to zero, but what other risks does it bring up?"

As shown in Table 20, impact on family and disclosure were themes that only emerged in the singles group. They were concerned that genetic testing might affect marriages of not only themselves, but also their siblings. Family planning was also a topic that was brought up by single women. They said that genetic testing would reveal whether they have diseases and that their intention of genetic testing would be to know what they carry for their children.

Women discussed disclosing genetic testing to family members (i.e., future husband, mother, sisters), friend, potential spouse, or medical professional (i.e., doctor). While some were

hesitant to tell their mothers since it would scare her more than anything, some were willing to share it with them. A participant stated that she would disclose it to a friend and not family because she would like to decide when to tell her family. Disclosing information on genetic testing to potential spouses were also brought up among single women. A participant said that she would wait until she gets married to discuss it with her future husband. Single women were concerned that the consequences would be the matchmaker knowing about family secrets and eventually having no men to get married to. Some participants were willing to disclose genetic testing to a doctor or a friend who was a doctor.

Table 20

Impact on Family and Disclosure

Themes	Selected Quotations
Impact on family	"I want to be informed and I'm only waiting now to get the full non-confidential screening where I'll know everything about all of the screenings. I'm waiting only now until my sister, until all my siblings are married, so that then I can find out and whatever I find out won't be reflective of them and their dating situations." "What you could do about you knowing you have the gene is different than what you can do if you pass it on. Because you can get tested to know if you can get breast cancer yourself versus whether or not you'll pass it on. We are talking about two different things here." "I think primarily just cause with genetic testing the large emphasis is on the decisions you are going to make like who am I going to marry, family planning and things like that but also your genes make up who you are now and who you're going to be and a lot of those tests will also tell you about, some people find out they have diseases, actual manifested diseases because they go for genetic testing with the intention of you know, what they carry for their children."
Disclosure	*Family member* "If I was married at the time I was tested, I would tell my husband first."

	"I know this sounds horrible but maybe I would do it after I'm married. I meet a person and discuss it as a couple. But I wouldn't want to do it before because I feel like it would be a heavy weight." "I don't know if I would tell my mother right away. I think I would decide with my sister and then tell my mom because it would scare her more than anything." "I just think if I got tested, I would tell my sisters that they should also get tested. Just to make the same informed decisions." "Mom" *Friend* "I would confide in a friend and not family is because my family is genetically similar to me and if I found any information, I would want to be able to decide when to tell them as opposed to them asking by the way, did you get tested?" "Maybe a friend who was a doctor." *Potential spouse* "So, in terms of like telling people, families guard their secrets very very carefully. In the really yeshivish community that I come from it's like nobody knows any of that stuff because it's like if you tell one person, then suddenly all it has to do is get back to one matchmaker and then the few boys that there are, and I come from a family that's mostly sisters, the few boys that there are, are going to disappear and then, you know." *Medical professional* "Doctor"

Results of Focus Groups and Stakeholder Dialogue Data

This section will discuss findings from the focus groups and stakeholder dialogue. A total of 555 quotations were analyzed (360 quotations from the focus groups and 195 quotations from the stakeholder dialogue). The results of the focus groups and stakeholder dialogue confirm that social, cultural, and religious factors will play a significant role in medical decision-making among the Orthodox Jewish community. According to the results, common themes among

women in the focus groups and participants in the stakeholder dialogue were facilitators/barriers to genetic testing, the role of religious figures and healthcare professionals in medical decision-making, influential factors, disclosure, implementation, and information needs. Prevention was discussed as the main reason why Orthodox Jewish women may consider *BRCA1/2* genetic testing. Negative emotions and impact on family/romantic relationships were shown to be barriers to genetic testing in the focus groups and stakeholder dialogue.

The role of religious leaders in medical decision-making was a theme that emerged in the focus groups and stakeholders. Married and single women shared whether they would consult religious leaders. Some of them said that they would seek religious figures to find out the *halachic* (Jewish law) implications. Others said that since they get tested for other diseases, they believe there is nothing *halachically* wrong about genetic testing. Also, they stated that they don't think health decisions are a religious issue. Similarly, discussion among the stakeholders included the role of religious figures when making medical decisions. Some said that women who have family history should consult *daas torah* (rabbinic authority) who understands medicine and that rabbonim shoud be educated. However, some said that there is no standard protocol from the Jewish community.

The narratives indicate that involving religious leaders (i.e., rabbi, rebbetzin, shadchan, kallah teacher, yoetzet halacha) in the conversation will be critical. As shown in my previous study, rabbis and other religious leaders in the Jewish community affect medical decisions on *BRCA1/2* genetic testing (Yi et al., 2017). The results of another study showed that it is critical to understand cultural factors and engage religious leaders in raising awareness within the community to increase the uptake of *BRCA1/2* genetic testing among the Orthodox Jewish population (Trivedi et al., 2018). Orthodox Jews often consult with rabbinic and communal

authorities in medical decision-making, which is consistent with their religious values (Coleman-Brueckheimer et al., 2009). Therefore, it will be crucial to share information about *BRCA1/2* genetic testing to religious and community leaders.

Healthcare professionals play an important role in medical decision-making in the Orthodox Jewish community. Therefore, providing *BRCA1/2* genetic testing knowledge to healthcare professionals will also be essential. Provider-facing breast cancer risk navigation tools, such as *BNAV*, can be used to provide *BRCA1/2* genetic testing information/resources and possibly obtain patients' information (i.e., breast cancer risk score) when linked to patient-centered decision aids. Having breast cancer risk scores will allow healthcare professionals to discuss *BRCA1/2* genetic testing efficiently during medical encounters. *BNAV* provides information around chemoprevention (breast cancer assessment, breast cancer chemoprevention, management of benign breast disease), genetic testing (*BRCA1/2* mutations: clinical manifestations and eligibility for genetic testing, multigene panel testing for cancer susceptibility genes, risk management strategies for hereditary breast and ovarian cancer syndrome), patient-centered care (communicating health risk, evidence-based methods, shared decision making, patient decision aids), and screening (breast cancer screening in average-risk women/high-risk women, mammographic density: implications for breast cancer screening). In addition to these existing topics, including information about cultural and religious factors related to medical decision-making in the Orthodox Jewish population for healthcare professionals will enable a comprehensive understanding of this religious group and will also be an effective way to discuss *BRCA1/2* genetic testing with this higher-risk population during limited time.

Women in the focus groups and community members in the stakeholder dialogue discussed information needs. As shown in the results, they are eager to learn more about

BRCA1/2 genetic testing and prevention. Since this study explored the social, religious, and cultural factors of Orthodox Jews, providing culturally-tailored education considering these factors will better assist their medical decision-making process. For instance, patient-centered decision aids can be utilized for Orthodox Jewish women to understand *BRCA1/2* genetic testing, know their risk score, and learn about preventive ways to reduce breast cancer risk. *RealRisks* can be culturally tailored specifically for the Orthodox Jewish population to be used as a platform to provide information about breast cancer risk (including higher risk in the Ashkenazi Jewish population), preventive measures, and informed choice. Applying the results of this study will help the Orthodox Jewish women understand the topic with a cultural and religious lens around *BRCA1/2* genetic testing during their medical decision-making process (i.e., barriers/facilitators to genetic testing, impact on family, influential factors). This will allow them to learn that social and cultural factors can be recognized around this topic in the Jewish population. Anonymous quotations from religious leaders (rabbis, kallah teachers) and healthcare professionals (doctors, genetic counselors) can also be included in the decision aid.

The second aim of the focus groups study was to examine whether perceptions of *BRCA1/2* genetic testing differ depending on marital status. The results show different responses between the two focus groups: married and single. While married women were less enthusiastic about the role of healthcare professionals in medical decision-making, single women were more supportive of their role. When discussing influential factors, family members and genetic counselors were only evident in married women. On the other hand, cost, emotions, and personal values were only brought up among single women. Impact on romantic relationships, medical procedures, and disclosure were shown to be barriers to genetic testing for single women.

Therefore, when discussing *BRCA1/2* genetic testing with single women, involving healthcare professionals, and having a conversation about cost, emotions, and personal values will be essential. Since these women think that healthcare professionals have a role in making medical decisions, consulting cost, and sharing their emotions and preferences during medical encounters could be a way to discuss *BRCA1/2* genetic testing. For married women, discussing the impact on family members and the role of genetic counselors will be important when making medical decisions around *BRCA1/2* genetic testing. Rather than leaving it to the individual, it would be effective if genetic counselors have open conversations with the Orthodox Jewish women about how the women think the results of genetic testing may affect their family. Then, genetic counselors can provide culturally-tailored education based on scientific evidence and preventive measures.