Published in final edited form as:

J Community Health. 2014 December ; 39(6): 1200–1208. doi:10.1007/s10900-014-9879-x.

Barriers to Cancer Screening among Orthodox Jewish Women

Rifky Tkatch, PhD¹, Janella Hudson, MA¹, Anne Katz, PhD¹, Lisa Berry-Bobovski, MA¹, Jennifer Vichich, BA¹, Susan Eggly, PhD¹, Louis A. Penner, PhD¹, and Terrance L. Albrecht, PhD¹

¹Department of Oncology, Wayne State University School of Medicine/Karmanos Cancer Institute

Overview

The purpose of the current study was to investigate the barriers to cancer screening among Orthodox Jewish women, an insular yet high cancer-risk community. Gaining a better understanding of the culturally specific needs of this community can lead to the creation of culturally appropriate cancer education programming.

Cancer Risk in the Orthodox Jewish Community

In the United States, breast cancer incidence rates are estimated at 1 in 8 women [1]. For women with a strong family history of the *BRCA* I or II mutation, however, incidence rates are much higher [2]. Ashkenazi Jews, who comprise the majority of Jews in the United States, have been identified as a group with a high risk of carrying one or both of these mutations and are at a significantly greater risk for breast, ovarian, and other cancers [3, 4]. Ashkenazi Jews are Jews with Central and Eastern European ancestry, but as used here, the term Ashkenazi refers to a shared genetic origin rather than a shared value or cultural belief system. Intermarriage among American Ashkenazi Jews and non-Jews is quite common [5, 6] and therefore, the rates of hereditary susceptibility to cancer and other conditions may decrease over time in this group. However, this is much less true for a subset of the Ashkenazi Jewish population, Orthodox Jews, whose numbers have steadily grown in size due to low rates of intermarriage outside the Orthodox Jewish community and high birth rates [5, 6]. Orthodox Jews, also called observant Jews or Torah Jews, share both a genetic origin and a strong set of shared values and cultural beliefs. Because of Orthodox Jews' very low rates of intermarriage, it is likely that these *BRCA* mutations will continue to be relatively more frequent among them than among many other racial/ethnic groups.

There is limited research on the specific cancer risk, health behaviors, and cancer screening behaviors among Orthodox Jewish women. This research, however, has indicated that this population may be at particularly high risk for breast cancer not only because of the genetic susceptibility, but also because of low rates of screening, low cancer-related health knowledge, low perceived cancer risk, and poor health behaviors related to diet and exercise [7–12]. In a study examining attitudes and beliefs associated with screening and mammography among different demographic groups in Israel, Baron-Epel [9] found that

fear, fatalism, and perceived effectiveness were associated with the logistic, technical and personal barriers to screening for Orthodox Jewish women. Freund et al. [11] found that Orthodox Jewish women in Israel perceived themselves at low cancer risk because of their religious lifestyle and religious belief system. In addition, some women in this study indicated that seeking medical attention may demonstrate a lack of faith in God and that illness was a direct message from God for the entire community. Fatalism and invoking faith as a reason not to be screened are particularly striking because they suggest religious beliefs play a role in barriers to screening for Orthodox Jewish women. There may be a potential contradiction of belief in God with the actual Torah obligation to take care of one's health [13] that may need to be further explored and clarified so that it can be explored in health education programs to overcome barriers to screening. The present study expands on this prior research by investigating the religious and general barriers to cancer screening among Orthodox Jewish women in the United States. The information derived from the present study may inform the development of culturally relevant education programs to address screening barriers among Orthodox Jewish women.

The last two decades of cancer education have significantly improved screening rates with tools such as mammography [14]. Public service announcements (PSA) and health education programs that include celebrities, humorous expressions, and slogans have raised awareness of the importance of cancer screening [15, 16]. However, health education programs are most effective when they are culturally tailored and programs that are effective in some communities may not be effective others [17, 18].

Among Orthodox Jews, Judaism is more than a religion; it is a way of life. The high religiosity and strict interpretations of the Torah lead to a very insular and self-contained community. Modesty (in dress and speech), the great importance placed on marriageability and family, adherence to the Sabbath and holidays, and dietary restrictions are Torah commandments that are high priorities among Orthodox Jews. Exposure to secular media is limited and discouraged. Alternatively, Orthodox Jewish media have strict standards on what is considered appropriate for disseminating to the general Orthodox community. Therefore many PSA's that use terminology not deemed modest to discuss in mixed company (e.g. breast or gynecological references) would not be utilized within Orthodox Jewish media. In short, insularity and self-containment within the Orthodox community may create barriers that are especially challenging when attempting to conduct research and deliver health education programs. It is important to consider prevalent cultural factors and barriers when developing culturally relevant cancer education programs [17, 19–21]. This is particularly important in communities that emphasize their religious perspective in cancer-related health behaviors [19–22]. Therefore, the purpose of this study is to identify barriers to screening. These barriers might include religious features unique to this community.

Current Study

The purpose of this study was to investigate barriers to cancer screening among Orthodox Jewish women in the metropolitan Detroit area. We sought to learn about barriers that may be unique to this insular and isolated community and those that they shared in common with more secular and integrated communities. In an effort to address the barriers related to

accessing the community and to be able to use the findings to develop culturally appropriate cancer screening education programs in the future, this study utilized some of the principles of a community-based participatory research (CBPR) approach.

As described by Israel (2001), community-based research requires the voice of the community in order to gain access, establish trust, and deliver credibility and viability of a research project [23]. CBPR principles emphasize the need to have active collaboration with the population being studied, to foster a co-learning environment, ensure projects are community driven, to disseminate the research in practical and useful ways, ensure the cultural appropriateness of the research and interventions, and to define the community as a unit of identity. CBPR principles have many challenges, yet the benefits of these principles translate into scientifically sound research that refines the research, builds trust with the community, and importantly spreads the research beyond the project and has the sustainability to continue the goals of the project [23–25].

Few studies have been conducted within the Orthodox community because, consistent with the value on insularity, research requires the involvement of Rabbinic leaders and other communal authorities [26, 27]. For example, in a study to explore Orthodox Jewish women's cancer experiences, Coleman-Brueckheimer et al. [27] created an advisory panel that included Rabbis and a community leader and included this advisory panel as partners in the research process. Therefore, in accordance with some of the CBPR principles, the first author, who is a member of this community, collaborated closely with the Detroit Council of Orthodox Rabbis (COR) and created a Community Advisory Board (CAB). The CAB consisted of leading women within the metro-Detroit area Orthodox Jewish community. The COR and the CAB reviewed all the study materials and provided feedback before they approved all study materials and process.

Method

The current study is the first phase of a larger study, whose overall goal is to develop a culturally appropriate educational screening programming for Orthodox Jewish women in the metro Detroit area. The goal of the first phase was to conduct focus groups among women in the community to gain their perspectives on cancer related issues, including barriers to screening as discussed in this study. The study protocol was approved by the University's Institutional Review Board.

Procedures

Qualitative research methods are ideal for understanding dimensions of a construct about which little is known [28]. Focus groups are an interactive process of communication that allow researchers to identify cultural group norms and shared or common knowledge. A moderator's guide for these focus groups was developed by the investigators based on previous research [9, 11, 29], the study research questions, and the input of the community members. The guide was designed to elicit perspectives on cancer-related health concerns including current screening practices, barriers to screening, and attitudes and beliefs about cancer (see Table 1), but the current study focuses only on perspectives related to barriers to

screening. Members of the CAB participated in a practice focus group and provided important feedback on the moderator's guide.

Participants

Participants were recruited via flyers distributed by CAB members and through word of mouth. In addition, the research team placed the flyers as an advertisement in the local Orthodox community circular. These flyers, which included the logo of the COR representing the Rabbinic endorsement of the project, invited the participation of women in discussion groups about health issues within the Orthodox Jewish community. Inclusion criteria were that participants be members of the community with membership in the local Women's Orthodox League. Fifty-three women contacted the research staff to indicate interest in participating in the study. The research staff collected self-reported age and cancer family history data over the phone so that homogenous focus groups could be created to capitalize on the shared experiences of participants [28]. Of the 53 women, 10 were cancer survivors. Women were scheduled for focus groups based on their age, family history of cancer, and availability to meet. Of the 43 women who were not cancer survivors, 18 were scheduled for 5 different focus groups: two groups (each), were composed of three women over the age of 40 with a family history; one group was composed of three women over the age of 40 without a family history; one group included four women under the age of 40 with a family history, and one group included five women under the age of 40 without a family history. The remaining 25 women were not included in the study because of their lack of availability to participate during the scheduled focus group times. In order to preserve the anonymity of participants and to assure confidentiality, only limited demographic data were collected at the start of the focus group. Women 40 and over (n=9) were about 53.33 (10.28) years old, 8 were currently married (1 was widowed), and had an average of 4.78 (2.39) children. Women under the age of 40 (n=9) were about 30.56 (5.39), all were married, and they had an average of 3.89 (2.01) children.

Focus Group Data Collection

Ideally focus group sessions should take place in a setting that is familiar and comfortable for participants [30]. Therefore, the research team conducted all of the focus groups at the Jewish Community Center, a meeting place that is centrally located, frequently used, and considered a familiar and neutral setting.

The third and fourth authors, (AK) and (LB), were the moderators of the focus group sessions. Both moderators had extensive training in focus group interviewing. The first author, (RT), attended all of the focus group sessions in the role of both Principal Investigator and community liaison. RT's presence in the focus group was intended to serve the dual purpose of building trust between the community and the moderators and in several instances as a translator of community language and culture. Community language in the focus groups was English with a number of Hebrew and Yiddish expressions used during the discussions. Focus group sessions were audio recorded. The length of each focus group session was approximately two hours. Participants received shopping gift cards for participation.

Analysis

Audio recordings were transcribed, de-identified and imported into NVivo, a qualitative software program [31]. The coding team consisted of six investigators. In addition, consistent with the adapted CBPR principles used in this study, a member of the CAB joined the coding team to provide an additional voice of the community perspective.

Transcripts were coded using a conventional content analysis approach [32]. Using an iterative process, members of the coding team read transcripts multiple times to identify and develop codes for emergent topics related to barriers to screening. The team then discussed and summarized themes based on meaningful clusters of codes.

Results

Seven themes were identified. A description of each theme follows followed by illustrative quotes.

Preservation of Hidden Miracles

Participants discussed their belief that God performs many miracles. However, participants explained that in Judaism there are two kinds of miracles: hidden and open. Hidden miracles happen behind the scenes and occur frequently. They are often disguised as coincidences in daily life and may not be noticed by the individual affected by these miracles. This belief is connected with the core belief that God runs the world. Open miracles can be easily identified as God's hand, but they occur much less frequently than hidden miracles. Participants explained that it was more likely that God will perform a hidden miracle related to a disease that has not yet been diagnosed as it is still considered hidden. Once a disease (specifically cancer) has been detected, the miracle of being healed transitions from hidden to open and the likelihood of this miracle occurring is significantly reduced. For this reason, participants described a reluctance to pursue screening that would potentially reveal a disease and lessen the possibility that God will perform a hidden miracle.

"We're aware that God put us in a physical world and He expects us to operate under the laws of the physical world. There are very few people who will tell you it's responsible not to go to a doctor. But...when you ask like, well, how does the community feel about screening...but I think there is this overall feeling of like, well, why do you have to open yourself up. Because, seriously, if you look deep enough, long enough at any person, you're going to come up with something...and there's also a concept that says "*ayn davar shruya ella bidavar someh min haayin*" that blessing only rests on things that are, that are hidden."

"...Once it's on that ultrasound screen, that's it. There's like nothing left to pray for, that type of thing. So, it's the same idea that if you know that you have something bad on a mammogram; it means that you, not only that you have to deal with it, it's really there. God's not going to take it away."

"I think the Torah [bible] says, like, Hashem [god] is with things that are hidden."

“There's also a concept that we, now that the temple has been destroyed, we have God's presence is in our lives constantly, but it's hidden. ...So, the idea that God will perform a hidden miracle for us is much more in tune with the spiritual forces that are around now. So, if a person, you know, there's a, that's always the ideal time to pray for someone, is before they've had surgery. You know, when they went, first came to the doctor, but didn't get the definitive diagnosis because, even if it was much worse, we do believe that prayer is that powerful, that God could change a diagnosis to something much less severe, and it wouldn't have to involve a splitting of the sea type of miracle, it could be a quiet, we're not at a level right now where we really deserve open miracles like that. So this idea that I'll perform a quiet hidden one for you, you don't even know what I did for you.”

“We think we know, but there's always a little room for God to make miracles in more natural ways. You know, with that, but again, we do want to give Him that room, you know, instead of like kind of forcing the hand”

Fate/Cancer as Inevitability

Participants discussed their belief that an individual's chances of developing cancer were largely determined by fate, and thus not affected by early screening or other preventative measures. To support this view, participants provided examples of family and community members of all ages that had succumbed to cancer despite healthy living and screening. Therefore, participants felt unsure if screening was an effective measure of detecting cancer early and preventing mortality.

“...He was the healthiest guy. He went for his annual checkup...he went for his annual checkup six months later and he was fine, then six months later he passed away, so you can check all you want.”

“I just feel like there's really not much...I mean, I can, without, you know, obviously look both ways before crossing the street but...oh, I hate to sound so, like fateful here, but if it's gonna hit you it's gonna hit you.”

“I also feel like there's really nothing I can do about it. I mean, you read the studies that say that, you know, you eat healthy and you know, you have a better chance or whatever, but I don't know; I feel like it's so, so common and it's just kind of like a scare”

“She made this big announcement about how: ladies, we have to screen ourselves, how she screened herself, and thank God they caught it, and she's here to tell the story that thank God she's alive because of screening. And she died like two years later of breast cancer.”

“I think also the fear with cancer is that it seems to come out of nowhere. There are certain risk factors, but you know children who have it, you know adults who have it, you know young women who have it, you know older women. So breast cancer may be like certain things are more likely to happen, but, we, we know kids with cancer who die of it young, or who, so that's a fear overall because you never know where that's coming from. Nobody expects a nine-year-old to get cancer, and I

think also that's why our kids are probably afraid of it. Because there are children, like, it's nice to say, "You'll get that when you're old. You'll get sick and you'll die when you're old." But at a certain point they realize, like, there are eight-year-olds who get sick and die of cancer. So, I think that creates part of the fear also. It doesn't seem like you can, you can do certain things to prevent it, but you can't really prevent it."

High Cost/ Lack of Insurance

Participants identified lack of insurance and the high cost of taking care of one's health as barriers for screening. There was discussion about the economic situation within the community and that many people are not insured or are underinsured. Therefore, seeing a doctor would be used for when someone really needed to see a doctor and not necessarily for preventative care or screenings. In addition, several participants believed that many community members might be unaware of free screening resources in the community.

"I would venture to say that a lot of families don't have good health insurance or full coverage health insurance. They have the basic minimum hospitalization and that's it. So going to the doctor is not much of an option, or it's not something they'll do as quickly as someone else"

"I think the information needs to get out and the support needs to know that insurance shouldn't be a barrier there are some resources."

"I really don't think we can discount the, you know, the financial..."

"the way the economic situation is they don't have the means, you know, they just probably for sure don't have the insurance...going to a doctor would be a last minute, you know, resort"

Competing Priorities

Participants discussed the many demands of everyday life in their role as Orthodox Jewish women. The daily responsibilities of caring for large families, including cooking and making other preparations for the observance of the weekly Sabbath and the large number of annual religious holidays often took precedence in women's lives over attending to their own health and pursuing screening. Participants expressed an awareness of the importance of screening, and in some cases, the screening guidelines, but also rationalized delaying screening in order to attend to more pressing responsibilities.

"But I had eight kids between the ages of 22 to um, 35, and I had to find the time when I wasn't nursing or pregnant. You know?"

"Because they have, their, their lives are busy and their health comes last."

"It's not a right or wrong thing. They're so busy with just life, you know, whether they have, you know, many, a large family or a job and a family, you kind of like put yourself last. You know, you worry about your children. Then you worry about your husband. And then you worry about yourself. So I feel that even though of course they want to be healthy and they know what to do, they don't always get to doing it for themselves."

“I feel like Orthodox women deal with an inordinate amount of stress. I think that in addition to the stressors that most people have, you know, family, job... everything becomes exponential because of the size of our families and everything that goes along with it because of our lifestyle... We were discussing the last holiday that we just had which was three days of consecutive entertaining... It's like three Thanksgivings in a row. Like every other month we're doing this on some level or another... and a lot of external pressure that we put on ourselves as well.”

Lack of Culturally Relevant Information

Overall, participants expressed the need for culturally relevant messaging to be developed and then endorsed by leadership within the Orthodox community. Unlike mainstream messaging, these “kosher” (e.g. culturally appropriate) messages would adhere to the cultural norms of modesty and potentially reframe preventative screening as a spiritual responsibility. In addition, participants explained that rabbinical endorsement, which carries great weight within the community, would lend credence to screening messages and improve screening rates among Orthodox women.

“I'm not hearing from anybody that it's important...um, I guess I'm not 40 yet so no one's telling me to go do a mammogram...um, I don't see anything in the community urging cancer screening, from what I've seen.”

“So the first doctor I went to, who was an idiot, said you're due for a PAP smear, and I said whoa. The next doctor asked. Why was I hesitant? I knew what a PAP smear was. Why was I hesitant? Because I did not have the clear knowledge if it causes the *niddah* [ritually impure] status on a woman. I didn't know.”

“I mean just in terms of like religiously and what the law would dictate, you wouldn't be able to use modesty to not do something that is important for your healthcare, so just being really technical about it, that wouldn't even be allowed. You couldn't let one thing override, you know, real healthcare that you need to provide yourself with.”

“But I think also that, that, that it's something to fall back on to say I don't want to know, so let me give it a spiritual component to it, and then, and then you can say, well, it's religious based that I'm not going for my mammogram. That sort of thing.”

“...But, above that, whatever we find is anytime that we've instituted a, any kind of program in the community that's successful, it has to address those core fears. It would have to come from the highly respected Rabbinic authority that would address those issues that really you might feel that you're doing a good thing by not doing this because you're not wanting to evoke this or evoke that, but you need to understand that God has given us these tools as, what, whatever the Rabbi would say, it would have to be, he would have to provide sources, whether they're mystical sources, Talmudic sources, whatever they are, that would counterbalance those fears in a way that would make it feel for women that spiritually they are really doing the right thing by going for screenings.”

“It’s so sad. It’s like why can’t people have more access to kosher, kosher knowledge?”

Lack of Information

While discussing screening, participants explained that they often lacked screening-related information. In addition to being unfamiliar with cancer screening guidelines, some women did not know if they had a family history of cancer, and how that might impact their need for screening. This issue of not knowing family history was a consequence of the Orthodox societal norms of not discussing cancer within families and within the community (including not even using the word cancer). Participants also reported that their attempts to conduct self-breast exams were frustrating as they were often unsure of what they should be feeling for and how to distinguish between normal and potentially abnormal breast tissue.

“Maybe they know to breast screen, that there should be breast screening, but what to do, how to do it, when to do it, maybe not.”

“Hey, do you know how many, we have so many patients and part of, you know, we ask a few questions, you know, is there family history of, you know, this and this and this cancer? And it’s like, ‘Oh, I don’t know.’”

“I just wanted to say on a very personal level, one of my, the things that holds me back from the, self- exams also, is I don’t really trust myself. I don’t, I almost feel like, I have this thing where I, I’m the opposite of a control freak.

“It’s not something I mentioned to my daughters”

“I don’t have a lot knowledge about it [cancer screening guidelines]. I don’t believe there’s a lot of information out there.”

Fear

Focus group members shared feelings of fear associated with screening. Some women feared experiencing physical discomfort during a mammography or other screening processes. Other participants reported feeling anxiety when considering the possibility of a positive diagnosis and the mental distress that they would potentially experience as a result. Some of these fears are not unique to this community, however, women discussed that the origins of this fear may be the result of the extreme fear of cancer within the community in general. The extent of this fear was described by participants as a reluctance within the community to use the word cancer, instead using the Yiddish term of *yenneh machlah* (the disease). Using the term cancer could “call” it to them. Therefore, the deep fear of the actual disease is a significant barrier to screening.

“I’m not advocating it, I’m not, you know, and when I don’t do my monthly exams it’s not like I’m proud of myself for it, it’s, I know that that’s a very fear-based reaction. I’m aware of that, but I, I think I’m just explaining to you what some of the mindset is behind it.”

“...but there, there are two, the main reason women don’t do let’s say breast, self-breast exams and, mammograms I think are even harder because you have to make

the call and make the appointment then go whatever, but the number one reason is that they're afraid they'll find something."

"I was scared...The fear of the pain, I mean, you know, would you want a pickup truck running over you?"

"I do. I think the number one reason is the fear, which is, I think is across the board, but I, I also think that there is a concept of you don't invite trouble. You just, you don't."

"So I don't know, in my family, we do say that. We will say yene machla [the disease]. The idea is that words, there is a belief that words have a cosmic parallel to them in the heavens. And that when you say something, when you give formation to a word, you are actually evoking certain reactions up on high. And so, you're trying, like, there are people who won't say the word television. They'll talk about that thing. You know what I mean? So, um, there, there is, there is different sensitivities that people have to different things, and the idea is that you don't, you don't want to be awakening those forces".

Discussion

Findings from this study describe several barriers to cancer screening among Orthodox Jewish women in this community. Although a strong belief in God, religious influences, cost, fear, and lack of culturally appropriate programming are barriers not unique to the Orthodox Jewish community [17, 19, 20], the concept of hidden miracles and the specific preferences for more modest educational programs and Rabbinical endorsement are barriers that are unique to the Orthodox community.

The influence of religious or spiritual beliefs on health behaviors is not a finding exclusive to the Orthodox Jewish community [19, 20]. Holt et al. found that high levels of spirituality among African American women may actually improve cancer-related health knowledge and behaviors [19]. In a sample of Jewish women that included but was not exclusively Orthodox, Bowen [33] found that women who had higher levels of Jewish identity were more likely to have had a mammogram. However, the faith-based barrier identified in this study emphasizes the role of belief in God as a possible barrier to screening for Orthodox Jewish women and is similarly found in the research of Freund et al. [11]. The concept of hidden miracles stems from participants' belief in God and the belief that he is always "taking care of things behind the scenes." The contradiction of believing in God to take care of one's health, but also the individuals' obligation to take care of one's health as commanded (discussed earlier) may be difficult for many individuals to navigate. Relying on the belief in God and the trust in his hidden miracles may also work as a barrier in conjunction with the theme of fear and the ability to use God as a reason to not screen may be a coping mechanism for the fear discussed in this study.

The theme of fear also had a number of religious connotations. Fear was a not a motivator; rather it was a reason to turn to God and not rely on oneself when it comes to cancer screening. In their review of the literature on the beliefs of health issues in Orthodox Jewish community, Coleman-Brueckheimer and Dein [26] discuss using religion as an explanatory

model of illness. In the context of this study, this religious explanatory model may serve as a coping mechanism of this fear and be a significant barrier to seeking cancer screening. Therefore, in order to develop education programs relevant to the Orthodox Jewish community, it is imperative to underscore the religious component of navigating the responsibility to take care of one's health and empowerment without diminishing the belief in God. Although these findings may illustrate the needs of Orthodox Jewish women, they may also be applicable to other religious communities that identify God as the primary source of all issues related to health and well-being.

Another important religious theme specifically emphasized the need for cancer education to be presented in culturally appropriate forms. Women discussed the need to have cancer education in ways that followed their value system, specifically emphasizing the need for modest speech related to cancer issues. They also discussed the Jewish Orthodox community's discomfort with the use of the word "cancer" in general. Significantly, women discussed the importance of the Rabbinic community endorsing cancer education programming in order for the general Orthodox community to pay attention to these messages. Previous research in the Orthodox Jewish community has underscored the value of the Rabbinic involvement both in the research process and in attitudes related to cancer screening [11, 27]. For example, Coleman-Brueckheimer investigated the role of Rabbinic involvement in the experience of women who were going through cancer treatment and found that women relied on this "socially sanctioned" in the health decision making process. Education programs targeted for this community will need to include the endorsement of a Rabbi and will need to be presented in a language and form that resonates with the belief system of Orthodox Jewish women. This format might emphasize a religious component to taking care of one's health and be delivered by a trusted member of the community.

The theme of lack of information emphasized the lack of communication in Orthodox Jewish families regarding cancer diagnosis and cancer risk. This may stem from the social consequences of a family history of cancer on the marriageability of other family members. This cancer-related stigma should be further explored on how it impacts cancer screening behaviors in this community.

Findings from this study are consistent with previous research on Orthodox Jewish women, which also discussed poor cancer-related health behaviors (including screening) [8, 12]. Other research exploring the screening attitudes of Orthodox Jewish women were consistent with some of our findings, especially themes regarding faith in God and the role of the Rabbi in health-related issues [11]. However, this study specifically identified the barriers related to screening and yields important insights on how individuals in the Orthodox community wish to acquire health information. This study provides a framework in which to create effective and religious cancer education program that will help overcome these barriers.

Strengths, Limitations, and Future Directions

This study utilized some of the CBPR principles to access a high-risk, but insular community. Content analysis was used to analyze focus group data in order gain knowledge about the barriers related to cancer screening. Although Orthodox Judaism has a distinctive

culture, there is much diversity within the Orthodox Jewish community (e.g. Modern Orthodox and Ultra Orthodox), which we were unable to account for in this study. Furthermore, as focus group data are not intended to be generalizable the findings of this study may not necessarily be representative of other Orthodox Jewish communities. Nevertheless, this study provides a unique perspective on the barriers related to cancer screening in the Orthodox Jewish community in the United States. Findings from this study will inform a culturally appropriate education program for Orthodox Jewish women concerning cancer-related health and screening. This study may also be helpful in understanding other insular religious groups and provide a theoretical approach in order to better understand the challenges in other communities.

Acknowledgments

This project was supported in part by National Institutes of Health/National Cancer Institute Grant U54 CA153606 (T. Albrecht, PI), The Jewish Fund, and services conducted by the Behavioral Field and Research Core supported in part by NCI Center Grant (P30CA22453) to the Karmanos Cancer Institute, Wayne State University School of Medicine.

References

1. Siegel R, Naishadham D, Jemal A. Cancer statistics, 2013. *CA Cancer J Clin.* 2013; 63(1):11–30. [PubMed: 23335087]
2. Cancer risks in BRCA2 mutation carriers. The Breast Cancer Linkage Consortium. *J Natl Cancer Inst.* 1999; 91(15):1310–1316. [PubMed: 10433620]
3. Hartge P, et al. The prevalence of common BRCA1 and BRCA2 mutations among Ashkenazi Jews. *Am J Hum Genet.* 1999; 64(4):963–970. [PubMed: 10090881]
4. Greenwood CM, et al. How old is this mutation? - a study of three Ashkenazi Jewish founder mutations. *BMC Genet.* 2010; 11:39. [PubMed: 20470408]
5. Lugo, L.; Cooperman; Alan; Smith; Gregory, A.; O'Connell; Erin; Stencel; Sandra, A., et al. Portrait of Jewish Americans: Findings from a Pew Research Center Survey of US Jews. Vol. 2013. Washington, DC: Pew Research Center;
6. Cohen, S.; Ukeles, M.; Jacob, B.; Miller; Ron. Jewish Community Study of New York: 2011 Comprehensive Report. New York: UJA-Federation of New York; 2012.
7. Tkatch R, et al. Breast Cancer Incidence Rates Among Orthodox Jewish Women. *J Immigr Minor Health.* 2013
8. Albert SM, Harlap S, Caplan L. Cancer screening among older women in a culturally insular community. *Prev Med.* 2004; 39(4):649–656. [PubMed: 15351529]
9. Baron-Epel O, Friedman N, Lerna O. Validity of self-reported mammography in a multicultural population in Israel. *Prev Med.* 2008; 46(6):489–491. [PubMed: 18407343]
10. Pfeffer N. Screening for breast cancer: candidacy and compliance. *Soc Sci Med.* 2004; 58(1):151–160. [PubMed: 14572928]
11. Freund A, Cohen M, Azaiza F. The Doctor is Just a Messenger: Beliefs of Ultraorthodox Jewish Women in Regard to Breast Cancer and Screening. *J Relig Health.* 2013
12. Shmueli A, Tamir D. Health behavior and religiosity among Israeli Jews. *Isr Med Assoc J.* 2007; 9(10):703–707. [PubMed: 17987756]
13. Deuteronomy. 4:9.
14. Garcia Fernandez A, et al. Mortality and recurrence patterns of breast cancer patients diagnosed under a screening programme versus comparable non-screened breast cancer patients from the same population: analytical survey from 2002 to 2012. *Tumour Biol.* 2013
15. Noar SM, et al. Public Figure Announcements About Cancer and Opportunities for Cancer Communication: A Review and Research Agenda. *Health Commun.* 2013

16. Hurley RJ, Riles JM, Sangalang A. Online cancer news: trends regarding article types, specific cancers, and the cancer continuum. *Health Commun.* 2014; 29(1):41–50. [PubMed: 23356571]
17. Kreuter MW, et al. Sociocultural characteristics and responses to cancer education materials among African American women. *Cancer Control.* 2003; 10(5 Suppl):69–80. [PubMed: 14581907]
18. Kreuter MW, et al. Responses to Behaviorally vs Culturally Tailored Cancer Communication Among African American Women. *American Journal of Health Behavior.* 2004; 28(3):195–207. [PubMed: 15152880]
19. Holt CL, Lukwago SN, Kreuter MW. Spirituality, breast cancer beliefs and mammography utilization among urban African American women. *J Health Psychol.* 2003; 8(3):383–396. [PubMed: 14670216]
20. Harper FW, et al. "It's up to you and God": understanding health behavior change in older African American survivors of colorectal cancer. *Transl Behav Med.* 2013; 3(1):94–103. [PubMed: 23646096]
21. Mor P, Oberle K. Ethical issues related to BRCA gene testing in orthodox Jewish women. *Nurs Ethics.* 2008; 15(4):512–522. [PubMed: 18515440]
22. Mark N, Roberts L. Ethnosensitive techniques in the treatment of the Hasidic patient with cancer. *Cancer Practice.* 1994; 2(3):202–208. [PubMed: 8055024]
23. Israel BA, et al. Community-based participatory research: policy recommendations for promoting a partnership approach in health research. *Educ Health (Abingdon).* 2001; 14(2):182–197. [PubMed: 14742017]
24. Balazs CL, Morello-Frosch R. The Three R's: How Community Based Participatory Research Strengthens the Rigor, Relevance and Reach of Science. *Environ Justice.* 2013; 6(1)
25. Israel BA, et al. Challenges and facilitating factors in sustaining community-based participatory research partnerships: lessons learned from the Detroit, New York City and Seattle Urban Research Centers. *J Urban Health.* 2006; 83(6):1022–1040. [PubMed: 17139552]
26. Coleman-Brueckheimer K, Dein S. Health care behaviours and beliefs in Hasidic Jewish populations: a systematic review of the literature. *J Relig Health.* 2011; 50(2):422–436. [PubMed: 21249524]
27. Coleman-Brueckheimer K, Spitzer J, Koffman J. Involvement of Rabbinic and communal authorities in decision-making by haredi Jews in the UK with breast cancer: an interpretative phenomenological analysis. *Soc Sci Med.* 2009; 68(2):323–333. [PubMed: 19019515]
28. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ.* 1995; 311(7000):299–302. [PubMed: 7633241]
29. Andrews CS. Defining and exploring modesty in Jewish American women. *J Relig Health.* 2011; 50(4):818–834. [PubMed: 21184282]
30. Krueger. D.L.M.a.R.A. Focus Group Kit. Vol. 1997. Sage Publications; p. 692
31. Ltd., Q.I.P. NVivo qualitative data analysis software. 2012
32. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005; 15(9):1277–1288. [PubMed: 16204405]
33. Bowen DJ, et al. Jewish identity and intentions to obtain breast cancer screening. *Cultural Diversity and Ethnic Minority Psychology.* 2003; 9(1):79–87. [PubMed: 12647327]

Table 1

Focus groups discussion questions

Question	How do you and your family make decisions about health? About your health practices?
Question	To what extent to people in the metro-Detroit Orthodox community worry or are concerned about their health and health risks they may encounter? Their long term-health?
Question	What are the most important health issues and health risks facing people in the community today?
Question	Is cancer a concern among women in the Orthodox community?
Question	What should people do about their concerns about cancer?
Question	Do you think most women in the Orthodox community know breast cancer screening guidelines?
Question	Should Orthodox women be encouraged to get screened? Why or why not?
Question	What are some reasons why women many not follow screening guidelines?
	- Lack of knowledge
	- Lack of perceived risk
	- Lack of time
	- Lack of insurance
	- Superstitions (e.g. undermining belief in God)
Question	Did/does modesty play a role in cancer screening?
Question	If it was your job to encourage women in your community to get screened what would you do?
Question	Are you aware of any women in your community who have had cancer?
Question	How does the community respond or react to these women? Are they supportive?
Question	Is this something people discuss (e.g. cancer)? Why or why not?
Question	Is there stigma attached to cancer? (saying the word calls cancer to you)
Question	What do you think people could do to overcome or eliminate this stigma?
Question	What do you think causes cancer?
Question	When you think about your family history, what do you think of in terms of the risk to the rest of your family, to other members of your family?
Question	What concerns or worries do you have about cancer for yourself and your family members?