Reluctant to Save a Life?
BRCA1 Gene Testing Among Orthodox Jewish Women

I. Introduction: The Challenge

In normative Jewish thought, “whoever saves a life, it is considered as if he saved an entire world” (Babylonian Talmud Sanhedrin 37a). This proposition recognizes the streams of putative descendants from, or those potentially influenced, by any one person. Rejecting BRCA1 gene testing challenges the application of the axiom among those who ardently proclaim its truth.

BRCA1 is a gene found on chromosome 17q. It is a tumor suppressor gene which codes for proteins, which in turn help rebuild damaged DNA. Therefore, when BRCA1 is mutated, the DNA remains damaged. When the DNA undergoes further damage, in what is termed a “second hit” by biologists, the cell can undergo unregulated division, which in some cases can lead to cancer. The BRCA1 mutation is a dominant mutation, meaning only one copy – rather than two – leads to a mutant phenotype of insufficiently repaired DNA. Children of an affected parent have a 50 percent chance of inheriting the mutant gene. A woman with a BRCA1 mutation has an 80 percent chance of developing breast cancer and a 55 percent chance of developing ovarian cancer. Furthermore, while other forms of breast cancer only occur in one breast, the BRCA1 mutation can lead to cancer in both breasts. There may also be an increased risk of fallopian tube cancers (for women) or prostate cancers (for men); the magnitude of this risk varies based on age and environment.

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1 For purposes of my analysis, “Orthodox” refers to the categories of “Centrist Orthodox,” “Chabad,” “Chasidic” and “Yeshivah,” but not “Modern Orthodox,” as used by the demographer Marvin Schick in his A Census of Jewish Day Schools in the United States. New York: Avi Chai, 2014. 6-8. Print. A more quantitative analysis than offered here would define more precisely the boundaries of “Orthodox.” The definition eludes easy description.


Women who screen positive for the \textit{BRCA1} gene in the United States have a range of preventative and treatment options. Women can undergo close monitoring, with biannual mammograms and pelvic exams; for women in the general population, only annual mammograms are usually recommended. Some women, in comparison, choose to have preventative double mastectomies and oophorectomies to materially minimize the risk of cancer. Angelina Jolie, whose mother died of ovarian cancer, opted to have a preventative double mastectomy and oophorectomy when she tested positive for the \textit{BRCA1} mutation, as she chronicled in an Op-Ed in the \textit{New York Times}.\textsuperscript{6}

In the United States, around 1 in 40 Ashkenazi Jews, who descend from Eastern Europe, Germany, and France, carry the \textit{BRCA1} mutation, compared to about 1 in 500 people in the general population.\textsuperscript{7} Genetic screening for this mutation – and as a natural extension of such screening, prophylactic double mastectomies and oophorectomies – have become accepted, especially for women with a family history of cancer. Many Orthodox, Ashkenazi Jews, however, have refrained from screening, and, all the more, the preventative surgeries.

Why do Orthodox Ashkenazi Jews refrain from screening and preventative surgeries for \textit{BRCA1} mutations, and what, if anything, should be done about this hesitation? By understanding and respecting the unique issues faced by Orthodox women, health care providers can better educate this group of women and their families about genetic screening and lessen the incidences of cancer.

II. **Social Constraints Applicable to Jewish Orthodox Women**

To understand why Orthodox women might refuse screening and prophylactic treatment for BRCA1 mutations, one must first start by understanding the insular and unique world in which these women live. Orthodox Jews adhere strictly to Jewish laws, with few ties to the outside world. Children are educated in private schools and attend private camps – and families live near others within a neighborhood. Women in these communities usually do not attend college. Given their limited education, and limited interaction with the outside world, many women do not know about the mutation and genetic screening. A study conducted in Detroit, invoking a community-based participatory research approach, confirmed that many Orthodox women refrain from genetic screening because of lack of knowledge, or more precisely, a perceived lack of access to information. Although no statistical analysis was conducted, many women felt they lacked screening-related information. As one woman from the study related, “I don’t have a lot knowledge about it [screening guidelines]. I don’t believe there’s a lot of information out there.”

Aside from restricted knowledge about genetic screening, marital matchmaking concerns play a large role in dissuading women from undergoing genetic screening. The family unit is paramount in Judaism. Most Orthodox Jews have arranged marriages when between the ages of 18-24, often with the help of a matchmaker. The presence of a BRCA1 mutation, in parent or child, could hurt a family’s chances of securing a good marriage, because of the likelihood of cancer for the women and her future offspring. Therefore many families do not get screened, to avoid the stigma, as if not knowing is equivalent to not existing. This need for privacy, really

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secrecy, to increase the odds of a “better” marriage results in many women not even knowing – and not wanting to know- if there is a family history of cancer. The word ‘cancer’ is not even used in these communities, in light of a superstition that expressing the word may lead one to get cancer; instead a Yiddish term, yeneh machlah, that translates to ‘the disease,’ is used instead.9

Some women who may otherwise get screened would not then undergo prophylactic mastectomies or oophorectomies, regardless of the outcome of their genetic screening, rendering the screening moot. A prophylactic mastectomy could be visible to the community and a woman who wants to keep the BRCA1 mutation private for modesty (in the sense of not drawing attention to her body) or matchmaking concerns would therefore not undergo the surgery.10 Beyond these social concerns, a prophylactic oophorectomy causes a woman to become infertile, and therefore, some woman may choose not to undergo the surgery for this reason.

Yearly mammograms and clinical breast exams are alternatives for prophylactic surgery in response to a positive result from the genetic test. In the general population, many women who have a family history of breast/ovarian cancer undergo these more intense exams regardless of genetic screening results.11 This is not common practice among Orthodox women who know they have a family history of breast/ovarian cancer. Women who fear stigmatization and would not undergo preventative surgery in any event do not see the importance of genetic screening and therefore do not do it.

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10 i.e. to secure a good marriage for herself or her daughter
11 This behavior minimizes the importance of genetic screening, without the prophylactic surgeries, for women who have a family history of breast/ovarian cancer. Because this is not common practice among Orthodox women with a family history of breast/ovarian cancer, however, this paper does not delve into the implications this practice would have on the benefits of genetic screening.
III. Economic Constraints

Many Orthodox Jews live on annual incomes at or below the poverty line.\textsuperscript{12} Fathers will customarily learn the Bible during the day, while their wives - with limited educations - are the breadwinners for the family. The high costs, and potentially the lack of insurance, deter Orthodox women from the screening. Up until 2007, $BRCA1$ genetic testing cost $4,000 for uninsured patients due to a patent by Myriad Genetics on the gene. Today such testing can still cost $1,000 for uninsured patients.\textsuperscript{13}

McCarthy found that women with a household income of less than $30,000 were fifty percent less likely to have had $BRCA1$ testing than women with a household income of more than $70,000.\textsuperscript{14} As one woman in the Detroit study remarks, “[A] lot of families don’t have good health insurance or full coverage health insurance…So going to the doctor is not much of an option, or it’s not something they’ll do as quickly as someone else.”\textsuperscript{15} Financial constraints greatly discourage Orthodox women from seeking genetic screening.

IV. Biblical Constraints

Beyond the social and economic issues surrounding genetic screening for the $BRCA1$ mutation, some in the Orthodox community believe that prophylactic mastectomies and oophorectomies are prohibited by the Bible, and do not see the importance of genetic screening without the prophylactic surgeries.

\textsuperscript{14} Ibid.
\textsuperscript{15} Tkatch
The Bible prohibits self-injury: “Do not cut your bodies for the dead or put tattoo marks on yourselves. I am the Lord” (Leviticus 19:28). Because there is still a small probability of getting breast or ovarian cancer even after the surgeries, some believe that these preventative surgeries are included under the category of unnecessarily hurting oneself. Furthermore, the Bible does not permit eunuchs to enter the community: “No one who has been emasculated by crushing or cutting may enter the assembly of the Lord” (Deuteronomy 23:1). Some recognized rabbis interpret this law as also applying to the removal of female gonads.

But along with the negative Biblical injunctions against harming oneself comes a superseding positive one: “Take heed to thyself, and keep thy soul diligently” (Deuteronomy 4:9, 4:15). Judaism believes that the body is on loan from God, and therefore it is a person’s responsibility to take care of his/her body, to serve God by stewarding what is His. Given this tradition, most authorities permit genetic screening and prophylactic mastectomies and oophorectomies, though some do not.

Many of the Biblical scriptures are countermanded in the Talmud, a compendium of commentaries compiled from approximately 200 – 600. For example, there is a description in the Talmud about a mother, Judith, who disguises herself and goes to her husband, a prominent rabbi. She asks him if it is her duty to procreate, and he responds no – it is only a man’s obligation. She then drank a sterilization potion (Babylonian Talmud Yebamoth, 65b).

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17 Ibid.
19 JPS Tanakh.
20 Greenberg, Dov, Rabbi. "Discussing Genetic Screening." Personal interview.
rabbis read this story as permitting a woman to remove her gonads, even if it may not be permissible for men.  

Many Orthodox people will consult their rabbi on medical issues, even when the rabbi is not familiar with the medical topics and concerns – another barrier to screening and prophylactic measures. Dr. Pnina Mor, a nurse at Shaare Zedek Medical Center in Israel, highlights the rabbi’s role:

“Although Jewish law obligates us to guard our health (Deuteronomy 4:9; 4:15), it does not necessarily follow that testing for genetic mutations is included in that obligation. In establishing obligation in actual situations, the rabbi will therefore take into account the influencing factors and employ a systematic approach in assessing danger in the circumstances.”

The rabbi’s pivotal role complicates the issues faced by Orthodox women. The Shulchan Aruch, or Code of Jewish Law, writes that if someone wants to eat on Yom Kippur, the Day of Atonement and a fast day, for medical reasons, that person must consult a doctor and not the rabbi. Given this precedent, some rabbis defer medical decisions to healthcare professionals, while others provide their own input. Steiner-Grossman found that almost 90% of the rabbis in his study believed that “counseling congregants about genetic diseases was a critical part of their job, yet most felt ill-prepared for the task.” Most rabbis permit genetic screening and prophylactic mastectomies and oophorectomies for all women, but some prohibit oophorectomies for women who have not had children yet, and still a few prohibit the testing and surgeries altogether. The range of rabbinic opinions regarding screening and preventative measures further complicates how Orthodox women approach the issue, because most women will take the advice of their rabbis, who advise

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22 Greenberg Interview.
24 Greenberg Interview
26 Aish.com
with limited medical knowledge and act within the dimming penumbra of these legal ambiguities.  

V. Possible Solutions

1. Educate Health Care Professionals

Genetic screening for the \textit{BRCA1} mutation for Orthodox women is a personal and complicated issue. Because the mutation is dominant, it cannot be dealt with in the same way as other genetic mutations common in Ashkenazi Jewry. For example, an organization called Dor Yeshorim, literally meaning “upright generation,” provides confidential genetic screening for ten recessive mutations common among Ashkenazi Jews. Two people who are contemplating dating or marriage send in blood samples and are informed if they are “compatible” or not, without ever being told if they are a carrier for one of the genetic diseases.\footnote{Greenberg Interview} This way, knowledge regarding who is a carrier is confidential and cannot hurt a person’s prospect of marriage. This cannot apply to \textit{BRCA1}, because it is dominant – only one parent needs to carry the mutation for the children to be at risk.

But Dor Yeshorim highlights the lengths that Orthodox will go to keep this kind of information private. Healthcare professionals must be educated about the sensitivity of a \textit{BRCA1} positive test for Orthodox women. Sharsheret, a national non-profit organization, provides support for Jewish women facing breast cancer. They educate their employees on the special issues in connection Orthodox women. For example, the employees should practice “modest and simple language when discussing diagnosis, surgery, and treatment,” as well as “respect the role of Jewish law and the rabbi in decision making.”\footnote{"Dor Yeshorim." Center for Jewish Genetics, Web.} This will ensure that the health care

\footnote{Sharsheret. Facing Breast Cancer as a Jewish Orthodox Woman. Sharsheret, Print.}
professionals relay the necessary information to the patients, but do so in a considerate and understandable way.

Healthcare professionals can also educate women on financial resources that are available to them. The Affordable Care Act requires all insurance plans that begin on or after August 1, 2012 to cover genetic testing if it is recommended by a provider. Furthermore, the Myriad Financial Assistance Program and the Cancer Resource Foundation both provide financial assistance to those who qualify. A woman should not let the financial aspect of genetic testing stop her from getting the screening because there are resources to help with finances.

2. Educate Orthodox Jewish Women

Healthcare professionals must be educated about the sensitivity of the issue for these women, but Orthodox women must also be educated about the importance of genetic screening. As one woman states, “Lack of awareness regarding health causes haredi (separatist) women to have higher mortality [rates] from breast cancer.” Genetic screening, even without the prophylactic surgeries, may increase the chance of detecting breast cancer at an earlier stage, and therefore may offer the patient a better chance of being treated successfully.

The New York Times interviewed Orthodox women who went through genetic screening and prophylactic surgery in Israel. Tzipporah, 38 years old and mother of seven children, watched her own mother die from breast cancer when she was five. She tested positive for the BRCA1 mutation while pregnant with her youngest child. After seeking advice from several rabbis, she had a mastectomy and oophorectomy after her child was born. She “talks openly

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30 Komen
31 Ibid.
32 This woman, Racheli Ibenboim, is spearheading a campaign to allow woman to be elected to the religious political party’s Knesset seats. 
"Female Haredi Activists to Haredi Factions: Allow Us to Run, or We’ll Boycott." Ynet News. Web. 8 Dec. 2014.
about her experience because she wants to reach other religious women.” As Tzipporah says, “You know why God did this to me? Because I’ve got a really big mouth”33 The article goes on to say that “she is spreading the word within the Orthodox community that genetic screening can save lives.”34

Having members of the Orthodox community educate their peers about the benefits of genetic screening is necessary because the women will not only be more comfortable discussing the topic, but is also more likely to listen to a friend within the community than a stranger. For instance, a member of the community, like Tzipporah, can lead an event at the local synagogue for women discussing the importance of genetic screening and different alternatives if one tests positive for the BRCA1 mutation, followed by a question and answer session. That member can also later meet privately with individuals.

The Detroit study cited on pages 3 and 5 above also highlights the importance of public service announcements that adhere to the cultural norms of modesty and potentially reframe preventative screenings as a spiritual responsibility.35 If critically important to their well-being, and even potentially a spiritual responsibility, women will be more likely to find time in their busy schedules to get a genetic screening test.

3. Educate Rabbis of These Communities

Because rabbis play such a huge role in the health decisions of their congregants, it is necessary to also educate rabbis about the benefits of genetic screening and prophylactic surgeries. Participants in the Detroit study explained that “rabbinical endorsement, which carries

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33 That is, Zipporah feels she has been called to be as an ambassador (as opposed to being punished for being boisterous).
35 Tkatch
great weight within the community, would lend credence to screening messages and improve screening rates among Orthodox women.”\(^{36}\)

Although a few rabbis prohibit screening and prophylactic surgeries, most hold them permissible. But this larger group does not stress these preemptive measures because they are unaware of the crucial role that genetic screening plays in early detection of breast and/or ovarian cancer. Therefore, educating rabbis will encourage them to elevate genetic screening as a priority for their congregants, which will in turn increase the numbers of women getting screened.

Emphasizing these religious and cultural obligations can reinforce the importance for a woman to seek genetic screening. Kreuter et al found that African American women who identified themselves as religious (measured from a questionnaire) were more likely to get a mammogram.\(^{37}\) As one woman from this study illuminates:

> When you understand that the Creator shapes and guides our day-to-day lives, you realize that tools of modern medicine like computers, x-rays, and mammogram machines are part of God’s plan for us. We must not ignore these gifts. We can use them along with prayer to stay healthy.

Bowen et al found the opposite among Jewish women. She found that Jewish women with high religious identity (which was measured through a questionnaire) had less interest in genetic testing.\(^{38}\) It is imperative to change this tendency in order to save countless lives.

\(^{36}\) Ibid.
VI. Conclusion

Although it may well be impossible to completely change Orthodox Jewish women’s attitudes towards genetic screening, much can be done to increase the numbers who are getting screened. White (non-Hispanic) women – including Ashkenazi Jews - have a higher mortality rate from breast cancer than both Asian-American and Pacific Islander women. With genetic screening, early detection and/or prophylactic surgery can drastically decrease the mortality rate. Increasing the acceptability and popularity of screening and prophylactic measures would in turn create a virtuous cycle in which the lowered risk of cancer would position the measures as more desirable and reasonable under the circumstances. Educating the Orthodox community and its leaders will makes genetic screening more “mainstream” among Orthodox women, and thus there will be less stigmatization surrounding it. The BRCA1 mutation would become a “treatable” threat, and therefore less likely to cause health, legal or matchmaking concerns.

39 Breastcancer.org