

Sarah Lawrence College

DigitalCommons@SarahLawrence

---

Human Genetics Theses

The Joan H. Marks Graduate Program in  
Human Genetics

---

5-2015

## Evaluating the impact of group cancer genetic counseling sessions in the BRCA Community Study

Beth Georges  
*Sarah Lawrence College*

Ronit Lebor  
*Sarah Lawrence College*

Anne Greb  
*Sarah Lawrence College*

Follow this and additional works at: [https://digitalcommons.sl.c.edu/genetics\\_etd](https://digitalcommons.sl.c.edu/genetics_etd)

---

### Recommended Citation

Georges, Beth; Lebor, Ronit; and Greb, Anne, "Evaluating the impact of group cancer genetic counseling sessions in the BRCA Community Study" (2015). *Human Genetics Theses*. 9.  
[https://digitalcommons.sl.c.edu/genetics\\_etd/9](https://digitalcommons.sl.c.edu/genetics_etd/9)

This Thesis - Open Access is brought to you for free and open access by the The Joan H. Marks Graduate Program in Human Genetics at DigitalCommons@SarahLawrence. It has been accepted for inclusion in Human Genetics Theses by an authorized administrator of DigitalCommons@SarahLawrence. For more information, please contact [alester@sarahlawrence.edu](mailto:alester@sarahlawrence.edu).

Evaluating the impact of group cancer genetic counseling sessions in the BRCA Community Study

Beth Georges<sup>1</sup>

Ronit Lebor<sup>2</sup>

Anne Greb<sup>3</sup>

RUNNING HEAD: Impact of Group Cancer Genetic Counseling in Low Risk BRCA Sessions

Anne Greb

1 Mead Way, Bronxville, NY, 10708

(914) 395-2605 (T)

(914) 395-2608 (F)

agreb@sarahlawrence.edu

**Submitted in partial completion of the Master of Science Degree at Sarah Lawrence College" May 2015**

---

<sup>1</sup> Joan H. Marks Graduate Program in Human Genetics, Sarah Lawrence College, Bronxville, NY, USA

<sup>2</sup> Joan H. Marks Graduate Program in Human Genetics, Sarah Lawrence College, Bronxville, NY, USA

<sup>3</sup> Joan H. Marks Graduate Program in Human Genetics, Sarah Lawrence College, Bronxville, NY, USA

## ABSTRACT

The Ashkenazi Jewish population has up to a 2.5% (1 in 40) carrier frequency for any of the three founder mutations in the *BRCA1* and *BRCA2* genes. The current standard of care suggests genetic testing for founder mutations in only those individuals with a personal or family history of *BRCA*-related cancers in addition to Ashkenazi Jewish ancestry; however, recent studies suggest that up to 51% of Ashkenazi Jewish *BRCA* mutation carriers have little or no family history of relevant cancers (Gabai-Kapara et al., 2014). Since there are currently no well-defined educational programs to address this problem, the purpose of this study was to design, implement, and evaluate the utilization of group genetic counseling and pre-counseling education among “low-risk” Ashkenazi Jewish individuals being offered genetic testing for *BRCA* founder mutations. Most participants showed a gain in knowledge after group genetic counseling, no negativity towards group genetic counseling, and a better understanding of *BRCA* mutations in the Ashkenazi Jewish population. The results of this study show that pre-counseling education can be effectively utilized in a group setting and that group genetic counseling can be utilized successfully for population screening.

**KEYWORDS:** cancer, low-risk, genetic counseling, Ashkenazi, Jewish, group counseling, group genetic counseling, pre-counseling education, *BRCA*

## INTRODUCTION

Approximately 12% (1 in 8) of women in the United States will develop breast cancer in her lifetime. Of these, 5-10% may carry inherited mutations, the majority of which occur in the *BRCA1* and *BRCA2* genes. The general population has an approximately 0.25% (1 in 400) carrier frequency for mutations in either gene. The Ashkenazi Jewish (AJ) population has a 2.5% (1 in 40) carrier frequency for any of the three known founder mutations in either gene: *BRCA1* 185delAG, *BRCA1* 5382insC, and *BRCA2* 6174delT (Gabai-Kapara et al., 2014; Levy-Lahad, 1997). The current standard of care suggests genetic testing for founder mutations only in those individuals with a personal or family history of *BRCA*-related cancers in addition to AJ ancestry.

Despite the high penetrance of cancer risk with *BRCA* mutations, recent studies suggest up to 51% of AJ *BRCA* carriers have little or no family history of relevant cancers (Gabai-Kapara et al., 2014). As this cohort would not meet current guidelines for *BRCA* testing, it is clear that current guidelines do not ascertain a large proportion of Ashkenazi Jews with actionable *BRCA* mutations.

There is currently debate over whether population screening for *BRCA* mutations is appropriate. Some feel the risks of such screening, including uncertain cancer risks, variants of unknown significance, monetary cost, and logistical complications of screening a very large population in whom *BRCA* mutations are relatively rare, makes it inadvisable (Levine & Steinberg, 2015). However, the AJ population is uniquely situated for population screening. Three founder

mutations account for most deleterious *BRCA* mutations (~95%), the population is relatively small, and the carrier frequency is roughly ten times higher than that of the general population.

The BRCA Community Study, an initiative implemented by the Program for Jewish Genetic Health through Albert Einstein College of Medicine and Montefiore Health System, is a pilot program designed to address the high incidence of founder mutations in the AJ population by exploring the feasibility of population screening in this community. The BRCA Community Study is enrolling individuals of Ashkenazi Jewish descent and, based on reported family histories, categorizing them into high-risk and low-risk groups. High-risk individuals are defined as having personal or family histories of *BRCA*-related cancers and are offered traditional genetic counseling and genetic testing. Low-risk individuals are invited to a group genetic counseling session and offered genetic testing.

Our study seeks to support and enhance the BRCA Community Study by reviewing previous studies on the implementation of written materials, pre-counseling education, and group genetic counseling; assessing which areas lacked exploration; and assisting in developing the written materials and structure for the group genetic counseling sessions.

## **Background**

### *Written Materials*

Patient research in other areas of population screening, including newborn screening, suggest proven methods by which to optimize the patient-friendliness of written materials used to

supplement patient education. In a broad overview of newborn screening brochures, Arnold et al. (2006), identified several measures by which to evaluate the patient-friendliness of written educational materials. These included readability (measured with a Flesch reading ease formula, with a 5<sup>th</sup> grade reading level receiving the highest score), easy-to-read layout (defined in part by larger font, avoidance of certain fonts, use of white-space, and visually organized content), clear illustrations serving a demonstrated purpose, clear message communication, a manageable amount of information, and cultural appropriateness (Arnold et al., 2006).

A qualitative study by Davis et al. (2006) suggested patients prefer the use of written material to accompany oral education as well as user-friendly presentations of relevant information in an easy to read format. The study surveyed patient and provider knowledge and awareness of newborn screening using focus groups and individual interviews. Patients uniformly indicated they would prefer to see concise information with fewer details and they wanted the written information to mirror information given to them orally.

### *Pre-Counseling Education*

Many models of delivering patient education have been explored. One such model is to provide education to patients prior to genetic counseling sessions. Pre-counseling education allows the participants in group genetic counseling sessions to attain a similar education level prior to entering a session (Albada et al., 2011; Green et al., 2001; Wang et al., 2005). Green et al. (2001) assessed the effectiveness of utilizing a pre-counseling interactive computer program in teaching women about genetics and breast cancer and concluded that instituting pre-counseling education

alleviated fear of embarrassment from lack of knowledge and optimized counseling sessions. A study by Wang et al. (2005) measured the effects of pre-counseling educational software and concluded that pre-counseling education allowed the participants to gain the same knowledge in less time and alleviated patients' feelings of being overwhelmed. This resulted in shorter genetic counseling sessions with no negative effects on patient education and allowed counselors to focus on areas requiring clarification.

Previous studies (Axilbund et al., 2005; Joseph et al., 2010) suggest presenting the same content using a variety of methods improves patient understanding. This variety may include group discussions, printed materials, and non-interactive slideshow presentations. It has been suggested that certain methods may be more accessible to patients because they require a lower degree of patient literacy and technology competency than computer-based methods (Axilbund et al., 2005).

### *Group Genetic Counseling*

Group counseling is one of several service delivery models in genetic counseling. Though the use of group genetic counseling (GGC) to address risks for hereditary cancer is relatively new, Ridge et al. (2009) have shown it to be a well-accepted method among patients. Ridge et al. (2009) investigated the utility of GGC specifically among patients whose indication was hereditary breast and ovarian cancer. The major questions in this study considered patient receptiveness to GGC rather than individual counseling, effectiveness of patient education with GGC, and the efficiency of GGC as compared to individual counseling. The group sessions were

designed to address all aspects of an individual session and incorporated the information traditionally provided during individual genetic counseling sessions through multiple forms of media, namely video and slideshow presentations. The counseling component of an individual session was provided through a facilitated group discussion where participants were invited to raise questions and concerns or share personal experiences or reactions to the information provided. This introduced a variation of the counseling aspect not typically seen in group genetic counseling (Ridge et al., 2009).

The sessions in the study conducted by Ridge et al. (2009) were evaluated based on three factors: receptivity to GGC sessions, effectiveness of group counseling, and efficiency of the group sessions. It was shown there are distinct advantages inherent in group genetic counseling. Most notably, these include the benefit of a shared experience among patients and increased efficiency allowing for a greater number of patients to be seen. It was observed that most participants seemed comfortable in a group setting and were willing to share personal information. This study also identified disadvantages inherent in GGC, including challenging group dynamics, including differences in demographics, and group influence on decision-making. With regard to the complexities of maintaining a beneficial group dynamic, the authors cite ensuring group homogeneity as a technique to reduce in-group conflict (Ridge et al., 2009).

### *Population Screening*

While the practice of population screening for autosomal dominant, variably penetrant conditions such as cancer predisposition is novel, the practice of population-based screening for autosomal



recessive conditions (e.g., Tay-Sachs disease, phenylketonuria, etc.) has existed for decades in the form of ethnic-based carrier screening and newborn screening. The success of population-based carrier screening programs historically has strongly depended on the goodwill and education of an engaged community. The Dor Yeshorim screening program in the Orthodox Jewish community and the 1971 National Health Strategy, which developed into state-mandated genetic testing for sickle cell in the African American community, were population screening programs done with and without the support of the communities they were meant to serve. The historical success and failure, respectively, of these two programs depended heavily on their acceptance and integration into the communities they were meant to serve (Wailoo & Pemberton, 2006).

Previous research acknowledges there is a high rate of acceptance in the current AJ population for carrier screening for recessive genetic conditions. Shkedi-Rafid et al. (2012) found this acceptance appears to extend to *BRCA* screening. Shkedi-Rafid et al. postulate the use of *BRCA* testing on a population scale may make pre-test counseling so impractical (due to restraints on cost, time, and qualified professionals) as to be unrealistic. They call for the development of an alternative solution.

### *Purpose of Study*

Currently, there are no well-defined educational programs or genetic counseling models designed to accommodate the educational and counseling needs of offering genetic testing for *BRCA1* and *BRCA2* founder mutations on a population-wide scale. The purpose of this study was to design,

implement, and evaluate the utilization of group genetic counseling and pre-counseling education among “low-risk” AJ individuals being offered genetic testing for *BRCA* founder mutations.

## MATERIALS AND METHODS

### **Ethical Considerations**

This study was approved under the Einstein IRB #2014-3174 as a part of the larger BRCA Community Study.

### **Participants**

Individuals who were accepted to participate in the low-risk arm of the BRCA Community Study were invited to take part in this study at the time of the group genetic counseling session.

Potential participants were advised about the authors and purpose of this study and the pre- and post-counseling surveys were explained. Stratification of risk was determined by the BRCA Community Study genetic counselors and all participants of AJ descent with no personal or family history of *BRCA*-related cancers were designated to be part of the low-risk arm of the study. The low-risk patients attended twice monthly group genetic counseling sessions conducted by genetic counselors at one of two locations within the Montefiore Hospital System. The four group genetic counseling sessions were executed during February and March of 2015.

Individuals under age 25 were not accepted to take part in the BRCA Community Study. All were English speaking, had at least one grandparent of Ashkenazi Jewish descent, and had never been tested for *BRCA* mutations.

## **Method**

### *Pre-counseling Education*

All BRCA Community Study participants categorized as “low-risk” were e-mailed a written educational packet designed by the BRCA Community Study prior to attending the group genetic counseling session. This packet contained information identical to that presented during the group genetic counseling sessions, including information about Ashkenazi *BRCA* mutations, risks associated with being a *BRCA* mutation carrier, testing for *BRCA* mutations, and preventive measures for carriers.

### *Group Genetic Counseling*

The development of the educational tool utilized during the group genetic counseling sessions was completed in three phases: original development, revision, and a trial session followed by further revision. All phases of development involved the authors of this study in addition to the genetic counselors and study coordinators affiliated with the BRCA Community Study. The tool was comprised of a 34-slide PowerPoint presentation, which included education about *BRCA* mutations, two facilitated discussion components as well as the genetic testing consenting process and information regarding the BRCA Community Study. The broad themes of the educational component included the role of *BRCA1* and *BRCA2* mutations in cancer development, preventive options for *BRCA* carriers, the frequency of *BRCA* mutations in the Ashkenazi Jewish population, and the risks, benefits, and limitations of *BRCA* testing.

Using the guidelines suggested in the literature, the educational tool was organized with patient-friendliness in mind. Educational information was presented concisely, utilizing easily understood images and accessible color schemes and fonts. In order to preserve a therapeutic atmosphere, the educational tool included two opportunities for the genetic counselor(s) to lead the participants in group discussions of colloquial understandings of *BRCA* and feelings associated with pursuing genetic testing. The first facilitated discussion component was placed at the beginning of the session as a facsimile of the opening contracting that takes place between genetic counselor and patient during an individual session. The genetic counselor posed the question, “What is the first thing that comes to mind when you hear *BRCA*?” and wrote responses on a board for participants to see and discuss with the group. The second facilitated discussion component was placed at the end of the session to replicate the discussion a genetic counselor and patient would typically have regarding attitudes and feelings about the prospect of genetic testing in an individual session. Participants were asked to anonymously write a one-word description of their feelings on an index card and give the cards to the genetic counselor(s). The feelings described by the participants were addressed by the genetic counselor(s) and made available for discussion within the group.

In addition to the original development and revision process of creating the educational tool, a trial session was conducted with the authors of this study and the genetic counselors associated with the BRCA Community Study, in order to identify further areas for improvement and generate potential answers to the facilitated discussion questions to aid future participants who might struggle to take part in the group activities.

## Measures

Information was collected via self-administered surveys conducted immediately prior to and following each low-risk group genetic counseling session. Items included in the surveys were constructed following a review of the literature, which identified key contributors to the efficacy of group genetic counseling, such as knowledge and patient comfort. The genetic counselors associated with the BRCA Community Study were consulted to provide expertise and advice in targeting the issues most pertinent for investigation.

### *Knowledge*

Participants' knowledge of the informational material covered during the group genetic counseling sessions was measured in two parts, by the pre- and post-counseling surveys. The surveys each contained five identical knowledge-based questions to measure prior knowledge as well as knowledge gained after the session. These questions assessed the participants' understanding of the broad themes included in both the pre-counseling education and group genetic counseling sessions. Examples of knowledge-based questions included in the surveys are "Who can be at risk to carry *BRCA* mutations?" (inheritance of *BRCA* mutations), "How does the risk for Ashkenazi Jews to carry a *BRCA* mutation differ from the general population?" (founder mutation frequency), "True or false: If someone is a *BRCA* carrier, he/she will definitely develop cancer" (risks for *BRCA*-related cancers), and "Individuals who are *BRCA* carriers can \_\_\_\_\_" (preventive measures available to carriers).

### *Patient Comfort*

Participants' comfort in the group setting was measured by three questions on the post-counseling survey. Participants were required to rate the extent to which they agreed with the first question, "I would have rather have met one-on-one with a genetic counselor." on a 5-point Likert scale ranging from "strongly agree" to "strongly disagree."

The second question required participants to describe their feelings about the group setting. Patient comfort in this setting was evaluated to ascertain whether group dynamics influenced individual decision making regarding genetic testing. The question, "Did the group setting make you feel intimidated or pressured in any way?" was answered by rating their feelings of intimidation or pressure on a scale including either, both, or neither feelings, e.g., "I felt intimidated," "I felt pressured to get tested," "I felt *both* intimidated and pressured to get tested," and "I felt neither intimidated nor pressured."

The third question required participants to describe their feelings about engaging in the facilitated discussion aspects of the session. The question, "How do you feel about the 'interactive' elements of the session?" was answered by checking all applicable answers. These included, "I felt comfortable participating," "I did not feel comfortable sharing my feelings in public," "I did not think it was a valuable part of the session," and "It enhanced my experience being in a group."

### *Pre-counseling Education Utilization*

Participants were required in the pre-counseling survey to answer whether they had read the pre-counseling fact sheet. In the post-counseling survey, participants were asked to describe their perception of its efficacy, as described below.

### *Patient Perception of Group Counseling and Pre-counseling Education Efficacy*

Participants' perceptions of the efficacy of both the pre-counseling education and the group counseling session were assessed by one question on the post-counseling survey. The question required participants to describe their feelings about the usefulness of the pre-counseling education and the group genetic counseling session. The statement, "I feel that I have a better understanding of *BRCA* in the Ashkenazi population now than I did before the session." was answered by rating feelings on a scale. Possible answers included, "Yes. I read the materials in advance, but today made everything much clearer," "Yes. I did not read the educational materials in advance," "No. This was redundant of the information available before I came today," and "No. I still do not have a clear understanding of this topic."

An area for additional freeform feedback was provided on the post-counseling survey.

## RESULTS

The pre-counseling and post-counseling surveys were administered to 11 individuals who participated in the four low-risk sessions in February and March of 2015. All participants consented to the surveys prior to beginning the group genetic counseling sessions. Participants

attended low-risk group genetic counseling sessions conducted by genetic counselors associated with the BRCA Community Study. Of the four group genetic counseling sessions administered, one group had four participants, one had five participants, and two had one participant each.

Table I lists results for the general demographic information collected.

### **Pre-counseling Education Utilization**

When participants were asked if they had read the educational packet provided to them prior to the group genetic counseling session, six (55%) indicated they had read the packet while five (45%) had not.

### **Knowledge**

Table II presents the number of individuals who answered the knowledge-based questions correctly on the pre-counseling and post-counseling survey. The participants' answers to the knowledge component of the pre-counseling and post-counseling surveys can be referred to in Table II. The average pre-counseling score was 79.5% while the average post-counseling score was 95.5%.

### **Patient Comfort**

Two participants did not answer these questions as they each attended the group genetic counseling sessions as the only participant, nulling their answers for the purpose of assessing patient comfort during a group genetic counseling session.



When asked if the participants would prefer to meet with a genetic counselor one-on-one, 4/9 (44%) reported they felt neutral, 4/9 (44%) reported they disagreed and would not prefer to meet with a genetic counselor one-on-one, and one (11%) reported they strongly disagreed. No participants reported they would prefer to meet with a genetic counselor one-on-one.

When asked *if the group setting made you feel intimidated or pressured in any way*, 9/9 (100%) participants answered they felt neither intimidated nor pressured during the group genetic counseling session.

Participants were asked to score their feelings about participating in the *interactive elements of the session*: 7/9 (78%) reported feeling comfortable participating, 1/9 (11%) reported it enhanced the experience of being in a group, and 1/9 (11%) reported both they felt comfortable participating and it enhanced the experience of being in a group.

### **Patient Perception of Group Counseling and Pre-counseling Education Efficacy**

Participants were asked if they felt they *had a better understanding of BRCA in the Ashkenazi population now than before the session*. Of the 11 participants, six (55%) reported they felt they had a better understanding of the information and they had read the educational pamphlet prior to the session, four (36%) reported they felt they had a better understanding of the information and they had not read the educational pamphlet prior to the session, one (9%) reported they did not

read the packet and did not feel they had a better understanding after the session as the information presented was redundant to information available before the counseling.

### **Facilitated Discussion**

Participants' responses to the first discussion question "What is the first thing that comes to mind when you hear *BRCA*?" can be found in Table III. Most individuals suggested a type of cancer or Angelina Jolie. Participants' responses to the second discussion question "How are they feeling about genetic testing?" can be found in Table III. Most individuals identified their feelings on a spectrum of readiness for testing, ranging from ready to unsure. No participants provided additional freeform feedback on the post-counseling surveys.

## DISCUSSION

This study aimed to evaluate the design and implementation of group genetic counseling and pre-counseling education among "low-risk" AJ individuals being offered genetic testing for *BRCA* founder mutations through the BRCA Community Study by measuring knowledge gain, patient comfort and patient perception of efficacy.

Pre-counseling education has previously shown reinforcement of information for clients and increased counselor efficiency during a cancer counseling session (Axilbund et al., 2005).

However, this theory has only been explored with regard to individual genetic counseling sessions. The results of this study show approximately half of the participants indicated they read the educational packet and felt they had a better understanding of *BRCA* in the AJ population

after the session than before it and approximately half of the participants indicated they had not read the packet. Of the six participants who read the pre-counseling education, all showed a gain in knowledge between the pre- and post-counseling surveys. Further investigation is needed to determine the knowledge gain solely from the pre-counseling education and whether it truly increases counselor efficiency.

It was notable that of the five participants who did not read the pre-counseling education, three showed a gain in knowledge on the pre- and post-counseling surveys and two showed a high baseline of knowledge on the pre-counseling surveys (i.e., answering all knowledge questions correctly) with no improvement or regression on the post-counseling surveys. These results could indicate the efficacy of the group genetic counseling sessions and a relatively high level of awareness and knowledge of *BRCA* in the population from which the participants were drawn.

Group genetic counseling for patients at increased risk for hereditary breast and ovarian cancer due to a positive family history has previously been studied with regard to patient comfort and patient knowledge. Applying group genetic counseling to population screening, where each individual enters the genetic counseling session with an identical risk to carry a *BRCA* founder mutation, however, is novel. Our results show a gain in knowledge for all patients from the pre-counseling survey to the post-counseling survey. With regard to measures of patient comfort, all respondents who took part group sessions ( $n=9$ ) indicated they felt neither pressured nor intimidated by the group setting and that the facilitated discussion components of the sessions were comfortable to participate in, enhanced the group experience, or both. No participants

reported preferring to have met individually with a genetic counselor with 44% reporting neutral feelings and 55% disagreeing or strongly disagreeing with preferring an individual meeting. One likely contributing factor to the strong trend towards patient comfort was the relative homogeneity of the groups. In addition to being of AJ descent and at a 1 in 43 risk to carry a founder mutation, all individuals had achieved at least a Bachelor's degree as their highest level of education and lived in the greater New York area. Of course, there is still a question of the effects of group heterogeneity due to age and possible differences in healthcare-seeking behaviors and traditions among different sects of Judaism on patient comfort. The global gain in knowledge and strongly rated patient comfort suggest that using this model of group genetic counseling for *BRCA* population screening is a practical framework for providing successful pre-test counseling to patients.

This study had several limitations. The most notable of these is the small sample size. Although the *BRCA* Community Study received a positive response from the community, many more participants in their study were designated "high-risk" than expected. The relatively low number of "low-risk" participants, combined with the limited duration of this study, contributed to the limited sample size. To preserve time, the length of the surveys was restricted and this created limitations to the scope of this study such that participants' reasons for not reading the packet were not identified and the structure of the surveys, could not ascertain whether participants felt they gained the most knowledge from the pre-education packet, the group session, both, or neither. Additionally, further study could determine which aspects of the pre-counseling education (i.e., repetition of material, higher baseline knowledge, or obtaining information

through more than one modality) were most valuable in contributing to gain in knowledge.

Another limitation lies in the lack of ascertainment with regard to why so many participants chose not to read the educational packet. Gaining a better understanding of participants' reasons for not reading the packet would help facilitate further revisions and improvements in patient-friendliness.

In the interest of optimizing the time used during the group genetic counseling sessions, our pre- and post-surveys were designed to be as concise as possible. In achieving this, certain demographic information including gender identification, sexual orientation, marital status, and parental status was not collected. Therefore, although our participants' responses may be generalizable to individuals of the same age groups and education levels, this study is unable to draw conclusions about the differences in experiences and understanding engendered by membership in different identity groups. Additionally, all participants in this study achieved a relatively high level of education, making them more likely to easily understand information about genetic testing. Their comfort in the group setting and ease in gaining knowledge about *BRCA* may not be applicable to individuals with different levels of education.

The results of this study show a broadly positive patient experience utilizing group genetic counseling as a service delivery model for pre-test counseling in terms of knowledge gain, patient comfort, and patient perceptions of efficacy. However, further research is necessary to evaluate the effects of this model with larger numbers of individuals of different demographic

and cultural backgrounds to gain a better understanding of its true impact on patient knowledge and comfort.

Beth Georges and Ronit Lebor declare that they have no conflicts of interest.

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Acknowledgements:

We would like to thank Anne Greb for her advisement; and Nicole Schreiber-Agus, Estie Rose, and Chani Wiesman Berliant for their guidance, support, and mentorship.



## APPENDICES

**Table I: Characteristics of participants at the time of the study**

<b>Characteristics (<i>n</i> = 11)</b>	<b><i>n</i></b>	<b>%</b>
Age		
25-35	3	27.3
35-45	2	18.2
45-55	2	18.2
55-65	3	27.3
65+	1	8.2
Level of Education		
Bachelor's Degree	4	36.4
Master's Degree	4	36.4
Doctoral Degree	2	18.2
Professional Degree	1	8.2



**Table II: Knowledge-based questions and answers on pre- and post-counseling surveys and correctly answered knowledge-based questions per participant**

<i>Correctly answered knowledge based question per participant (n=11)</i>	<b>Pre-counseling</b>		<b>Post-counseling</b>	
Theme of Question	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
Inheritance	10	91	11	100
Founder mutation frequency	11	100	11	100
Risk for <i>BRCA</i> -related cancers	11	100	11	100
Preventive measures available to carriers	3	27	9	82

  

<i>Pre-counseling Survey (n=11)</i>	<b>n</b>	<b>%</b>
Questions and answers		
1. Who can be at risk to carry <i>BRCA</i> mutations? (check all that apply)		
Men	10	91
Women	10	91
Individuals who have had cancer	10	91
Individuals with a family history of cancer	10	91
Individuals without a family history of cancer	11	100
2. How does the risk for Ashkenazi Jews to carry a <i>BRCA</i> mutation differ from the general population?		
Their risk is tenfold higher	11	100
Their risk is the same	0	0
Their risk is lower	0	0
3. True or false: If someone is a <i>BRCA</i> carrier, he/she will definitely develop cancer.		
True	0	0
False	11	100
4. Individuals who are <i>BRCA</i> carriers can _____ (check all that apply)		
Reduce their risk of developing cancer	6	55
Ensure that their mutation is not passed down to future children	4	36
Inform their blood relatives of their cancer risk	11	100

  

<i>Post-counseling Survey (n=11)</i>	<b>n</b>	<b>%</b>
Questions and answers		
1. Who can be at risk to carry <i>BRCA</i> mutations? (check all that apply)		
Men	11	100
Women	11	100
Individuals who have had cancer	11	100
Individuals with a family history of cancer	11	100
Individuals without a family history of cancer	11	100
2. How does the risk for Ashkenazi Jews to carry a <i>BRCA</i> mutation differ from the general population?		
Their risk is tenfold higher	11	100
Their risk is the same	0	0
Their risk is lower	0	0
3. True or false: If someone is a <i>BRCA</i> carrier, he/she will definitely develop cancer.		
True	0	0
False	11	100
4. Individuals who are <i>BRCA</i> carriers can _____ (check all that apply)		
Reduce their risk of developing cancer	9	82
Ensure that their mutation is not passed down to future children	11	100
Inform their blood relatives of their cancer risk	11	100

**Table III: Responses to facilitated discussion questions****Facilitated Discussion, Part 1**


---

“What the first thing that comes to mind when you hear *BRCA*?”

Cancer	Angelina	Breast Cancer
Ovaries	Breast Cancer	Angelina Jolie
Prostate cancer	Ovarian Cancer	Pancreatic Cancer
A lot of cancer	Ashkenazi Jewish	

---

**Facilitated Discussion, Part 2**


---

“How are you feeling about genetic testing?”

Nervous	Apprehensive	Anxious about results
Informed	Ready	Fine
Concerned	Unsure	Scared because stepdaughter is BRCA+ but otherwise okay

## REFERENCES

- Albada, A., Dulmen, S., Lindhout, D., Bensing, J., Ausems, M., (2012). A Pre-visit Tailored Website Enhances Counselees' Realistic Expectations and Knowledge and Fulfills Information Needs for Breast Cancer Genetic Counselling. *Familial Cancer*, 11.1, 85-95.
- Arnold, C. L., PhD, Davis, T. C., PhD, Ohene Frempong, J., MS, Humiston, S. G., MD, MPH, Bocchini, A., BA, Kennen, E. M., MA, & Lloyd-Puryear, M., MD, PhD. (2006). Assessment of newborn screening parent education materials. *Pediatrics*, 117, S320-S325. doi: 10.1542/peds.2005-2633L
- Axilbund, J. E., Hamby, L. A., Thompson, D. B., Olsen, S. J., & Griffin, C. A. (2005). Assessment of the use and feasibility of video to supplement the genetic counseling process: A cancer genetic counseling perspective. *Journal of Genetic Counseling*, 14(3), 235-243.
- Davis, T. C., PhD, Humiston, S. G., MD, MPH, Arnold, C. L., PhD, Bocchini, J. A., Jr, MD, Bass, P. F., III, MD, MS, Kennen, E. M., MA, et al. (2006). Recommendations for effective newborn screening communication: Results of focus groups with parents, providers, and experts. *Pediatrics*, 117(2), S326-S340. doi: 10.1542/peds.2006-1568
- Gabai-Kapara, E., Lahad, A., Kaufman, B., Friedman, E., Segev, S., Renbaum, P., ... & Levy-Lahad, E. (2014). Population-based screening for breast and ovarian cancer risk due to BRCA1 and BRCA2. *Proceedings of the National Academy of Sciences*, 111(39), 14205-14210.
- Green, M., Mcinerney, A., Biesecker, B., Fost, N., (2001). Education about Genetic Testing for Breast Cancer Susceptibility: Patient Preferences for a Computer Program or Genetic Counselor. *American Journal of Medical Genetics*, 103.1, 24-31.
- Levine B., Steinberg K., (2015). Proposed Shift in Screening for Breast Cancer. *Journal of the American Medical Association*, 313(5), 525.

- Levy-Lahad, E., Catane, R., Eisenberg, S., Kaufman, B., Hornreich, G., Lishinsky, E., et al. (1997). Founder BRCA1 and BRCA2 mutations in Ashkenazi Jews in Israel: Frequency and differential penetrance in ovarian cancer and in breast-ovarian cancer families. *American Journal of Human Genetics*, 60, 1059-1067.
- Ridge, Y., Panabaker, K., Mccullum, M., Portigal-Todd, C., Scott, J., & McGillivray, B. (2009). Evaluation of Group Genetic Counseling for Hereditary Breast and Ovarian Cancer. *Journal of Genetic Counseling*, 18(1), 87-100. doi: 10.1007/s10897-008-9189-5
- Shkedi-Rafid, S., Gabai-Kapara, E., Grinshpun-Cohen, J., & Levy-Lahad, E. (2012). BRCA genetic testing of individuals from families with low prevalence of cancer: experiences of carriers and implications for population screening. *Genetics in Medicine*, 14(7), 688-694.
- Wailoo, K., & Pemberton, S. (2006). *The troubled dream of genetic medicine: Ethnicity and innovation in Tay-Sachs, cystic fibrosis, and sickle cell disease*. Baltimore: Johns Hopkins University Press.
- Wang, C., Gonzalez, R., Milliron, K., Strecher, V., Merajver, S. (2005). Genetic Counseling for BRCA1/2: A Randomized Controlled Trial of Two Strategies to Facilitate the Education and Counseling Process. *American Journal of Medical Genetics Part A* 134A.1, 66-73.