Evaluation of the Support Provided to Male *BRCA1/2* Mutation Carriers: Are Their Needs Being Met or Can Genetic Counselors Do Better?

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by
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ABSTRACT

Evaluation of the Support Provided to Male *BRCA1/2* Mutation Carriers: Are Their Needs Being Met or Can Genetic Counselors Do Better?

A thesis presented to the Graduate Program in Genetic Counseling

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Inherited mutations in the *BRCA1* and *BRCA2* genes are associated with hereditary breast and ovarian cancer syndrome (HBOC), a cancer susceptibility condition which significantly increases a woman's risk for breast and ovarian cancer compared to the general population. Hence, HBOC is primarily associated with women while male carriers of a *BRCA1* or *BRCA2* mutation have a significantly increased risk for a variety of cancers as well. Research and efforts to support individuals affected with HBOC have been heavily focused on women, and little acknowledgment is given to the cancer risks and needs of male carriers. The purpose of this study was to get a better understanding of what resources and supports genetic counselors should offer to male *BRCA* mutation carriers, who are also fathers, to best serve their needs. Seven men who are a *BRCA1* or *BRCA2* mutation carrier and have biological children were recruited from an online support group and an online foundation to participate in a semi-structured phone interview. The major topics addressed included what was provided by the genetic counselor, what their experience was with supports and resources, their concerns, and how fatherhood impacted their experience with being a carrier. Thematic analysis of the interview transcripts was performed in ATLAS.ti (v.8) and seven themes were identified: (1) an overall positive

impression of the genetic counseling session; interest in (2) more medical management options, (3) informational resources, and (4) support groups and opportunities to connect with others; (5) a need for recognition and awareness of male *BRCA* mutation carriers, (6) concern for children, and (7) normalization. This study showed that male *BRCA* mutation carriers have similar needs for informational and emotional supports and resources as women affected with HBOC.

Keywords: Support, Needs, Men, HBOC, *BRCA*, Mutation, Male Carriers, Resources, Children, Fathers, Genetic Counseling

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Introduction

Cancer has been recognized as one of the leading causes of death worldwide (National Cancer Institute, 2017). While most cancers are sporadic, 5-10% of cancers are hereditary and can affect families through multiple generations. To identify the presence of a mutation that may increase a person's chance to develop cancer, people increasingly choose to undergo genetic testing. Some undergo genetic testing for the sake of knowing, while others use that knowledge to make reproductive decisions, cancer screenings, or undergo prophylactic surgery to significantly reduce one's cancer risk. Angelina Jolie, for instance, experienced a strong family history of breast cancer and chose prophylactic surgery when she was identified as a *BRCA* mutation carrier. Ever since Angelina Jolie wrote about her experience in the New York Times (Jolie, 2013), the public has become more aware of genetic testing and preventative options for women at risk for *BRCA*-related cancers (Kamenova, Reshef, & Caulfield, 2014). According to one study, uptake of *BRCA* testing increased by 64% within fifteen business days after her story was made public (Desai & Jena, 2016). Commonly *BRCA1* and *BRCA2* mutations are associated with an increased chance to develop breast and ovarian cancer (Lindor, McMaster, Lindor, & Greene, 2008) and, therefore, are strongly associated with women. However, it is a misperception that *BRCA* mutations only affect women (Liede et al., 2000). While male *BRCA1* or *BRCA2* mutation carriers have a lower lifetime chance of breast cancer than female carriers, they are at a significant increased chance compared to non-carriers and are at an increased chance for other cancers including prostate (Lindor et al., 2008). A lot more of the research to date have followed female carriers (Pal et al., 2013), likely due to the higher cancer risk overall. Hence, much

research and advocacy has been dedicated to women's experiences of being a *BRCA1* or *BRCA2* mutation carrier and much less attention has been paid to the needs and experiences of men when they learn of their carrier status. The existence of male and female *BRCA1* and *BRCA2* mutation carrier specific support groups suggests that there are struggles and needs that are unique to each gender.

Being a *BRCA1* or *BRCA2* mutation carrier confronts carriers and family members with important and difficult medical decisions, but it can also create emotional challenges. As Hesse-Biber (2014) emphasizes, men are known to be less willing than women to seek help from medical professionals as any form of illness may be perceived as a weakness and a threat to their masculinity. According to Shafer and Wendt (2015), the masculine view constructed by society may discourage men from seeking help. As another study reported, men struggled to seek psychosocial support as they perceived asking for help and showing emotions as threats to their masculinity (Wenger & Oliffe, 2014). They also stated that they struggled with accepting help from others as they felt that expressing emotional pain was a burden to others and would be perceived as a weakness.

One purpose of support groups is the access to people who have had similar experiences and may provide a sense of comfort and common understanding. However, as a study by Hughes and Phelps (2010) suggests, traditional face-to-face support groups may not meet everyone's needs. In their study, 17 female *BRCA1* or *BRCA2* mutation carriers revealed that they saw value in using websites, internet chat forums, newsletters, and phone lines as resources of support which suggests that a greater variety of support networks should be available for *BRCA1* and *BRCA2* mutation carriers. Since only female carriers participated in this study, these findings cannot be generalized to male carriers. However, according to the women who participated, men would

benefit from more anonymous support resources, such as websites, since they perceived men may avoid face-to-face support groups to keep things private. Therefore, further research is needed to find out what kind of resources male carriers find useful or would like to have access to in order to support them more effectively.

Genetic counselors are often the ones providing support and referrals to other resources and one of the main resources provided to patients are support groups. However, as previously stated, some individuals may not want to participate in face-to-face support groups or may not be able to attend due to demographics or other reasons (Hughes & Phelps, 2010). Also, since many men find it challenging to show vulnerability, reaching out to support groups may not serve their needs (Wenger & Oliffe, 2014). In fact, support groups for men are sparse compared to the abundance of female-focused *BRCA* support groups. As female *BRCA1* and *BRCA2* mutation carriers have greater representation in research and support groups compared to male carriers, it is necessary to assess whether male *BRCA1* and *BRCA2* mutation carriers receive the help and support they desire and would find useful. Hence, this study aimed to learn from men who have gone through genetic counseling with the goal that their feedback and suggestions can help the genetic counseling community improve the care that is currently provided to male *BRCA1* or *BRCA2* mutation carriers. This study focused on male carriers who have biological children as fatherhood and the possibility of passing on the mutation to their children may add further complexity to their needs. The goal was to evaluate the supports and resources that are currently offered and listen to participants' suggestions to create a variety of resources and coping strategies that will better serve the needs of male *BRCA1* or *BRCA2* mutation carriers. Possibly, this information may also be useful for male carriers of other cancer susceptibility syndromes or who are faced with other challenging life circumstances.

Methods

The qualitative study followed a semi-structured interview process using an interview guide. Because there was no existing information regarding the value of the supports and resources men who are *BRCA1* or *BRCA2* mutation carriers receive through genetic counseling, the goal was to gather qualitative data to learn about each participant's individual experience. In December 2017, the Brandeis Committee for Protection of Human Subjects, operating under Federalwide Assurance #FWA00004408, deemed the protocol to be exempt from further Institutional Review Board (IRB) oversight in accordance with 45 CFR 46.101(b)(2).

Recruitment Procedures

During the time frame of December 2017 until March 2018, study participants were recruited through HIS Breast Cancer Awareness (https://www.hisbreastcancer.org), a foundation that aims to educate and create awareness about male breast cancer, and The *BRCA* Brotherhood, a private Facebook group geared towards men who are carriers of a *BRCA* mutation. The administrators of each platform had approved (Appendix A) the content of the recruitment note (Appendix B) and agreed to post it once the study was approved by the Brandeis IRB. The recruitment material was re-posted periodically over the time period of the recruitment.

Once the recruitment was posted, interested individuals contacted the interviewer directly by email. Due to the large volume of inquiries by men and women, everyone received an email that listed the inclusion criteria and asked them to confirm that they met the eligibility requirements. Eligible participants had to be a carrier of a *BRCA1* or *BRCA2* mutation, have biological

children, be over 18 years old, currently reside in the United States, and speak English. The mutation status was reported and not confirmed by official records.

Once confirmation of eligibility was received, the interested participants were provided with an information sheet (Appendix C) which described the purpose of the study, the risks and benefits, and the study procedures, and the request to record the interview. The email also asked them to confirm their interest to participate once they read through the information sheet and encouraged them to reach out to the interviewer about any questions or concerns. Interviews were scheduled on a rolling basis and once agreement to be recorded was confirmed the session was recorded using freeconferencecall.com.

Interview Guide

A semi-structured interview guide (Appendix D) was used for data collection. The major domains explored included eliciting background information regarding their experience with genetic counseling; the role of fatherhood in their experience with being a *BRCA1* or *BRCA2* mutation carrier; their concerns around their carrier status; the resources and supports they were provided by their genetic counselor; their experience with supports and resources; information regarding an evaluation of the services provided by genetic counselors. In total, the interviews lasted from about 40 to 80 minutes. To maintain each participant's confidentiality, minimal personal identifiable information was collected. Notes were taken during the interview as a backup for the recording but were kept separate from the name and email address of the participant.

The recorded interviews were labeled with an assigned study code and uploaded to a secure drive supported by Brandeis University (Box.com) to protect participant confidentiality and then

sent to a transcription service to be transcribed. The completed transcripts were also uploaded to box.com once received.

Data Analysis

Responses to the interview questions were manually analyzed using an inductive approach to identify themes. An inductive approach, which identifies new themes from data, is useful when little information is known about a topic. The data was analyzed to determine themes that describe the experiences of fathers who are *BRCA1* or *BRCA2* mutation carriers with genetic counseling regarding the supports and resources they were provided. ATLAS.ti, a qualitative data analysis software program, was used to help code responses.

Results

Demographics

A total of seven participants were interviewed. The participants differed in their current age, number of years since they had genetic testing, whether they had a personal history of cancer, and by how many children they had and of what gender and age (Table 1). The current age ranged from forty-three to seventy-four years old. The number of years since learning their carrier status ranged from two to thirteen years. Out of the seven participants, four have had a personal history of cancer. Two of the participants have two daughters, two participants have one son and one daughter, one participant has two daughters and one son, one participant has one son, and one participant has one son and another son who was born female. The current age of the participants' children ranged from three to forty-five. Each participant was assigned a study number in the analysis.

Table 1: Demographics of Participants

Participants	Current Age	Age at Testing	Years Since Testing	Personal History of Cancer	Gender and Current Age of Child/Children
Participant 1	65 years	63 years	2	Yes	Son, 33 years
Participant 2	43 years	40s years	~3	No	Daughter, 9 years
Participant 3	54 years	48 years	6	Yes	Son, 21 years Son, 19 years
Participant 4	70 years	61 years	9	Yes	Daughter, 39 years
Participant 5	74 years	67 years	7	No	Son, 45 years Daughter, 41 years
Participant 6	70 years	57 years	13	Yes	Daughter, 41 years Son, 39 years
Participant 7	45 years	42 years	3	No	Daughter, 7 years Daughter, 5 years Son, 3 years

Upon interviewing this cohort, seven major themes were identified: (1) An overall positive impression of the genetic counseling session; (2) interests in more medical management options; (3) lack of informational resources; (4) utility of support groups and opportunities to connect with others; (5) a need for recognition and awareness of male *BRCA* mutation carriers; (6) concern for children; and (7) normalization.

Impression of the Genetic Counseling Session

We asked participants about their experience with genetic counseling, including how helpful the genetic counselor was with addressing questions and concerns. Five of the seven participants described their experience with their genetic counselor as overall positive. Four emphasized that the genetic counselor gave thorough explanations and addressed questions and concerns appropriately. One participant emphasized the value of seeing a genetic counselor prior and after genetic testing as he reported a delayed realization of the impacts of testing for the known mutation in his family:

> *"I really didn't give it much thought. I said, "Okay. She has got this mutation. Let me check it out." Not really thinking about what possible consequences there might be if I turned out that I was also BRCA positive. It wasn't until later that the impact of that kicked in."*

However, three participants shared a negative experience with their genetic counselor. One participant felt as if the genetic counselor lacked specific knowledge of cancer genetics. One participant expressed disappointment with the genetic counselor's lack of awareness of available clinical trials and the lack of interest in getting him set up with trials that were available in outside facilities. A different participant had the impression that the fact that he is a male negatively impacted the content and emotional support the genetic counselor provided:

> *"I think there could have been probably a little more—maybe compassion, I don't know.* […] *Since this counselor was female—that perhaps she gave a more conciliatory, a more thorough explanation, and possibly even more compassionate counseling to females"*

Interest in More Options for Medical Management

We asked participants what information was provided to them regarding cancer risks and medical management options. All of the participants shared that they were told about the appropriate cancer screening recommendations. In discussing the medical management options for *BRCA* mutation carriers, three participants pointed out that there is a lack of options for male *BRCA* mutation carriers compared to women. Two of those participants shared that the combination of increased cancer risks and the lack of preventative options is anxiety provoking due to the ongoing anticipation of when and in which form a cancer will develop. One of the participants pointed out that, opposed to women, men lack options to be proactive and this may discourage some men from pursuing genetic testing:

> *"I think there's a certain fatalism among men that, "Yeah, I can go, and get tested for this stuff, but knowing doesn't make any difference, whatsoever, and there's nothing proactive that you can really do. I don't think that's entirely true, but I think that's the conception, but it is also relatively limited what you can do. You can't really get your – yeah, can you prophylactically take this time bomb out of my pelvis? […] I really wish I could get a bilateral mastectomy, and it would put it to rest. And I don't know what menopause is like, but gosh, if I could do it, I might go for it. "*

While talking about the medical management options, two participants mentioned a strong interest in receiving information about available clinical trials from their genetic counselor. Further, another participant desired a more comprehensive approach of care by providing lifestyle or nutritional suggestions as preventative strategies. While he noted that there may be a lack of scientific evidence, he also emphasized the benefits of a comprehensive approach:

> *"At least having some sense of that's part of the team approach, so you have a counselor, and you have some docs, and maybe nutritionists, lifestyle folks, as an integrated practice, I think would be very good."*

Lack of Informational Resources

The third theme that arose from the responses of the participants was the utility of informational resources. We wanted to explore whether the participants received any resources that were focused on providing factual information regarding being a *BRCA* mutation carrier. None of the participants was provided with any resources. As one participant states:

"Well, the simple answer to that is a big zip. Nothing."

However, all of the participants expressed value in having access to a list of resources that address information regarding cancer genetics, *BRCA* mutation related facts, progress in research, and updates regarding cancer screenings and preventions. As one participant pointed out, he believes that men could benefit from a take-home brochure to summarize some of the essential information that was covered in the session:

"Pretty much just slap us upside the head and tell us to do our homework, you know. That's the main kind of thing. No, that's really it, just I think having a take-home device is something, yeah, something tangible that they can go and review and fall back on later when they do come up with questions, because they don't come up with any while they're in the office. […] As a male, I tend to really not come up with too many questions."

As two participants emphasized, they believe that knowledge is power. One participant shared that he has been actively involved in sharing information with others through public events, hosting lectures by medical professionals, and has used books, such as "A Cancer in the Family", and the podcast "*BRCA* Perspectives", accessible through the *BRCA* Foundation, as sources of information and to maintain current on scientific progress. Another participant shared that he has created the Facebook group "*BRCA* Brotherhood" to allow male *BRCA* mutation carriers access to current information. He states:

"Well, at FORCE we say knowledge is power and that's what we, and that's why I'm out there doing all of these things and trying to talk to people and posting whatever I can on my regular Facebook page just to make my Facebook friends aware of what is going on."

Other sources commonly mentioned consisted of the "*BRCA*responder" on Twitter, the Facebook groups "*BRCA* Commons" and "*BRCA* Advanced 101 & 102 Journal Club", the FORCE organization, and the HIS Breast Cancer Awareness Foundation. Among the participants was a common desire to be aware of regular updates regarding screening or scientific advances in treatments. One participant states:

> *"I wanted all the information I could get. I wanted to know all I can about myself. You know, the more information, the more screening, the more testing, the better."*

Another participant explained that without access to regular updates, it is unclear whether no progress has been made in medical science or whether he is simply not aware of it and missing important opportunities to reduce his risks of developing a cancer. Relating it to other situations in life, he shares that having confirmation that he is doing everything he is supposed to do, gives him a feeling of empowerment.

Utility of Support Groups and Opportunities to Connect with Others

In addition to inquiring about informational resources, we also wanted to explore whether the participants were made aware of any support groups. All of the participants shared that no support groups were provided through their genetic counselor. However, five reported that they have participated in support groups or events that facilitate communication with others regarding being a *BRCA* mutation carrier. It took self-initiative and involvement from family members to get them connected with support groups. One participant shared that he had a hard time finding a support group that would accept him as the majority of groups were exclusively for females. All five of these participants described their involvement as positive and as opportunities to have access to valuable information. These participants pointed out that support groups have been useful to stay informed about upcoming conferences, lectures, public events, fun activities, and updates regarding medical management and progress in research. Three of the five who

participated in support groups have had a personal history of cancer. One participant, who had breast cancer, emphasized the emotional impact support groups have had on him. He explains that the support group created an environment in which members have a unique experience in common with one another and can use the space to cope at their own pace.

> *"Everybody needs support. I think it would be very difficult to go through breast cancer and recovery without a support system if it doesn't come from your family. And often your family, after a year or two, says, "Alright, get over it. You're well now. Get on with life." They don't really come out and say, "We're tired of hearing your story," but what they mean is, "We're tired of hearing your story." But you can go to the group and there are always new people who want to hear your story and you can tell it occasionally so that it stays fresh with you."*

He further described that the support group has had a positive impact on his outlook on life which inspired him to help others regain hope and to focus on survivorship. In addition to helping people in the support group, he also volunteers as a support over the phone for people who are unable to join in-person.

> *"It's talking about it, being able to tell your story, being able to reconnect, but also being able to serve as an example to other people. Often people come there newly diagnosed who are really in shell shock. They come with that deer in the headlight look, thinking, "I've got breast cancer. I'm going to die." And you can be there and say, "No, I'm alive 13 years later." […] Yeah, it's a devastating illness. It's not a sprint. It's a marathon. It's a new experience. You've got to learn a new language. You've got to do a new reality. […] Every now and then we have somebody who dies and we have to deal with the loss too, because it's a reality, although we tell people, "You come to this group to die you're in the wrong group, because we're concentrating on living our lives to the fullest.""*

Furthermore, two participants emphasized that support groups and public events may be beneficial for the entire family. One participant acknowledged that finding out about being a carrier for a cancer predisposition gene can have impacts on the entire family. He shared that he hosts workshops that are focused on facilitating conversations about how family members can support one another:

> *"My concern is also the men who are the fathers, husbands, brothers, partners, sons of women who have cancer and what role they need to play as a support for those women. So, it's my focus is not just men who have the genetic mutation but how they affect the whole family dynamic."*

Two participants state that they have not taken advantage of support groups. One participant described men not as social and another participant stated that he prefers reaching out to family and friends if needed.

Overall, support groups were described as great ways to connect with others and to stay engaged and updated on relative topics. However, one participant urged to be careful when suggesting support groups to men. He suggested that it would appropriate to make men aware of the existence of support groups but to avoid giving them the impression that they need the support as this may imply that they are weak.

> *"Men don't seek out other men for support. And that's common. Anything that suggests that we are, you know, weak and in need of counseling, I think that would not go over well."*

Another participant suggested to focus on actionable information instead of psychosocial aspects:

> *" They probably are going to be a little bit – more want to orient the conversation towards, "What do I do next?" as opposed to, "How do I feel now?" Yeah. I think there's some truth in that stereotype for whatever it's worth."*

A Need for Recognition and Awareness of Male BRCA Mutation Carriers

The fifth theme that stood out among the responses of the participants was how society perceives male *BRCA* mutation carriers. Six of the seven participants felt that there is a lack of recognition and awareness that men can be carriers of a *BRCA* mutation and have associated cancer risks. One participant pointed out that there is an uneven recognition of female and male *BRCA* mutation carriers:

> *"Men do get the shorter end of the stick. I mean every October is Breast Cancer Awareness Month, but it seems to be all about women, which is fine, but there is no, there is very little recognition that men have to be part of that discussion also. [..] Women know that there are support groups, but the information that there are support groups available for men is not publicized. It gets drowned out. There is no National Men's Cancer Month. I don't know if it would make a difference, but there is no Men's Cancer Awareness Month. And while men are aware of the possibility of getting prostate cancer, skin cancer, colon cancer, even pancreatic cancer, a lot of men are not aware that they can get breast cancer. And so that, again that*

education being so important."

He also argues that a lack of awareness may lead to ignorance because, according to him, men tend to ignore issues if there is no reason for concern. Further, he argues that male breast exams should become a part of a routine annual physical exam.

Further, it was pointed out that the color pink in association with breast cancer can send a message of exclusion and emphasize the sense that men with breast cancer are in the minority. One participant shared that he had to wear a pink gown in the breast center and said:

> *"It's sort of an acknowledgement that well you're an outsider here, you're somewhat different, we're not used to treating you."*

Another participant also emphasized that there is a lack of awareness that men can be affected with breast cancer and that recognizing that risk may help the inclusion of men in support groups that primarily consist of women:

> *"He is not here just to be a nice guy. He is one of us. He is a member of this club, reluctantly, but he is a member of the club." And I think that that opens their eyes up. People will say, "I didn't know men could get breast cancer." I say, "Well, I didn't either until I got it.""*

Additionally, one participant acknowledged that there is a lack of groups and resources for male *BRCA* carriers which inspired him to create the Facebook group "*BRCA* Brotherhood":

> *"I mean it's not like the BRCA Sisterhood Facebook page [which] has thousands and thousands of members, and that is certainly understandable because of the overwhelming majority of cancer is related to women, but men still have the voice."*

Another participant expressed a lack of trust in medical professionals. He had the impression that some medical professionals were either not aware of the risks associated with being a male *BRCA* mutation carrier or that they did not take the risks seriously. He shared that it had been very stressful having to repeatedly educate medical professionals about the appropriate screening guidelines and to correct misinformation:

> *"At one point when my daughter lived in New York City she would go every year to one of the top gynecologists in Manhattan and every year she went, and they filled out the information*

form, and is there a history of cancer in your family, yes, which of your parents is it, and she wrote "My father" and the doctor said, "Well you don't have to worry about that if it comes from your father.""

Hence, he recommended that medical school place a stronger emphasis on education about hereditary cancers so that there is a common understanding of cancer risks for male and female *BRCA* mutation carriers among health care providers.

Further, two participants point out that men may have similar concerns regarding physical appearance after a risk reducing surgery as women. One participant shared:

"An important issue for a lot of women is reconstruction. They're trying to get their bodies back in some kind of semblance. […] Body issue is also, I think, for me an issue. It probably took two years, maybe three years before I was comfortable going on the beach without a shirt or hopping in the hot tub at the vacation place without a sweatshirt."

Another participant shared that there was a lack of access to male reconstruction surgery:

" There was a lot of stress involved with finding somebody who would do an oncological double mastectomy and then build up as a male chest instead of a female one, and there is hardly anybody that does that. There is men when they get breast cancers, I guess everyone who we have talked to is in their 50s, 60s, 70s, and they didn't bother to rebuild."

Concern for Children

The sixth theme that arose from the participants was whether fatherhood had an effect on their experience with being a carrier of a *BRCA* mutation. All of the seven participants shared that their strongest concern was regarding their children. Some of the concerns included losing their child to cancer, the sacrifices that come along with risk reducing surgery, and passing on the gene mutation to further generations such as grandchildren. All of the participants shared that they either already had open communications with their children about their risks or they intend to approach an open communication once their child is old enough so that they can emotionally prepare them and make them aware of their risks and options. As one participant shared, his

concern was greatly reduced because she was proactive and took advantage of risk reducing options. Another participant said:

> *"I am just thankful that we have so many more options today. It's not a death sentence. If it's caught early it is certainly a treatable disease. It can be a chronic disease, but it's not a death sentence anymore. […] I am certainly sorry that she has to deal with it. I'm just glad she has the information my mother never had."*

Another participant shared that the fact that there are options for women to reduce their cancer risks helped him cope and accept that his children would be at increased risks for cancers if they inherited the mutation. His primary fear is that they would not take advantage of these options.

> *"I think knowledge, especially when it comes to ladies, is truly empowering, because they do have some ability to change their fate a little bit. "*

Overall, the participants acknowledged that it was out of their control what genes their children inherited. Additionally, all of the participants shared that their relationship with their children had not been affected by passing on the gene mutation and some reported that their relationship may actually have become stronger.

Normalization

The last theme that arose from the participants was a sense of normalization and positivity in regard to being a carrier of a *BRCA* mutation. Five of the seven participants mentioned that acceptance and normalization had helped them adjust to the fact that they carry a *BRCA* mutation. It was a common theme that they learned to live with being a *BRCA* mutation carrier and accepted a new reality. One participant shared he focuses on living life to the fullest and that having gone through cancer has helped him gain perspective of what is important in life. Further, the participants emphasized that everyone experiences hardship at some point in life. As one participant phrased it:

> *"We all got something."*

Further emphasizing that normalization was a common theme, one participant said that he does not think about being a *BRCA* mutation carrier except when a scheduled screening is approaching. Another participant points out:

> *"I'm the same as I always have, except that I'm getting older. […] And I intend to go on living a normal life for as long as I can."*

Further, one participant shared that his daughter was the one who put things in perspective for him when he expressed his distress with passing on the *BRCA* mutation to her:

> *"I had said to my daughter at one point, I don't remember when, but it was at one point I said to her, "I know it's a totally irrational feeling, but I feel guilty for passing the gene along to you." And she turned around and said, "Yeah, I understand, but think of all the wonderful genes you passed along.""*

Discussion

Overall, this study revealed that male *BRCA* mutation carriers are interested in receiving information about available resources that can be used as references for information, updates on medical management, and as sources of support and personal connections. While the majority of the participants were satisfied with their genetic counseling experience, they recognized that, compared to women, there is a lack of risk reducing medical management options for male carriers. Hence, the interest in actionable options was repeatedly emphasized. As a study by Uzzo et al. (2004) points out, many men use nutritional supplements to reduce their risk for prostate cancer and while this attempt lacks scientific evidence to date, it may give men a sense of control.

Further, there was a strong interest in informational resources among the participants. As pointed out by Moynihan et al. (2017), information seeking may be a way for men to seek help while maintaining a sense of self-reliance and control over the circumstances. While only one participant emphasized the value of emotional support that he has experienced within a support groups, the majority of the participants shared that support groups have been a useful resource for information and to collaborate with others who have a similar interest in being aware of current information and appropriate medical management. One participant pointed out that suggesting support groups to men could be taken personally and imply that they are weak. This supports previous studies which argue that men tend to be more reluctant to seek emotional support than women in order to protect their masculinity (Wenger & Oliffe, 2014). According to Hughes and Phelps (2010), websites, internet chat forums, newsletters, and phone lines may be

useful resources of support for male carriers, especially for men who prefer a more anonymous environment.

Additionally, efforts should be taken to raise awareness that men are at equal risk to inherit a familial *BRCA* mutation and that there are associated cancer risks and needs in men as well as in women. Another study supports this finding as fourteen out of twenty-one male *BRCA* mutation carries mentioned that health care providers and society lack knowledge and awareness of how *BRCA* mutations can affect male carriers (Suttman, Pilarski, Agnese, & Senter, 2018). This lack of awareness could potentially cause delayed diagnoses and a lack of appropriate medical care for at-risk individuals. In addition, increased awareness within society at large is also important. As was pointed out by one participant who had to wear a pink gown in the breast center, creating an environment that is either gender neutral or acknowledging both genders would further communicate a sense of inclusion and help normalize the experience of male *BRCA* carriers. This is further supported by another study which suggests that events and educational materials for individuals affected with HBOC should be less feminized and created more consciously with regard to male *BRCA* mutation carriers (Suttman et al., 2018).

As our study showed, fatherhood played a role in the experience of the participants as their children were their greatest concern regarding being a carrier of a *BRCA* mutation. Participants who have disclosed their carrier status to their older children emphasized the importance of continual and open communication within their family when sharing information regarding inheritance, cancer risks, and options for medical management. In many cases the open communication on carrier status has brought participants and their children closer. Disclosure and discussion of hereditary cancer risk information is known to be anxiety provoking and distressing to parents (Werner-Lin, Merrill, & Brandt, 2018). Although these participant's

vignettes represent "success stories" with regards to disclosure to children, we did not delve specifically into how participants approached disclosure. Genetic counselors and healthcare providers should be aware that the emphasis on open communication, as illustrated by the vignettes presented in this study, may be a key component when discussing disclosure to family members in post-test counseling sessions with newly diagnosed *BRCA* carriers. Two key papers that provide additional guidance to providers in helping parents think through the disclosure process have been authored by Werner-Lin et al (2018) and Patenaude and Schneider (Patenaude & Schneider, 2017).

Study Limitations

This study has several limitations, including small sample size, recall bias, selection bias, diversity in the participants, and potential effects of the interviewer on the responses and response interpretations. Only seven individuals were interviewed due to time and budget constraints. Since this is a qualitative study with a small sample size, findings are not generalizable to all men who are carriers of a *BRCA* mutation and have biological children. Since this is a retrospective study, there is a potential for recall bias as the responses may have been affected by the time that had passed between the interview and the time they had genetic testing. We primarily recruited participants through the Facebook group "*BRCA* Brotherhood" and the social media platforms of the "HIS Breast Cancer Awareness Foundation". Other participants learned about the study through word of mouth and reached out to the interviewer. Hence, there is a possibility for selection bias as it is unknown what factors motivated their participation. It may be that male carriers who are more interested in resources and supports were more likely to know about the study and willing to discuss their experiences. Further, the participants differed from each other in age, time since testing, whether they had a personal history of cancer, and by

how many children they had and of which gender. Hence, the diversity in the participant characteristics could have influenced their experiences and responses. For instance, men with a personal history of cancer may be more involved in seeking supports and resources compared to men who are unaffected. The same interviewer conducted the semi-structure phone interviews however given the qualitative nature of the chosen research method the participants' responses may have been influenced by the interviewer. Additionally, there is a potential for a personal bias as the analysis and interpretation of the responses relied on the interviewer.

Practice Implications

This study provides important insights into the utility of resources, supports, and an increased awareness among the medical community and general public regarding male *BRCA* mutation carriers. A more comprehensive approach of medical care for male *BRCA* mutation carriers could potentially help to compensate for the lack of actionable options available to male carriers. As was suggested in this study, this could come in the form of a more comprehensive care involving, for example, a nutritionist, and by providing current information on available clinical trials. Further, providing a list of informational resources that allow individuals to stay informed on advances in research, events, workshops, and other relevant information would be appropriate based on the responses of the participants. Depending on personal preference, informational resources could be provided in the form of take-home brochures, handouts, or a list of web-based resources. While support groups can be valuable resources of information as well as emotional support, it is important to be mindful of the possibility that some men may perceive support groups as a threat to their masculinity. Hence, it would be appropriate to provide a list of support groups with the emphasize that they can be useful resources of both support and information, depending on what a person may want to get out of it.

Further, increased awareness of how *BRCA* mutations can affect male carriers would ensure appropriate education and care for at risk individuals, as well as facilitate the inclusion of male *BRCA* mutation carriers in the efforts of cancer risk awareness among society. Efforts should be taken to educate medical professional about hereditary cancers in men and women and to create a more gender-neutral environment regarding cancer risk awareness among society.

Finally, this study showed that being a carrier of a BRCA mutation can have implications for the entire family. Therefore, some families may benefit from guidance on how to communicate with family members, particularly children, and workshops that address these issues could be helpful resources.

Research Recommendations

As far as we know, this is the first study to focus on the resources and supports that are provided by genetic counselors to fathers who are carriers of a *BRCA1* or *BRCA2* mutation. Among the participants of this study, no supports and resources were provided as part of their genetic testing. All of the participants would have liked to receive resources that satisfy an interest in informational references or emotional supports, or both. Given that the goal of this study was to evaluate the services provided by genetic counselors to ultimately better serve the needs of male *BRCA* mutation carriers, a larger sample size could potentially give us a better understanding of what resources and supports are overall considered most useful. It would be interesting to collect a variety of available resources such as books, foundations, various websites, and support group, and create a survey that would be distributed to male *BRCA* mutation carriers to assess which of these resources they have used and what their experiences have been like. This would help to evaluate some of the resources and may also make the participants aware of resources they had not heard of before.

Further, future studies could investigate whether male *BRCA* mutation carriers would be more likely to participate in support groups if they were exclusively for men. A recent study found that 50% (eleven out of twenty-one) male *BRCA* mutation carriers were interested in male-focused support groups as potential sources of relevant information as well as a means of sharing and expressing concerns (Suttman et al., 2018). A study by White et al. (2014) showed that 61% (207 out of 337 participants) of a cohort of female *BRCA* mutation carriers were interested in talking with other female mutation carriers as a source of support. Among our study, there was no strong emphasize on seeking support exclusively from men. In fact, regarding in-person support groups, one participant pointed out that he feels more comfortable among women and another participant mentioned that male-only support groups would not be necessary and also unfeasible due to the rarity of men affected with a *BRCA*-associated cancer. Hence, it would be interesting if further studies addressed the opinions of male *BRCA* mutation carriers regarding male-only support groups.

Conclusion:

Genetic testing can have serious implications on physical and mental health of the person going through testing as well as the entire family. Hence, genetic counselors are trained to support patients through their genetic testing experience and provide supports and resources as needed. Since female *BRCA* mutation carriers have a significantly increased risk for breast and ovarian cancer compared to the general population, many resources and supports have been established for women. This study was the first of our knowledge to explore what resources and supports were provided to male *BRCA* mutation carriers and whether their needs were addressed by their genetic counselor. We learned that none of the genetic counselors provided information regarding informational resources or support groups but that male *BRCA* mutation carriers were interested in such resources. To meet individual needs, it would be helpful to have a variety of resources available, including take-home materials such brochures or handouts, websites, foundations, and support groups. Despite their concerns regarding the cancer risks of their children, the participants maintained that they had a positive outlook on life and incorporated their carrier status as being an aspect of their life but not central to everyday living. Additionally, male *BRCA* mutation carriers find comfort and a sense of empowerment in being aware of clinical trials and updates in research and screening guidelines. Providing a comprehensive approach to care by addressing nutrition and lifestyle could give an additional sense of control over their fate. Increased awareness among health care professionals is important to ensure appropriate medical care for male *BRCA* mutation carriers. Further, normalizing the fact that men are at increased risk for cancers traditionally associated with women as well as other

cancers, may help them feel less isolated and could potentially increase male participation in resources of support that can be beneficial to themselves and the entire family.

Appendix A: Permission Letters

Permission Letter

The BRCA Brotherhood Facebook Group

Brandeis University Institutional Review Board
Human Subjects in Research (IRB)
Bernstein Marcus, MS 116
415 South Street
Waltham, MA 02456

November 6, 2017

Dear Brandeis University IRB:

On behalf of the BRCA Brotherhood, I am writing to grant permission for Anna-Lena Nassar, a second year student in the Genetic Counseling Master's Program at Brandeis University, to recruit participants for her study through our closed Facebook group. I am aware of the purpose of the study and that she wants to conduct a qualitative study to interview male BRCA 1 or 2 mutation carriers. I have reviewed the recruitment material and agreed to periodically post it in the Facebook group over the next 4 months. We are happy to participate in this study and contribute to this important research.

Sincerely,

Dave Bushman
Administrator

Permission Letter

Brandeis University Institutional Review Board
Human Subjects in Research (IRB)
Bernstein Marcus, MS 116
415 South Street
Waltham, MA 02456

October 26, 2017

Dear Brandeis University IRB:

On behalf of HIS Breast Cancer Awareness, I am writing to grant permission for Anna-Lena Nassar, a second year student in the Genetic Counseling Master's Program at Brandeis University, to recruit participants for her study through our online platforms. I am aware of the purpose of the study and that she wants to conduct a qualitative study to interview male BRCA 1 or 2 mutation carriers. I have reviewed the recruitment material and agreed to periodically post it on our various social media outlets over the next 4 months. We are happy to participate in this study and contribute to this important research.

Sincerely,

Vicki Singer Wolf,
Co-Founder, HIS Breast Cancer Awareness

Appendix B: Recruitment Materials

Recruitment Note for The BRCA Brotherhood (private Facebook group):

"Research Volunteers Needed! If you are a father, we want to hear from you! I am conducting phone interviews with fathers who are *BRCA*1 or 2 carriers and have seen a genetic counselor to evaluate the resources and supports provided through genetic counseling. This is an exciting opportunity to share your experiences and help the medical community better support men who face similar challenges. If you take part in the study, you will receive a $25 Amazon.com gift card via e-mail to thank you for your time and valuable insight. I am a genetic counseling graduate student from Brandeis University and I am conducting this study as part of my master's degree thesis project. Participation in this research study is voluntary and the data collected during the study will be kept confidential. If you have biological children, live in the U.S., speak English, and are interested in participating, please contact me, Anna-Lena Nassar at annalenanassar@brandeis.edu."

Recruitment Note for HIS Breast Cancer Awareness

"Research Volunteers Needed! If you are a father who carries a *BRCA*1 or 2 mutation, we want to hear from you! I am conducting phone interviews with fathers who are *BRCA*1 or 2 carriers and have seen a genetic counselor to evaluate the resources and supports provided through genetic counseling. This is an exciting opportunity to share your experiences and help the medical community better support men who face similar challenges. If you take part in the study, you will receive a $25 Amazon.com gift card via e-mail to thank you for your time and valuable insight. I am a genetic counseling graduate student from Brandeis University and I am conducting this study as part of my master's degree thesis project. Participation in this research study is voluntary and the data collected during the study will be kept confidential. If you have biological children, live in the U.S., speak English, and are interested in participating, please contact me, Anna-Lena Nassar at annalenanassar@brandeis.edu."

Appendix C: Information Sheet

BRANDEIS UNIVERSITY
DEPARTMENT OF BIOLOGY
GENETIC COUNSELING GRADUATE PROGRAM

Information Sheet: Evaluation of the Support Provided to Male *BRCA* 1/2 Mutation Carriers: Are Their Needs Being Met or Can Genetic Counselors Do Better?

Principal Investigator: Gayun Chan-Smutko
Student Researcher: Anna-Lena Nassar

Introduction
The research team is conducting this study to explore the experiences fathers who are *BRCA1* or *2* mutation carriers had with supports and resources they received through genetic counseling. The study will focus on fathers as fatherhood and the possibility that a child may have inherited the mutation might further add complexity to their experiences. The hope is to evaluate the supports and resources genetic counselors are currently providing to male *BRCA1* or *2* carriers to determine whether their needs are being met or if there is room for improvements.

The student researcher who is carrying out this study is a second year student in the Genetic Counseling Master's Program at Brandeis University. The Principal Investigator is overseeing the study and is an Assistant Director of the Brandeis Genetic Counseling program. She is also a certified and licensed genetic counselor. She has provided genetic counseling services at Massachusetts General Hospital for the past 15 years.

You are being invited to participate in this study because you:
- Are a carrier of a *BRCA1* or *2* mutation,
- Have biological children,
- Are over 18 years old,
- Currently reside in the United States, and
- Speak English

Please read this info sheet carefully. Participating in this research study is voluntary and you should not feel any pressure to take part. We encourage you to ask questions if you want more information about any part of the study. You will be asked if you understood all the information in the information sheet, whether you have any questions, and if you voluntarily agree to participate in the study, before we begin the interview. You can decide to withdraw from this study at any time and for any reason.

Purpose
The purpose of this study is to gain insight into how well the resources and supports provided by genetic counselors are geared towards the needs of fathers who are *BRCA1* or *2* mutation carriers. We hope to learn about your experience with genetic counseling and how you perceived the supports and resources that were offered by your genetic counselor. We also want to learn how the provided services could be improved to better serve the needs of men who are faced with similar challenges.

Procedures

If you agree to take part in the study, a phone interview will be scheduled at your convenience. The interview will be audiotaped using www.freeconferencecalling.com and is expected to last between 30- 45 minutes. The interview will consist of a series of questions regarding your experience with genetic counseling, the role of fatherhood in your experience with being a *BRCA1* or *2* mutation carrier, the kinds of resources and supports that were provided to you through genetic counseling, and how adequately the genetic counseling service addressed your concerns and needs. An additional sequence of questions will be asked at the end of the interview to gather demographic and social information. Notes will be taken during the interview as a backup for the recording.

Risks
This study poses minimal risk to you. If you are uncomfortable answering a particular question you can chose not to answer the question or end the interview at any time.

There is always the risk that your information could be accidently disclosed to people not connected with this study; however, we will do our utmost to secure your information, so your identity and disclosed information remains confidential.

Benefits
People often experience benefits, such as reduction of stress, by having the opportunity to talk about their experiences. Additionally, your participation in this study will likely help us gain a better understanding of the challenges fathers who are *BRCA1* or *2* mutation carriers encounter and how the medical community can better address their concerns and needs. It is our hope that information obtained from this study will serve as inspiration for conducting larger and more focused studies in the future, which may impact male *BRCA1* or *2* mutation carriers and their families.

Participation
Participation in this research study is completely voluntary. If you decide to participate in this study, you may decline to answer any question(s) and you may withdraw from the study at any time and for any reason without consequences. Your participation in this study will not affect the availability or quality of healthcare services provided to you. You may also decide not to participate in this study.

Privacy and Confidentiality
All data obtained during this study will be kept confidential. After the phone interviews are conducted, your name will be removed from the interview transcript and only the student researcher will know which participants provided which interview responses. All data will be uploaded to box.com, an encrypted site, to keep the data confidential and maintain privacy for all participants.

After your name has been removed from the interview transcript data from this study will be reviewed by the research committee. The research committee includes Gayun Chan-Smutko, who is the Assistant Director of the Brandeis Genetic Counseling program and a genetic counselor at MGH Boston, Susan Mecsas-Faxon, a genetic counselor at Harvard Vanguard Medical Associates, and Dr. R. C. Mellors, who recently retired after 37 years of practice as an internist and rheumatologist.

There is a possibility that data obtained from this study will be published in a peer-reviewed journal, but data will not have identifying information on it in order to protect the participants. Data will be kept until December 31st, 2019 for presentation and publishing purposes and will then be destroyed.

Payment
If you choose to participate in this research study, you will receive a $25 Amazon.com gift card via e-mail to thank you for your time and valuable insight.

Cost
Other than the time you spend answering questions during the phone interview, there will be no cost to you to participate in this study.

Whom to Contact
If you have any questions about the study, please contact the student researcher, Anna-Lena Nassar, by e-mail at annalenanassar@brandeis.edu.

You may also contact the Principal Investigator for this study, Gayun Chan-Smutko, by e-mail at gchansmutko@brandeis.edu.

If you have questions about your rights as a research study subject, please contact the Brandeis Committee for Protection of Human Subjects by e-mail at irb@brandeis.edu or by phone at (781)-736-8133.

Appendix D: Interview Guide

- Review of Information Sheet
- Do you have any questions about the information sheet?
- Do you agree to participate?
- Do you agree to be recorded?

I. Introduction – Brief introduction of myself and the study.

Overall Goal: How do you think genetic counselors could improve how they are supporting/helping fathers who are *BRCA1* or *2* mutation carriers?

II. Key Questions

Contracting

1. Tell me about your experience with genetic counseling
    - When did you see a genetic counselor?
    - What motivated you to seek genetic counseling?
        - Have you or any family members had cancer?
        - Your risk to be a carrier and/or develop cancer?
        - Cancer risk of children?
2. What did you know about genetic testing before you went through genetic counseling for *BRCA*?

Fatherhood

1. How many children do you have? How many are daughters/sons?
    - How old were your children at the time you underwent genetic testing?
2. Do you feel that having children has played a role in your experience with being a mutation carrier? If yes, what are some examples?
3. Do you feel that your carrier status has impacted your relationship with your children? If yes, can you describe in what ways it has impacted your relationship?
4. Have your children had genetic testing?

If they had testing:

5. How involved were you in their decision to get testing?
6. How did their test results impact you?

If his children have not had testing:

5. What is your perspective on your children having genetic testing?
    - Have any of your children had cancer?
6. What guidance did you want/would like to have in talking about genetic testing with your children?

7. When your children decide to have testing, what are some of your concerns?
    - Cancer risk?
    - Insurance discrimination (Disability, Long-term care, and Life insurance)?

Concerns/Risk assessment

8. When you learned that you were a carrier of a *BRCA1* or *2* mutation, what were some of your concerns?
9. How comfortable did you feel with the genetic counselor discussing your worries and asking questions?
    - Prompt: Can you expand on that?
10. How did the genetic counselor address your concerns?
11. How did knowing that you are a carrier affect your perception of your chance of developing cancer?
12. What screening methods were offered to you?
    - What screenings have you been doing?

<u>Resources</u>

13. Besides screening/surveillance methods, what other resources and supports were provided by your genetic counselor?
    - What were they focused on?
    - What aspect interested you?
    - If you used any of them, how helpful would you describe them?
        - What did you like/not like?
    - What were some of the reasons you were you reluctant to use others?
14. Did you learn of any other resources that were not offered by your genetic counselor?
    - What kind were they?
    - Did you use any of them? If yes, what aspects interested you?
        - How helpful would you describe them?
        - Would you suggest them to others?
    - What were some of the reasons you were you reluctant to use others?
15. What role has the support group played in your life (HIS Breast Cancer, Male *BRCA* mutation carrier Facebook support group)?
    - How did you hear of the group?
    - When did you join the group?
    - What motivated you to join?
    - What are your thoughts on men only groups versus groups for men and women?

<u>Reflective evaluation</u>

16. Reflecting on what we just talked about, how would you evaluate the services received through genetic counseling in helping you through these various challenges?

III. **Closing Question** – Is there anything you would like to add? Do you have any further comments/suggestions on how men who are fathers and *BRCA1* or *2* carriers can be better supported?

IV. **Summary** – Thank you for discussion. Brief summary of major comments.

V. **Collection of demographics, contact information (not recorded)**

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