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Impact of Service Delivery Model on Patient Perceptions and Utility of Genetic Counseling for Hereditary Breast and Ovarian Cancer: An Exploration of Group Genetic Counseling

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IMPACT OF SERVICE DELIVERY MODEL ON PATIENT PERCEPTIONS AND
UTILITY OF GENETIC COUNSELING FOR HEREDITARY BREAST AND
OVARIAN CANCER: AN EXPLORATION OF GROUP GENETIC COUNSELING

by

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ABSTRACT

Patients at risk for hereditary breast and ovarian cancer (HBOC) traditionally participate in individual cancer genetic counseling sessions to be educated about cancer genetics concepts, their personal cancer risks and genetic testing. With expanding technology and increased public awareness of HBOC, referrals to cancer genetic counseling services have grown. The current number of practicing genetic counselors struggles to meet the demands of increased referrals, so new service delivery models need to be explored. The purpose of this study is to assess the utility of group genetic counseling for HBOC by evaluating the perspectives of patients that received group genetic counseling versus perspectives of those that received individual genetic counseling. We aimed to determine patient satisfaction and comfort level while also assessing the time efficiency and patient receptiveness to group sessions. Sixty-eight individuals with a new diagnosis of breast cancer participated, were randomly assigned to group genetic counseling (n=30) or individual genetic counseling (n=38) and gave perspectives on their genetic counseling session. Results demonstrate that each study cohort reported high satisfaction with their genetic counseling session. Participants in the group genetic counseling cohort were less likely to be overwhelmed by information given in their appointments ($p=0.01$). Comfort levels were similar between the two study groups and a majority of participants reported high comfort levels after their appointment. A majority of participants in the individual genetic counseling stated that they would not be willing to participate in group genetic counseling had they been given

the choice and cited privacy and comfort as the main reasoning. Additionally, our study found that group genetic counseling led to a significant savings in genetic counselor time ($p=0.0008$). This study demonstrates that group genetic counseling shows promise by reducing the genetic counselor time per patient, which allows for the ability to see more patients, while providing similar satisfaction and benefits to patients as individual genetic counseling models.

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CHAPTER 1
LITERATURE REVIEW

1.1 Overview of hereditary breast and ovarian cancer

In 2017, there were approximately 255,180 new cases of breast cancer in the United States. Currently, breast cancer is the second leading cause of cancer death in women, accounting for 40,610 deaths last year. While most of these cancers are sporadic, 5-10% of breast cancer has a hereditary component (ACS 2017). Because of this, The National Comprehensive Cancer Network (NCCN) guidelines outline which patients should be evaluated for Hereditary Breast and Ovarian Cancer (HBOC) syndromes. For example, NCCN guidelines state that all patients with breast cancer at or under 50 years old, those with triple-negative breast cancer at or under 60 years old, those with metastatic HER2 negative breast cancer and those with breast cancer at any age meeting specific family history criteria should receive genetic counseling for HBOC (NCCN 2019). Other professional societies, such as the American College of Obstetricians and Gynecologists (ACOG), the American Cancer Society (ACS) and the Society of Gynecologic Oncology (SGO), have also weighed in with criteria for patients that should be referred for genetic counseling, including unaffected women with a family history meeting specified criteria (ACOG 2015; SGO 2014; ACS 2017) . Detection of these cancer predisposition syndromes can change patient management though the option of a risk-reducing surgery, increased surveillance, and potential targeted therapy options. In addition, identification of a hereditary cancer syndrome will impact at-risk family

members. HBOC syndromes are caused by autosomal dominant inherited germline pathogenic variants that result in an increased risk for cancers, such as breast and ovarian cancer. *BRCA1* and *BRCA2* are high-risk genes that account for up to 50% of HBOC cases. Starting in 1996, genetic testing for HBOC was focused on sequencing the *BRCA1* and *BRCA2* genes. However, as research has evolved, it has become clear that of those with HBOC, only around 30% have been identified to have a *BRCA1* and *BRCA2* pathogenic variant through genetic testing (Okur et. al. 2017). With advancing research, the genetics community has continued to research and learn more about other cancer susceptibility genes that may confer risks to developing breast and ovarian cancer, such as *CHEK2*, *ATM*, and *PALB2* (Wang et. al., 2018). NCCN management guidelines for individuals with pathogenic variants in these and several other genes are now available.

1.2 Evolution of genetic testing for cancer predispositions

With the advent of next-generation sequencing (NGS) technology, the clinical approach to genetic testing in oncology has shifted. An increasing number of providers are moving toward multi-gene panels, which allows clinicians to analyze for many HBOC predisposition genes simultaneously (Crawford et. al. 2017). Additionally, studies have shown that testing multiple genes simultaneously may be more efficient and cost effective for patient diagnosis (Dancey et. al. 2012). There has been a rapid growth in the number of multi-gene panel genetic tests available in recent years. From March 2014 to August 2017, 14,000 new genetic tests became available, with about two to three panel tests entering the market every day (Phillips et. al. 2018). This evolution toward panel testing has resulted in the improved identification of pathogenic variant carriers but has also challenged the understanding of the expression of these gene pathogenic variants.

Through advances in genetic testing technology, researchers and clinicians have been able to identify and consequently test for many more genes that confer a high lifetime risk of specific cancers (Okur et. al. 2017).

Increased knowledge of genetic predisposition genes has uncovered that some groups of patients who have undergone *BRCA1* and *BRCA2* testing in the past with negative results may benefit from being tested again with more comprehensive panels. Our current technologies have increased the detection rate of deletions and duplications in *BRCA1* and *BRCA2*, which could uncover pathogenic variants in these genes that were previously not found. Also, patients with previously negative results on previous *BRCA1* and *BRCA2* tests may have one or more pathogenic variants in other HBOC genes. In a recent study, it was found that 9% of a retested cohort had a pathogenic variant in a gene that predisposes a higher risk of breast cancer (Crawford et. al. 2017). Of the identifiable mutations in the retested cohort, 8% were in genes other than *BRCA1* and *BRCA2*.

With more individuals being tested for cancer predisposition gene pathogenic variants, there has been an increased public awareness of cancer genetics and risk. The so-called “Angelina Jolie effect” has been described in the literature (Guo et. al. 2017). In May 2013, actress Angelina Jolie wrote an op-ed, published in the New York Times, sharing her experience about undergoing genetic testing and discovering she had a pathogenic variant in the *BRCA1* gene. She openly shared her decision making process that led to a risk-reducing double mastectomy and oophorectomy (Jolie 2013). News media outlets publicized her story and experience across the world. In studies conducted in the UK, researchers found that referrals to genetic counseling services increased nearly 2.5 fold in the months following public dissemination of Angelina Jolie’s genetic testing

experience. In a retrospective United States study looking at the number of *BRCA1* and *BRCA2* tests ordered following Jolie's article, there was an 80% increase in the number of *BRCA1* and *BRCA2* tests from April 2013 to June 2013 (Guo et. al. 2017). Referral and testing rates have continued to stay at an increased rate and demand for *BRCA1* and *BRCA2* testing specifically has increased among patients and providers. This "Angelina Jolie effect" has been global in its reach and appears to have impacted the increase in referrals to cancer genetics and genetic counseling (Evans et. al. 2014; Guo et. al. 2017).

Precision medicine efforts have turned toward the use of targeted therapies for cancer in both individuals who have somatic pathogenic variants in their tumor and those with germline pathogenic variants. These therapies have offered dramatic improvements in the treatment of cancer. Beginning in 2010, oncologists began researching a class of drugs called PARP inhibitors to treat ovarian cancers in individuals with a germline *BRCA1* or *BRCA2* pathogenic variant. Treatment of *BRCA1* and *BRCA2* positive patients with PARP inhibitors has been associated with higher survival rates than those without *BRCA1* or *BRCA2* pathogenic variants that are treated with PARP inhibitors. Drugs have also been approved for those with metastatic HER2-negative breast cancer who carry a germline pathogenic variant in *BRCA1* or *BRCA2* (Konecny et. al 2016).

Together, the advent of new technologies, increased public awareness of *BRCA1* and *BRCA2* and personalized medicine efforts have resulted in an increase in referrals for genetic counseling for hereditary cancer risk assessment and a need for more genetic counselors (Buchanan et. al. 2016). The availability of genetic counselors is one of the rate limiting factors for patient access to genetic counseling services (Hoskovec et. al. 2018). With the current number of practicing genetic counselors, there are struggles to

meet the demands for genetic counseling referrals. It has been predicted that with the increased demand for genetic counseling, the supply of genetic counselors will not meet needs until 2024-2030 (Hoskovec et. al. 2018). This underscores the need to evaluate the effectiveness of current delivery service models and consider other service delivery models (SDM) that can be implemented into the cancer genetics clinic to increase access.

1.3 Genetic counseling service delivery models

1.3.1 Individual genetic counseling

The usual standard of care for cancer genetic counseling has followed the traditional service delivery model which involves one-on-one in-person initial sessions with follow up and results disclosure occurring by telephone or other means (Cohen et. al. 2013). According to the 2018 Professional Status Survey report from the National Society of Genetic Counselors (NSGC), 96% of genetic counseling is performed using this method (NSGC 2018). The essential elements of cancer genetic counseling sessions include: intake of personal and family medical history, cancer risk assessment and education, pretest counseling, informed consent for genetic tests and psychosocial assessment (Riley et. al. 2012). The purpose of cancer genetic counseling is to identify and counsel individuals at increased risk of developing cancer and distinguish between those that are at high or moderate risk and those at average risk. It utilizes a combination of pedigree analysis and genetic testing to identify hereditary cancer syndromes and explain specific cancer risks for individual patients. This information is then used to develop a management plan for cancer screening, prevention, and risk-reduction (Riley et. al 2012). These elements assist in helping patients understand complex genetic and risk information to make informed decisions about their healthcare while also addressing

psychosocial concerns that may arise. With the introduction of multi-gene panel testing, genetic counselors have had to shift the way they approach education about testing options for hereditary cancer. In the past, genetic counseling educational efforts focused on specific genes, like *BRCA1* and *BRCA2*, but current education has become broader when discussing multi-gene panels. It is difficult to educate patients about all the possible manifestations in the many genes that are being tested, so cancer genetic counselors have adopted a more general education focus regarding cancer genes and possible risk scenarios (Okur et. al. 2017).

Traditional individual sessions allow for genetic counselors to tailor information for the patient's specific risk and psychological needs (Rothwell et. al. 2012). Research has shown that long-term outcomes for patients participating in traditional HBOC cancer genetic counseling sessions include decrease in anxiety, improved accuracy of perceived risk, and overall satisfaction (Meiser et. al. 2001). However, this service delivery model has proven to be appreciably time intensive with most sessions requiring an average time of 46-60 minutes, and most genetic counselors reporting that they see 8-9 patients per week (Wham et. al 2010). Finally, patients typically have to wait an average of 1-3 weeks to get an individual, in-person cancer genetic counseling session upon referral (NSGC 2018). Advances in precision medicine allow surgeons and patients to make more informed surgery decisions based on germline genetic testing results, so reduced wait times for appointments are paramount. To keep up with genetic expertise demands and technological advances, effective service delivery models for genetic counseling need to be explored to find ways of optimizing patient consultation, education, and testing (Cohen et. al. 2016).

1.3.2 Alternative genetic counseling service delivery models

Many SDMs have been investigated in the field of genetic counseling. While use is relatively infrequent and typically not the sole method practiced, telephone genetic counseling, telegenetics, and group genetic counseling have shown promise in the field of genetic counseling (Buchanan et. al. 2016). Initial expected advantages of these alternative methods are convenience, decreased travel time, improved access to care, and reduced wait times. Disadvantages include logistical issues with billing and reimbursement, equipment set up, making arrangements for genetic testing, and the inability to see the patient. However, genetic counselors currently using SDMs reported that the convenience to the patient and genetic counselor outweighs the disadvantages to alternative SDMs used (Cohen et. al. 2016).

1.3.3 Telephone genetic counseling

Telephone genetic counseling is the second most frequent SDM being used with 59% of genetic counselors reporting that they utilize this model at least some of the time (NSGC 2018). Of this group, cancer genetic counseling was the most reported specialty practicing this SDM. A majority of genetic counselors who reported using telephone counseling also reported using another service delivery model in conjunction. Patients accessing telephone genetic counseling tend to live farther distances from clinics offering genetic counseling, with a majority reporting that they live over four hours away (Cohen et. al. 2013). In a randomized trial comparing telephone genetic counseling and in-person genetic counseling for *BRCA1* and *BRCA2*, the authors found similar high satisfaction with genetic counseling in each group (Peshkin et. al. 2016). Additionally, the telephone genetic counseling group found that the genetic counseling session was more convenient

for them compared to driving to the clinic. During telephone sessions, some of the patients experienced technological difficulties with the telephone. Surprisingly, this was not found to have an impact on satisfaction. However, those who received telephone genetic counseling perceived lower levels of support and emotional recognition than those who had in-person genetic counseling. They also were more likely to report that they had difficulty maintaining attention during their session. In similar studies, no difference in patients' knowledge, distress, decisional conflict, and cancer worry were seen between the telephone counseling and in-person genetic counseling groups (Platten et. al. 2012; Schwartz et. al. 2014). Cost savings have also been seen for patients and institutions using telephone genetic counseling over in-person cancer genetic counseling (Schwartz et. al. 2012). Overall, convenience for provider and patient, decreased cost, and similar satisfaction ratings are justifications for telephone genetic counseling, but challenges still persist with technological complications, deficits in perceived psychosocial support from genetic counselors, and difficulties in patient attentiveness with telephone genetic counseling when compared to an in-person SDM.

1.3.4 Telegenetics

Telegenetics, or providing genetic counseling via live videoconferencing, has also been studied and appears promising as an effective SDM in genetic counseling clinics. Around 18% of genetic counselors report using this model at times in their practice, but it is rarely the sole SDM used by a genetic counselor (NSGC 2018).

Typically, this SDM consists of an urban genetics clinic providing genetic counseling to a patient who has come to a different, often rural, healthcare facility closer to their home to have genetic counseling. Some disadvantages of this method from a provider point of

view include obtaining support staff at the remote side and having a physical space at both the host and remote location (Cohen et. al. 2016). However, this model has been shown to reduce costs and patients receiving this method of genetic counseling have reported similar satisfaction as those having in-person genetic counseling sessions (Buchanan et. al. 2015). In a study of cancer telegenetics use in a geographically remote setting of Maine, it was found that this model may also help increase access to cancer genetic counseling services in underserved areas (McDonald et. al. 2014). Unlike telephone genetic counseling, telegenetics has been shown to facilitate psychosocial assessment as well as in-person cancer genetic counseling (Zilliacus et. al. 2011). However, in a randomized trial of telegenetics versus in-person cancer genetic counseling, in-person genetic counseling patients were more likely to attend their appointments. They found that 32% of their study population reported that they would have preferred in-person genetic counseling (Buchanan et al. 2015). Similar to telephone genetic counseling, technology problems were a disadvantage to this SDM. In this study, 15% of the sessions experienced technical problems, and consequently, 7% had to be rescheduled (Buchanan et al. 2015). In summary, telegenetics may provide similar psychosocial and satisfaction benefits as in-person genetic counseling while reducing costs, but poor attendance and technological problems are disadvantages for this SDM.

1.3.5 Group genetic counseling

An encouraging SDM that may not have the disadvantages experienced in telephone genetic counseling or telegenetics is group genetic counseling. This method is currently the least used alternative, with only 7% of genetic counselors reporting that they utilize this SDM at least some of the time (NSGC 2018). Most of the genetic counselors

using group methods report utilizing this SDM less than 10% of the time in their practice and instead rely on other SDMs for a majority of their practice. Typically, in group genetic counseling, patients with similar or the same indications will have pretest genetic counseling together. This is sometimes followed by shorter individual discussions to address personal issues or specific family history (Buchanan et. al. 2016).

Many studies have corroborated that group genetic counseling has similar satisfaction ratings and knowledge scores compared to individual in-person genetic counseling (Benusiglio et. al. 2017; Buchanan et. al.2016; Cloutier et. al. 2017; Listol et. al. 2017; Otten et. al. 2015; Ridge et. al. 2009). In a study of group genetic counseling in HBOC patients, satisfaction was similar to those who had individual genetic counseling sessions and knowledge scores significantly increased between pre- and post-assessments in both group and individual genetic counseling sessions (Calzone et. al. 2005). Additionally, group genetic counseling has been found to have a similar attendance rate to traditional methods (Benusiglio et. al. 2017). This provides preliminary evidence that group genetic counseling does not inhibit the patient's ability to learn new information and may have better attendance than telegenetics.

Group genetic counseling also appears to confer similar psychosocial benefits as individual in-person genetic counseling. In a study looking at group genetic counseling in the prenatal setting for women with positive integrated prenatal screening or maternal serum screening for Down syndrome, the authors found that outcomes for decisional conflict were similar to that of patients who participated in traditional individual genetic counseling. However, they found that anxiety decreased more significantly in individual genetic counseling compared to group settings. The authors concluded that this may be

because individuals seen in the group setting did not have the opportunity to meet with a genetic counselors one-on-one in this particular study (Cloutier et. al. 2017). This could indicate that one-on-one genetic counseling following the group session is important for reducing patient anxiety.

The Impact of Event Scales (IES) measures intrusive thoughts, avoidance, denial, and blocking of thoughts related to a specific life event or stressor. In one study looking at group versus individual genetic counseling for those at high risk for harboring a BRCA pathogenic variant, they found that IES were similar in group sessions when compared to in-person genetic counseling (Calzone et. al. 2005). Another similar study found that depressive symptoms and anxiety were similarly decreased in group genetic counseling when compared to individual genetic counseling (Listol et. al. 2017; Otten et. al. 2015). Perceived personal control has also been found to be similar between individual and group genetic counseling methods (Rothwell et. al. 2012). This provides preliminary evidence that group genetic counseling does not increase patient distress and is meeting psychosocial needs similarly to individual genetic counseling.

Shared experiences between patients has been shown to be a unique benefit of group genetic counseling when individuals have the opportunity to discuss experiences and concerns within the group. In a study of group genetic counseling, researchers found that these opportunities helped women to feel supported in group genetic counseling sessions and promoted normalization (Ridge et. al. 2009). This may be a promising advantage to group genetic counseling compared to individual methods because an important part of the genetic counseling process is providing patient support.

Group genetic counseling has shown promise for increasing efficiency by decreasing per-patient time for genetics providers. Most genetic counselors report spending less than 30 minutes on individual components of the session, compared to 46-60 minutes for traditional genetic counseling methods (Buchanan et. al 2016; Cohen et. al 2013). Clinicians have reported being able to see more patients in a shorter amount of time which may help to increase access to genetics services. In a study assessing group genetic counseling in an underserved population in Texas, researchers found that group genetic counseling allowed increased access to cancer genetic services by allowing limited providers to spend less time per patient and consequently see more patients and reduce wait times (Woodson et. al. 2015). A majority of genetic counselors utilizing this SDM reported that they do not bill for their service; however, when genetic counselors did bill, they most commonly used the 96040 GC code, followed by consultation codes 99241-99245 or 99251-99255 and evaluation and management codes 99201-99205 or 99211-99215 (Cohen et. al. 2013).

While preliminary research has demonstrated some potential benefits of group genetic counseling, there are potential challenges with this SDM. In a study of group genetic counseling for HBOC, they found that group interactions were associated with tension or lack of comfort, especially when some individuals in the group met criteria for testing while others did not. Genetic counselors have found difficulty in accommodating specific individual needs, diffusing group conflict, and maintaining confidentiality while in group sessions (Ridge et. al. 2009). These findings suggest that group genetic counseling for some indications instead of similar indications may be more favorable in the cancer setting to help reduce undesirable group interactions. A single study found that

a group setting was associated with fewer individuals undergoing genetic testing compared to those in an individual setting (Rothwell et. al. 2012). This may be attributed to group influences on decision making but this discrepancy in test uptake has not been evaluated in other studies. Finally, questions remain about whether group genetic counseling would be widely accepted by cancer genetic counseling patients and providers. One study found that a high rate of patients initially declined group genetic counseling and reported a concern about privacy and decision making in a group setting (Ridge et. al. 2009).

1.4 Rationale

Although there are several publications analyzing group genetic counseling, many studies have been non-randomized and allow patients to choose their preferred method of genetic counseling (Buchanan et al 2016; Listol et al 2017; Otten et al 2015; Ridge et al 2009; Rothwell et. al 2012; Woodson et al 2015). Inherent bias may play into the patient responses within these studies. More studies need to address patient satisfaction and opinions in a randomized fashion to better understand patient's perceptions and acceptability of group genetic counseling. Additionally, most studies were conducted and evaluated based on genetic counselors disseminating education on *BRCA1* and *BRCA2* testing only. As panel testing continues to be prevalent in cancer genetic counseling, group genetic counseling needs to be reassessed as an acceptable SDM.

1.5 Purpose

As cancer predisposition genetic testing referrals increase, streamlined approaches to genetic counseling and education are needed to allow for better access to genetic services. Service delivery models such as group genetic counseling may help meet the

demand while maintaining quality of care. The purpose of this study was to assess the utility of group genetic counseling for HBOC by evaluating patient perspectives of group genetic counseling versus patient perspectives of individual genetic counseling. The aims of the study are as follows:

1. Determine patient satisfaction and comfort level with group genetic counseling.

This will be measured by questionnaires that assess cancer genetic counseling satisfaction, patient comfort and distress.

- a. *Hypothesis: Those participating in group genetic counseling will be as satisfied and comfortable as those participating in individual genetic counseling.*

2. Evaluate the time efficiency of group genetic counseling compared to individual genetic counseling which can impact access to genetic counseling services. This will be measured by comparing the amount of genetic counselor time spent per patient in each service delivery model.

- a. *Hypothesis: Group genetic counseling will reduce provider time per patient compared to individual genetic counseling.*

3. Determine if patients are receptive to participating in group genetic counseling sessions for HBOC. This will be assessed by investigating if participants receiving individual genetic counseling would be willing to participate in group genetic counseling sessions in the future.

- a. *Hypothesis: Participants receiving individual genetic counseling sessions will be hesitant to participate in group genetic counseling sessions.*

Overall, this study aims to provide insight into a service delivery model that may improve the efficiency of hereditary breast and ovarian cancer genetic counseling while maintaining the current high levels of patient satisfaction and comfort.

CHAPTER 2

IMPACT OF SERVICE DELIVERY MODEL ON PATIENT PERCEPTIONS AND UTILITY OF GENETIC COUNSELING FOR HEREDITARY BREAST AND OVARIAN CANCER: AN EXPLORATION OF GROUP GENETIC COUNSELING

2.1 Abstract

Patients at risk for hereditary breast and ovarian cancer (HBOC) traditionally participate in individual cancer genetic counseling sessions to be educated about cancer genetics concepts, their personal cancer risks and genetic testing. With expanding technology and increased public awareness of HBOC, referrals to cancer genetic counseling services have grown. The current number of practicing genetic counselors struggles to meet the demands of increased referrals, so new service delivery models need to be explored. The purpose of this study is to assess the utility of group genetic counseling for HBOC by evaluating the perspectives of patients that received group genetic counseling versus perspectives of those that received individual genetic counseling. We aimed to determine patient satisfaction and comfort level while also assessing the time efficiency and patient receptiveness to group sessions. Sixty-eight individuals with a new diagnosis of breast cancer participated, were randomly assigned to group genetic counseling (n=30) or individual genetic counseling (n=38) and gave perspectives on their genetic counseling session. Results demonstrate that each study cohort reported high satisfaction with their genetic counseling session. Participants in the group genetic counseling cohort were less likely to be overwhelmed by information given in their appointments ($p=0.01$). Comfort levels were similar between the two study groups and a majority of participants reported high comfort levels after their appointment. A majority of participants in the individual genetic counseling stated that they would not be willing to participate in group genetic counseling had they been given the choice and cited privacy and comfortability as the main reasoning. Additionally, our study found that group genetic counseling led to a significant savings in genetic

counselor time ($p=0.0008$). This study demonstrates that group genetic counseling shows promise by reducing the genetic counselor time per patient, which allows for the ability to see more patients, while providing similar satisfaction and benefits to patients as individual genetic counseling models.

2.2 Introduction

In 2017, there were approximately 255,180 new cases of breast cancer in the United States. While most of these cancers are sporadic, 5-10% of breast cancer has a hereditary component (ACS 2017). The National Comprehensive Cancer Network (NCCN) guidelines outline which patients should be evaluated for Hereditary Breast and Ovarian Cancer (HBOC) syndromes. Detection of these cancer predisposition syndromes can change patient management through the option of a risk-reducing surgery, increased surveillance, and possible targeted therapy options. In addition, identification of a hereditary cancer syndrome will impact at-risk family members. The most common genes implicated in HBOC are *BRCA1* and *BRCA2*. In the past, genetic testing for HBOC has focused on sequencing of *BRCA1* and *BRCA2* genes, however, as research has evolved, it has become clear that there are many more genes that cause HBOC (Okur et. al. 2017). The genetics community has continued to research and learn more about these other cancer susceptibility genes, such as *CHEK2*, *ATM* and *PALB2* (Wang et. al., 2018) and NCCN management guidelines for individuals with these pathogenic variants are now available.

With the advent of next-generation sequencing (NGS) technology, the clinical approach to genetic testing in oncology has shifted. An increasing number of providers

are moving toward utilizing multi-gene panels (Crawford et. al. 2017), which allows clinicians to analyze for many HBOC predisposition genes simultaneously. This evolution toward panel testing has resulted in the improved identification of pathogenic variant carriers, as well as challenged the understanding of the expression of these gene pathogenic variants. NGS testing methodology has also improved the detection rate of pathogenic variants in *BRCA1* and *BRCA2*.

With more individuals being tested for cancer predisposition genes, there has been an increased public awareness of cancer genetics and risk. In May 2013, actress Angelina Jolie wrote an op-ed sharing her experience undergoing genetic testing and finding she had a pathogenic variant in the *BRCA1* gene. She openly shared her decision-making process that led to a risk-reducing double mastectomy and oophorectomy (Jolie 2013). Studies have found that genetic counseling referrals and the number of *BRCA1* and *BRCA2* tests ordered have increased since this widely publicized story (Evans et. al 2014; Guo et. al. 2017). As demand for services has evolved, precision medicine efforts have also turned toward the use of targeted therapies both for individuals who have tumor pathogenic variants and those with germline pathogenic variants. These therapies have offered dramatic therapeutic improvements in the treatment of cancer. For example, oncologists now use a class of drugs called PARP inhibitors to treat ovarian cancers and metastatic HER2-negative breast cancers in individuals with *BRCA1* or *BRCA2* pathogenic variants (Konecny et al. 2016; Dancey et al. 2012).

Together, the advent of new technologies, increased public awareness of *BRCA1* and *BRCA2* and personalized medicine efforts have resulted in an increase in referrals for genetic counseling for hereditary cancer risk assessment and a need for more genetic

counselors (Buchanan et. al. 2016). With the current number of practicing genetic counselors, there are struggles to meet the demands for genetic counseling referrals. It has been predicted that with the increased demand for genetic counseling, the supply of genetic counselors will not meet needs until 2024-2030 (Hoskovec et. al. 2018). This underscores the need to evaluate the effectiveness of current delivery service models and consider other service delivery models (SDM) that can be implemented into the cancer genetics clinic in order to increase access.

The current standard of care for cancer genetic counseling has followed the traditional service delivery model which involves one-on-one in-person initial sessions with follow up and results disclosure occurring by telephone or other means (Cohen et. al. 2013). The essential elements of cancer genetic counseling sessions include: intake of personal and family medical history, cancer risk assessment and education, pretest counseling, informed consent for genetic tests and psychosocial assessment (Riley et. al. 2012). It utilizes a combination of pedigree analysis and genetic testing to identify hereditary cancer syndromes and explain specific cancer risks for individual patients. This information is then used to develop a management plan for cancer screening, prevention and risk-reduction (Riley et. al 2012). These elements assist in helping patients understand complex genetic and risk information to make informed decisions about their healthcare while also addressing psychosocial concerns that may arise. However, since the increase in panel testing, genetic counselors have had to shift the way they approach education about cancer and testing options. In the past, genetic counseling has focused on specific genes, like *BRCA1* and *BRCA2*, but current education has become broader when discussing multi-gene panels.

Research has shown that long-term outcomes for patients participating in individual HBOC cancer genetic counseling include decrease in anxiety, improvements in perceived risk, and overall satisfaction (Meiser et. al. 2001). However, this service delivery model has proven to be appreciably time intensive and results in increased patient wait times. To keep up with genetic expertise demands and technological advances, effective alternative genetic service delivery models need to be explored to find ways of optimizing patient consultation, education and testing (Cohen et. al. 2016).

An encouraging new SDM is group genetic counseling. Typically, in group genetic counseling, patients with similar or the same indications will have pretest genetic counseling together. This is sometimes followed by shorter individual discussions to address personal issues or specific family history (Buchanan et. al. 2016).

Many studies have corroborated that group genetic counseling has similar satisfaction ratings and knowledge scores compared to individual genetic counseling. Group genetic counseling has also been found to have similar attendance rates compared to traditional methods (Benusiglio et. al. 2017). This provides preliminary evidence that group genetic counseling does not inhibit the patient's ability to learn new information and may have better attendance than some of the other alternative SDMs utilized (e.g. telephone genetic counseling and telegenetics).

Group genetic counseling appears to confer similar psychosocial benefits when compared to individual genetic counseling. Several studies have shown that this SDM does not increase patient distress or decrease patient comfort (Calzone et. al. 2005; Listol et. al. 2017; Otten et. al. 2015). Shared experiences between patients has been shown to be a benefit of group genetic counseling when individuals have the opportunity to discuss

experiences and concerns with a group. This may be a promising advantage to group genetic counseling compared to individual methods because an important part of the genetic counseling process is providing patient support.

Additionally, this SDM has also shown promise for increasing efficiency by decreasing per-patient time for genetics providers. In many studies, clinicians have reported being able to see more patients in a shorter amount of time, helping increase access to cancer genetic services in their clinics.

While preliminary research has demonstrated some potential benefits of group counseling, there are potential challenges with this SDM. Group interactions may cause tension, especially when some individuals in the group met criteria for testing while others did not. Genetic counselors have found difficulty in accommodating specific individual needs, diffusing group conflict, and maintaining confidentiality while in group sessions (Ridge et. al. 2009). These findings may indicate that group genetic counseling for some indications instead of similar indications may be more favorable in the cancer setting to help reduce undesirable group interactions. Some studies have also found decreased test uptake with group genetic counseling sessions. Finally, questions remain about whether group counseling would be widely accepted by cancer genetic counseling patients.

Most studies of group genetic counseling have been non-randomized and allow for patients to choose their preferred method of genetic counseling. Inherent bias may play into the patient responses within these studies. Our study aims to address patient satisfaction and opinions in a randomized fashion to better understand patient's perceptions and acceptability of group genetic counseling. Also, a majority of studies

were conducted and evaluated based on genetic counselors disseminating education on *BRCA1* and *BRCA2* testing only. As panel testing continues to be prevalent in cancer genetic counseling, group genetic counseling needs to be reassessed as an acceptable SDM. Our methods include evaluating group genetic counseling with the inclusion of panel genetic testing education.

The purpose of this study is to determine patient satisfaction and comfort level with group genetic counseling. We aim to evaluate the time efficiency of group genetic counseling compared to individual genetic counseling, as well as test uptake between the two groups. Additionally, we want to assess if patients would be willing to participate in group genetic counseling if given the option. We predict that group genetic counseling will have high satisfaction levels and will improve efficiency. We also believe that patients will be willing to participate in group genetic counseling if given the choice.

2.3 Materials and Methods

2.3.1 Participants

Eligible participants were newly diagnosed breast cancer patients who met NCCN criteria for HBOC genetic risk evaluation and were referred to Palmetto Health USC Medical Group for hereditary cancer genetic counseling. Only English-speaking participants were included in the study due to limited resources available for interpretation from English to other languages. Participants were enrolled from August 2018 to February 2019.

2.3.2 Procedure

Palmetto Health USC Medical Group Cancer Genetic Counseling clinic implemented group genetic counseling sessions into their practice beginning in August 2018 to find new methods for reducing provider time per patient. Patients referred for the indication of

newly diagnosed breast cancer were scheduled in a group genetic counseling session that occurred once a week. A maximum of four patients were scheduled for one group genetic counseling session. The remaining referrals in that week were assigned to individual genetic counseling sessions. If there were not at least two patient referrals during any given week, a group genetic counseling session was not held. If time permitted, family medical history was taken over the phone prior to the session by a USC genetic counselor or genetic counseling assistant. Those who did not have their family history taken over the phone prior to their session had family history intake during their sessions. For the group genetic counseling cohort, this meant that the family history was taken during the individual portion following the group genetic counseling session. For participants with family history taken over the phone prior to their session, the provider assessed if the patient's family history was indicative of cancer a non-HBOC syndrome, or if there was a known pathogenic variant carriers in the family. If either of these situations were encountered, the patient was re-assigned to an individual cancer genetic counseling to maintain group uniformity.

For the group genetic counseling sessions, genetics education was given by one of the three board-certified cancer genetic counselors at USC. This education piece operates much like a typical individual genetic counseling session where hereditary cancer genes, inheritance, management guidelines, test options, and possible test results are described. The genetic counselor used similar visual aids to those used in individual genetic counseling sessions to explain concepts to the group, and patients were given the opportunity to ask questions about the material throughout. Following the group session, each patient was seen individually by one of the three USC cancer genetic counselors to

either take the pedigree (if needed) or review any pertinent family history, provide personalized risk assessment, and address any personal questions and psychosocial concerns in private. During this part, decisions were made about genetic testing, and the consent form was signed. A physician then met briefly with the patient as part of the billing and check out process, which is also standard in our individual genetic counseling sessions.

Following a completed genetic counseling session, whether provided in a group setting or individual setting, patients were invited to participate in the study. Interested participants were asked to read the recruitment letter (Appendix A). Those who agreed to participate completed the post-genetic counseling questionnaire pertinent to the method of genetic counseling they received – either group or individual genetic counseling. Participants that completed the survey could enter their name into a raffle for a gift card. Personal information was maintained separate from the questionnaire.

The genetic counselor conducting the session recorded the number of minutes spent in each session, including the one-on-one portion and the group portion of the group genetic counseling sessions. We calculated overall counselor time spent per patient for both the individual and group genetic counseling cohorts. Due to changes in the pre-appointment process during the study period, we separated the participants who had their family history taken over the phone before the session by a genetic counseling assistant and the participants who had their family history taken in person during their sessions. Our analysis primarily focused on data from participants who had their family history taken during the session. Overall time was calculated by taking the sum of time spent with patients and dividing it by the number of patients seen. Counselor time per patient

for also calculated for those who had their family history taken over the phone prior to their genetic counseling session.

2.3.3 Instrument

One questionnaire was developed for each type of session - individual and group genetic counseling (Appendix B and Appendix C). We measured patient satisfaction in both questionnaires using an adaption of a widely validated cancer genetic counseling satisfaction measure (DeMarco et. al. 2004). This measure included a Likert-scale from one (strongly disagree) to five (strongly agree). The original measure published by DeMarco et. al. has six items, however we added a seventh and eighth item: “I felt that the information was overwhelming” and “I feel like I understood the information presented during my appointment”. This addition was used to assess patient perceptions of feeling overwhelmed and their assessment of their own comprehension of the information in their counseling session. The scale had a low level of internal consistency, as determined by a Cronbach’s alpha of 0.508. As a result, each item on the measure was analyzed individually instead of as a combined satisfaction score. Participants were also asked in both arms to rank their overall satisfaction on a scale of one (least satisfied) to five (most satisfied). Both questionnaires concluded with questions to gather demographic information (e.g. age, race, education level) and an open response question to leave any comments, suggestions, or concerns.

Both study cohorts’ questionnaire had a comfort and anxiety measure that shared 4 items. Each item used a Likert-scale from one (strongly disagree) to five (strongly agree). The measure had a low level of internal consistency, as determined by a Cronbach’s alpha of 0.138. As a result, each item on the measure was analyzed

individually instead of as a combined score. The group genetic counseling questionnaire also had an additional 5-item measure assessing comfort and necessity for the individual portion of their genetic counseling experience using the same Likert-scale. Spaces for open response about experiences in both the group and individual portion of the group genetic counseling session was included after each measure. The individual genetic counseling questionnaire also had a unique item that assessed if patients would be willing to receive their genetic counseling in a group setting using a scale from 1 (not willing) to 5 (most willing). An open response question assessing reasoning for this response was listed below to gain more insight into patient opinions and ideas.

2.3.4 Statistical analysis

Both quantitative and qualitative data were captured in survey responses. Reliability analysis using Cronbach's alpha was conducted on the satisfaction and comfortability/anxiety measures. Descriptive statistics were conducted for all variables within each study group. Chi-squared tests were used to determine significant demographic differences between each group. In situations where only two variables existed, Fisher's exact test was used to determine significant differences. Independent sample t-tests were conducted to analyze the questionnaire items and compare the two study group means. ANOVA analysis was then conducted for statistically significant items identified from our independent sample t-test to determine effect size. ANOVA analysis was also used to determine differences in responses to items based on demographics of the participants. SPSS software was used for data analysis and a p-value of 0.05 was used to indicate statistical significance. Due to lack of responses in the open-

ended questions, the principal investigator and co-authors descriptively summarized the qualitative data instead of coding the data.

2.4 Results

2.4.1 Demographic information

A total of 68 individuals participated in our study; 38 individuals who had individual genetic counseling (56%) and 30 who had group genetic counseling (44%). Demographic characteristics of the participants are summarized in Table 2.1. The sample population consisted of mostly Caucasian (60.3%; n = 41), Non-Hispanic (85.3%, n=58) individuals. All participants were female with a mean age of 54 years old. A majority reported having at least a bachelor's degree (51.5%, n=35). Of the 50 individuals (74%) whom responded to the demographic question regarding income, most reported an income of \$25,000-\$50,000 (25%, n=17). A majority of participants reported having private or employer based health insurance (61.8%, n=42), being married (61.8%, n=42), and having a family history of cancer (80.9%, n=55). Most individuals did not bring anyone with them to their appointment (55.8%, n=40); however, of the 28 that did, it was most often a significant other (46.4%, n=13). Demographic characteristics of the participants in each study group (group and individual genetic counseling) is also summarized in Table 2.1. No statistically significant difference in demographics was appreciated between the individuals participating in group versus individual genetic counseling. For the group genetic counseling cohort, the average group size was 2.5 patients (range 2-4 patients).

2.4.2 Satisfaction

Participants in both study groups were asked to complete a measure that used an eight-item Likert-scale measure (1 = strongly disagree; 5 = strongly agree) to assess satisfaction, overwhelming feelings and perceived clarity of the information covered in their session. A summary of the means for each item per study group is listed in Figure 2.1. For the individual genetic counseling study group, the participants most strongly agreed with the items “The genetic counseling (GC) appointment was valuable to me” and “My genetic counselor helped me to identify what I needed to know to make decisions about what would happen” (M=4.89, 4.87 respectively). For the group genetic counseling study group, the participants most strongly agreed with the items “The genetic counseling appointment was the right length of time I needed”, “The GC appointment was valuable to me”, and “I feel like I understood the information presented during my appointment” (M=4.97, 4.93 and 4.93 respectively) Overall, both study groups ranked most items as 4 or greater which correlates with “agree somewhat” or “strongly agree”; however, the group genetic counseling study group reported slightly higher ratings on most items compared to those participating in individual genetic counseling sessions although there was no statistically significant difference. For both study groups, most participants disagreed with the item “I felt that the information was overwhelming” with the individual genetic counseling group cohort rating an average of 2.74 and the group genetic counseling cohort rating an average of 1.77. Independent samples t-tests and ANOVA was run to determine if there were significant differences in the responses between the two study cohorts and the effect size. This showed statistical significance that those in group genetic counseling reported feeling less overwhelmed from the

information given compared to those in individual genetic counseling sessions (p-value = 0.01, $\eta^2 = 0.31$).

Those in group genetic counseling rated the item “The GC appointment was the right length of time I needed” higher than those participating in individual genetic counseling with analysis approaching statistical significance (p-value = 0.057; $\eta^2 = 0.23$). Overall, the remaining items on this measure were comparable between the two study groups and no significant differences were appreciated (Table 2.1) as both groups reported high levels of satisfaction and value in their genetic counseling experience and low levels of feeling overwhelmed. ANOVA analysis was used to determine if there were differences in overall satisfaction and feelings of being overwhelmed based on demographic information provided. Analysis demonstrated that those who reported being a widow were less satisfied overall with their genetic counseling appointments (p-value = 0.04; $\eta^2 = 0.44$) and those who were single or divorced were more overwhelmed by the information given during their genetic counseling sessions (p-value = 0.02; $\eta^2 = 0.47$) in both the group and individual genetic counseling cohorts. No other differences in satisfaction and feelings of being overwhelmed were significantly associated with demographic variables.

Overall satisfaction with the genetic counseling appointment is summarized in Figure 2.2 and demonstrates no statistical significant difference between the two study groups, with both reporting high overall satisfaction.

2.4.3 Comfort and anxiety level for group genetic counseling sessions

Participants in the group genetic counseling sessions were asked about their comfort level and anxiety associated with the group portion of their genetic counseling

using a Likert-scale from 1 (“strongly disagree”) to 5 (“strongly agree”). A summary of the mean responses to the items is listed in Figure 2.3. A majority of participants reported that the group genetic counseling sessions reduced anxiety about genetic testing (M=4.33), allowed them to learn enough to make informed decisions about testing (M=4.8) and allowed them to learn from others (M=4.8). Additionally, a majority of respondents denied that group genetic counseling sessions were uncomfortable (M=1.57) or kept them from asking questions they wanted to ask (M=1.5).

2.4.4 Comfort and anxiety level for individual genetic counseling components

Both study groups were asked about their comfort and anxiety associated with the individual portion of their genetic counseling experience through Likert-scale measures (1=strongly disagree; 5=strongly agree) created by the authors. Both study cohorts’ questionnaire shared 4 items; however, the group genetic counseling survey had an additional item to assess the necessity of the individual genetic counseling component for group genetic counseling sessions. A summary of the responses to this survey are seen in Figure 2.4 and demonstrates that overall participants in both the individual and group genetic counseling study cohorts reported that their anxiety about genetic testing decreased ($p=0.958$), they learned enough to make informed decisions about genetic testing ($p=0.272$) and they had enough time to ask personal questions in their genetic counseling experience ($p=0.522$). Additionally, both study cohorts reported similar low levels of feeling uncomfortable with their individual genetic counseling experience (Figure 2.4). A majority of the group genetic counseling cohort reported that the individual portion of their genetic counseling sessions was necessary after the group

genetic counseling portion (M=1.17). There was no significant difference in the responses between study groups.

The majority of participants receiving only individual genetic counseling (87%, n=33) reported that they would not be willing to participate in group genetic counseling. A summary of their response rate can be seen in Figure 2.5.

2.4.5 Qualitative results

The questionnaire for both study groups included free response questions to gather qualitative data among participants. The individual genetic counseling cohort questionnaire included two free response items that allowed the participants to elaborate on their previous responses.

The majority of the individual genetic counseling cohort stated they would not be willing to have group genetic counseling (n=33; 87%). The most cited explanation for not wanting to participate in group genetic counseling was concerns for privacy. Respondents were concerned about sharing personal or family health information in a group and preferred to have privacy when discussing this information. Other respondents were concerned that group genetic counseling would not allow them to ask individualized questions. Of the participants who stated that they would be willing to participate in group genetic counseling, none responded to the free-response item to elaborate more on their preferences. Overall comments among the individual genetic counseling cohort overwhelmingly stated that their appointment was informative and helpful.

The group genetic counseling cohort questionnaire included three free response items that allowed the participants to elaborate on their responses given in the quantitative measures. The first free response item probed into the participant's

satisfaction ratings and had a response rate of 36.7% (n=11). A majority of participants that answered this item described satisfaction with the specific genetic counselor they saw during their session. Participants cited that the group genetic counseling sessions were informative and easy to understand. Other comments related to the welcoming nature of the group and highlighted that individuals in the group asked questions that helped participants learn more information. One participant stated that she had a difficult time processing personal information in a group setting by stating “It was hard to process information so personal in a group of strangers.”

The second free response item explored the participant’s comfort and anxiety level ratings for their one-on-one time with a genetic counselor. Like the previous question, many participants referenced their satisfaction with their specific genetic counselor. All responses were positive and cited that the one-on-one time was informative, helpful and valuable. A final open-ended question about the overall appointment found that the session helped with participant stress levels and was a positive experience.

2.4.6 Time efficiency

A summary of the data can be seen in Figure 2.6 and demonstrates that the average counselor time spent by the genetic counselor per patient was 35.8 minutes in the group genetic counseling sessions and 52.4 minutes in the individual genetic counseling sessions (p=0.0008). For the subset of patients that had their family history taken over the phone prior to their genetic counseling session (n=21), the average counselor time spent by the genetic counselor per patient was 32.7 minutes for group genetic counseling and 55 minutes for individual genetic counseling sessions (p=0.003).

The average times of the group and individual portions for the group genetic counseling sessions was calculated. For the subset of the group genetic counseling cohort that had their family history taken during the sessions, the group portion of their sessions were an average of 23.3 minutes and the individual portion of their session was an average of 24.2 minutes. For the subset of the group genetic counseling cohort that had their family history taken before the sessions, the group portion of their sessions was an average of 24.2 minutes and the individual portion of their session was an average of 18.7 minutes. There was no statistical difference in the group portion time or the individual time between the two subset cohorts. This data is depicted in Figure 2.7.

2.4.7 Test uptake

For the 68 participants, test uptake was recorded to determine if there was a difference in genetic testing uptake between study groups. Each of the 68 participants elected to pursue genetic testing to give a test uptake percentage of 100% in both study groups.

2.5 Discussion

Advances in genetic testing technology and increased public awareness of HBOC has led to an increase in cancer genetic counseling referrals (Guo et. al 2017). The current number of practicing genetic counselors cannot currently meet these demands so practitioners are trying to increase efficiency within their genetic counseling clinics, in some cases by implementing new service delivery models (Hoskovec et. al 2018). Before additional service delivery models can be used clinically, the genetics community needs to ensure that models result in equivalent levels of patient care. Group genetic counseling is a service delivery model that been studied to understand its benefits and limitations

compared to individual genetic counseling. Many group genetic counseling studies in the literature allow patients to self-select their service delivery model and include a mix of patients with a variety of indications relating to HBOC, such as personal history of breast cancer, family history of breast cancer or familial mutations in HBOC genes (Benusiglio et. al 2017; Calzone et. al 2005; Ridge et. al 2009; Rothwell et al. 2012; Woodson et. al 2015). Our study placed participants into group and individual genetic counseling cohorts and focused solely on those with a diagnosis of breast cancer meeting national criteria for evaluation for HBOC. We aimed to determine the utility of group genetic counseling for this specific group of individuals by assessing patient satisfaction and comfort, efficiency of the service delivery model, testing uptake and receptiveness to the group model. Overall, we found that individuals participating in group genetic counseling had similar reported satisfaction, comfort and anxiety levels compared to those in individual genetic counseling. Those in group genetic counseling also reported being less overwhelmed by the information given during their sessions compared to individual genetic counseling participants. However, we also found that most participants in individual genetic counseling were not receptive to the idea of group genetic counseling.

2.5.1 Patient satisfaction

It was hypothesized that participants in both cohorts would rate high levels of satisfaction. In the literature, studies comparing group and individual genetic counseling cohorts have reported high overall satisfaction in group genetic counseling with no statistical differences in satisfaction from those receiving individual genetic counseling (Ridge et. al. 2008; Rothwell et. al. 2011). Our results mirrored past research by showing that both group and individual genetic counseling cohorts were satisfied with their

appointments with no statistical differences. This reinforces conclusions made in previous studies that those participating in group genetic counseling are generally highly satisfied with their appointments.

Comprehension and psychosocial support are two important aspects of the traditional individual cancer genetic counseling process and play an important role in the satisfaction of patients receiving cancer genetic counseling (Riley et al. 2012). In our study, both cohorts reported high levels of perceived comprehension of the material covered in their genetic counseling sessions. Other studies have shown that knowledge gained during group genetic counseling was similar to that of individual genetic counseling (Ridge et al. 2009; Rothwell et al 2012). While we did not examine knowledge scores, our data further suggests that group genetic counseling confers the same perceived levels of comprehension as individual genetic counseling. Patients also felt heard and understood by their genetic counselor in both cohorts, indicating that group genetic counseling may provide similar levels of psychosocial support. Both of these essential genetic counseling elements were not negatively affected by group genetic counseling, and we believe that high levels of perceived comprehension and support in our cohorts likely played in role in the high satisfaction ratings between the two groups.

2.5.2 Patient comfort and anxiety

Some studies have found no statistically significant difference in stated comfort and anxiety for patients involved in group vs. individual genetic counseling, with most reporting low levels of anxiety and high comfort following both types of sessions (Rothwell et. al, 2011; Calzone et. al 2005). However, one study reported greater reduction in anxiety in individual genetic counseling sessions compared to group genetic

counseling sessions (Cloutier et. al. 2017). It should be noted that this contradicting study was conducted in a prenatal setting, which may not be comparable to study population in the cancer setting. The prenatal setting may involve parents or individuals that are making time sensitive, life-altering decisions which could have an effect on feeling anxious in a group setting. In our cohort specifically, decisions would not have the same gravity and did not have the same time sensitivity issues. Our results showed that both the individual and group genetic counseling cohorts reported high comfort levels and low anxiety levels post-genetic counseling with no statistically significant differences between the two cohorts. Our study supports the previous research that found that group genetic counseling is comfortable and does not increase anxiety for most patients in the cancer setting.

2.5.3 Group dynamic considerations: benefits

Those in the group genetic counseling cohort were less likely to report being overwhelmed by the information given during their genetic counseling session. We hypothesize that this difference can be partially attributed to the benefit of positive group dynamics. A similar study investigating group genetic counseling for those meeting genetic testing criteria for HBOC found that group settings offered empowerment to the patients because they were surrounded by individuals going through similar experiences (Benusiglio et. al. 2016). Research has also shown that individuals with breast cancer can benefit from being in support groups that allow interaction with peers going through a diagnosis (Taleghani et. al 2012). While group genetic counseling does not function as a support group, individuals may feel a similar sense of community and benefit from shared experiences. This may consequently lead to feeling less overwhelmed by

information given in their genetic counseling sessions as they are surrounded by those encountering the same circumstances.

Most participants in the group genetic counseling did not report feeling inhibited in their ability to ask questions. This is consistent with research on group intervention for breast cancer patients, which shows that patients are comfortable exploring their experiences and concerns in a group setting (Spiegel et al. 2003). In fact, similar to other studies, our study found that patients appreciated learning from others when hearing answers to questions they may have not thought to ask (Benusiglio et al. 2016).. This may be a benefit to group genetic counseling over traditional individual genetic counseling in that it provides the opportunity for the patient to learn more information through the lens of different patient perspectives and concerns.

2.5.4 Group dynamic considerations: concerns

Some studies have encountered negative group dynamics in group genetic counseling sessions, such as group conflict, that could have an impact on patients' experiences with this service delivery model (Ridge et al. 2008; Rothwell et al. 2011). These conflicts centered around some individuals meeting criteria for testing and other group members not, autonomous decision-making about genetic testing uptake and difficulties accommodating individual needs. We did not experience similar conflicts in our group genetic counseling sessions, perhaps because of the uniformity in the group indications and time allocated to an individual genetic counseling sessions after the main group education sessions.

All patients in our group genetic counseling sessions were new diagnoses of breast cancer and all met criteria for genetic testing. Perhaps because of this, we did not

encounter group conflict involving some participants meeting criteria and some not. In studies of group therapy, it has been shown that conflict is reduced in groups composed of individuals with similar circumstance due to cohesiveness and built trust which may also translate to the genetic counseling clinic as well (Ridge et. al. 2008).

Finally, most of our group genetic counseling cohort reported that the individual genetic counseling time was necessary after the group session and allowed them enough time to ask their personal questions. It is possible that the opportunity for conflict due to individual concerns that has been reported in past studies was reduced because patients knew they would have time to address their personal concerns during the individual session. This follow up individual time appears to be necessary and beneficial to patient satisfaction. These findings may point to helpful factors to consider when designing a group genetic counseling SDM.

2.5.5 Efficiency of group genetic counseling

This study was also focused on determining if group genetic counseling increases efficiency in the cancer genetic counseling clinic. We hypothesized that incorporating group genetic counseling into our care would help to reduce genetic counselor time per patient. We found that genetic counselor time per patient in the group genetic counseling cohort was significantly less. This could increase efficiency in our clinic because genetic counselors could see more patients in the same amount of time they would typically only see one patient. Our results mirror findings in previous studies examining efficiency of group genetic counseling in the cancer setting (Calzone et al 2005; Cloutier et. al 2017; Ridge et. al 2008).

During a portion of our data collection, we had genetic counseling assistants that took family history on the phone before group and individual genetic counseling sessions. Not surprisingly, this saved time. The decrease in overall genetic counselor time per patient seen in the group genetic counseling cohort when family history was taken prior to the session was less than expected, but overall there was a time savings benefit of taking family history prior to genetic counseling sessions. Even though it was not statistically significant, perhaps due to low numbers in each group, it still highlights a benefit of having a genetic counseling assistants in clinics to provide increased efficiency advantages with the group genetic counseling service delivery model (Pirzadeh-Miller et al. 2016). Use of genetic counseling assistants and technologies such as electronic pedigree collection via on-line HIPPA-compliant portals should be further studied to determine their impact on efficiency and patient satisfaction.

Previous research studies reported difficulties in coordination of group genetic counseling due to issues with the logistics of scheduling group sessions (Calzone et. al. 2005; Ridge et. al 2008). In our program, we only had one available date and time for group genetic counseling sessions. While this did not result in coordination problems during our study, this may be a limitation to filling up group genetic counseling sessions in clinics where there is only one available day and time for group genetic counseling. Adding multiple group sessions per week would give more options to patients when scheduling.

A study of group genetic counseling for HBOC hypothesized that logistical issues for scheduling group appointments would increase with attempts to homogenize group participants (Ridge et. al 2008). Stratifying our group genetic counseling cohort to

include just those with a new diagnosis of breast cancer meant there were less patients available to fill the group sessions which could affect the efficiency benefits of group genetic counseling overall. Although scheduling a larger group would maximize the impact of time savings, we believe the benefits in homogenizing the group to provide more specific education and promote positive group dynamics, outweigh the downside of having a smaller average group size.

2.5.6 Patient receptiveness to group genetic counseling

Studies in the literature have shown that, when given the choice, patients receiving cancer genetic counseling prefer to have individual genetic counseling over group genetic counseling (Ridge et al 2008; Rothwell et. al 2011). In this study, we also found overwhelmingly that given a choice, most would not have been willing to have a group genetic counseling session. Similar to main themes cited in other studies, most of our participants cited privacy concerns and worries about discussing personal information in a group setting as their main reasons for not being receptive to group genetic counseling (Ridge et al 2008). However, as discussed earlier, those participating in group genetic counseling via random assignment reported similar satisfaction and comfort levels as those in individual genetic counseling. During our data collection, no individuals assigned to group genetic counseling declined during the scheduling process once they were informed of the nature of the appointment. Individuals scheduling the genetic counseling appointments offered a brief explanation of the group genetic counseling process to patients during the scheduling process. They explained that the group portion of their session would be mainly education and that they would also have individual time with a genetic counselor to address specific concerns and testing

decisions. This may have helped ease the worries of those hesitant about group genetic counseling and served to set expectations. Also, since group genetic counseling was the only option offered, individuals may have not thought about it or had any worries going into their session. It appears that when group genetic counseling is presented as the norm and explained while scheduling the appointment, patients are receptive to this service delivery model. This is reinforced by a study that asked participants their preferred service delivery model post-genetic counseling and found that most participants preferred the model they were randomly assigned (Calzone et. al 2005). The idea of random assignment or presenting group counseling as the norm is important to consider when designing a group genetic counseling SDM.

It should be noted that in the group genetic counseling cohort, we did have one patient who reported being uncomfortable with their group genetic counseling session; however, she did not state specific reasons why. It is no surprise that this service delivery model may not be best suited to every individual, as with any service delivery model; but, our data shows that a majority of patients had positive experiences with group genetic counseling.

2.5.7 Testing uptake in group genetic counseling

A study looking at group genetic counseling for HBOC have reported differences in test uptake between group and individual genetic counseling and cite concerns about group influence on decision making (Rothwell et al 2011). The Rothwell et al study investigated individuals with a personal and/or family history that met NCCN testing guidelines and indicated an a priori risk of a BRCA1/2 mutation above 25%. Furthermore, their group genetic counseling cohort had more unaffected individuals (35.7%) than their individual

genetic counseling cohort (16.1%). Both of these factors could explain the difference in test uptake. Unaffected individuals may have other factors that weigh into their decision to pursue testing that those affected do not experience, such as not being the best person to test in a family or concerns about life insurance. In our study, we found no difference in testing uptake between the two study cohorts. Since all of our patients were affected with cancer, they may have been more motivated to pursue testing for treatment decisions. It can be argued that, with this indication especially, many patients come into sessions with plans to undergo genetic testing. Also, our patients also were not asked to discuss their testing choices in the group setting, and they reflected positively on the individual meetings following group genetic counseling sessions. Obviously, eliminating group influence cannot be guaranteed with this model, but individual time with a genetic counselor can help patients to explore their views separate of the group to come to an autonomous decision.

2.6 Limitations and future research

2.6.1 Limitations

Our study population was primarily composed of highly educated Caucasian women with a new diagnosis of breast cancer. Due to this uniformity in participant demographics, our findings may not stratify to other populations. Different sexes, races and education levels may have different comfort levels, satisfaction and receptiveness to group genetic counseling, especially when seen together in a group. Also, our sample size was relatively small. Differences in time efficiency and patient perspectives may be better seen in a larger sample. We also assessed patient perceptions of their genetic

counseling session immediately after, while they were still in our clinic. This may not accurately depict patient perspectives in the long term.

Our cohorts were exclusively made up of those with a personal, recent diagnosis of breast cancer. With this homogenous group, we cannot predict that these results would be seen in a study cohort with mixed indications for cancer genetic counseling.

Individuals with different indications may have different responses. For example, unaffected populations may need more time for discussions on decision making than those in an affected population who meet criteria.

Some of the time efficiency data was derived from a subset of individuals that had their family history taken over the phone prior to genetic counseling sessions by genetic counseling assistants. We did try to account for this and still found that group genetic counseling is more time efficient than individual genetic counseling, even when family history is taken during the session. However, we realize that some of the data given in our results is not applicable to clinics who do not have access to genetic counseling assistants or electronic pedigree collection prior to genetic counseling sessions.

Finally, our group sizes were relatively small. Although groups could be as large as 4, they were not all filled. This was mainly due to the number of patients with a new diagnosis of breast cancer referred, which varied by week. Another limiting factor was patients' availability since group genetic counseling was only held on one day and time a week. This could have impacted the efficiency of this service delivery model. However, as the number of individuals increases in a group genetic counseling session, the time savings would presumably only become more significant.

2.6.2 Future research

We found benefits to homogenizing our group genetic counseling cohort. However, completing a similar study on patients with different indications would assess if group genetic counseling is beneficial for other types of patients beyond those with a new diagnosis of breast cancer. Additionally, we realize that satisfaction and comfort level are not the only defining characteristics of an effective service delivery model. Further research needs to be conducted to understand the effects of group genetic counseling on other factors such as depression levels, cancer worry, and knowledge. It may also be beneficial to study patient perceptions at different time intervals following genetic counseling sessions to assess the long-term impact of group genetic counseling. Additionally, while we found that group genetic counseling offers increased efficiency in the cancer clinic, we could not say with certainty that this affects direct access to cancer genetic counseling services. Finally, groups in underserved and less educated communities should be evaluated to see if these results are true among a more diverse population. This study did not directly measure the impact of group genetic counseling on the overall number of patients that could be accommodated by a single genetic counselor, although we infer that more patients could be seen based on the time savings demonstrated. More specific studies need to be done to assess how this service delivery model can impact access to cancer genetic counseling overall.

2.7 Conclusion

As cancer genetic counseling referrals increase, the current landscape of genetic counseling service delivery is shifting towards incorporating additional models of care into the clinic to accommodate demands. Group genetic counseling provides an effective

way to increase efficiency while maintaining similar patient satisfaction and comfort levels experienced in individual genetic counseling. Group genetic counseling may also have the added benefit of making the large amount of information covered in a genetic counseling session less overwhelming. However, the individual time following group genetic counseling also appears to be important to allow for discussion about patients' specific history and concerns while promoting autonomous decision making. In addition to the individual time, this study highlighted the potential benefits of homogenizing group indications or circumstances when designing a group genetic counseling service delivery model. It also demonstrates the benefits of presenting group genetic counseling as the norm and not offering different service delivery model options to patients. Even though most patients are satisfied and are comfortable in a group setting, when given the choice, patients are unlikely to choose group genetic counseling. While more research needs to be done to assess a more diverse population and benefits to other patient groups, we believe group genetic counseling is a promising service delivery model that can be beneficial for patients and providers in the cancer genetic counseling clinic.

Table 2.1 Demographic characteristics of study participants

Characteristics	Individual (%)	Group (%)	Total (%)	p-value
Age (n= 65)				0.375
20-30	2.6	3.3	3.1	
31--40	15.8	3.3	10.8	
41-50	21.1	40.0	30.8	
51-60	23.7	20.0	23.1	
61-70	10.5	23.3	16.9	
71-80	23.7	3.3	15.4	
Race (n=68)				0.300
Caucasian	55.3	66.7	60.3	
African American	34.2	30.0	32.4	
Asian	0.0	3.3	1.5	
Multiracial	2.6	0.0	1.5	
Did not respond	7.9	0.0	4.4	
Ethnicity (n=68)				0.913
Hispanic	2.6	3.3	2.9	
Non-Hispanic	84.2	86.7	85.3	
Did not respond	13.2	10.0	11.8	
Education (n=68)				0.986
Some High School	2.7	3.3	2.9	
High School or GED	13.5	10.0	11.8	
Some College	24.3	20.0	22.1	
Associates/Technical Degree	5.4	6.7	5.9	
Bachelor's Degree	29.7	30.0	29.4	

Postgraduate Degree	21.6	23.3	22.1	
Did not respond	2.7	6.7	5.9	
Income (n=68)				0.443
Less than 25K	10.5	6.7	8.8	
25K-50K	26.3	23.3	25.0	
50K-75K	7.9	20.0	13.2	
75K-100K	18.4	10.0	14.7	
100K-125K	0.0	6.7	2.9	
More than 125K	10.5	6.7	8.8	
Did not respond	26.3	26.7	26.5	
Health Insurance (n=68)				0.228
Private or Employer Based	50.0	76.7	61.8	
Medicaid	7.9	3.3	5.9	
Medicare	7.9	10.0	8.8	
Tricare	10.5	3.3	7.4	
Other	7.9	3.3	5.9	
Did not respond	15.8	3.3	10.3	
Relationship Status (n=68)				0.121
Single, Never Married	15.8	3.3	10.3	
Single, Living with Significant Other	2.6	0.0	1.5	
Married	50.0	76.7	61.8	
Widowed	7.9	3.3	5.9	
Divorced	21.1	6.7	14.7	
Separated	0.0	3.3	1.5	
Did not respond	2.6	6.7	4.4	

Family History of Cancer (n=68)				0.527
Yes	84.2	76.7	80.9	
No	10.5	20.0	14.7	
Did not respond	5.3	3.3	4.4	
Support individual present at appointment (n=68)				0.861
Yes	42.1	40.0	41.2	
No	57.9	60.0	58.8	
Support individuals (n=28)				0.342
Friend	0.0	8.3	3.6	
Child	12.5	16.7	14.3	
Significant Other	37.5	58.3	46.4	
Sibling	12.5	8.3	10.7	
Parent	37.5	8.3	25	

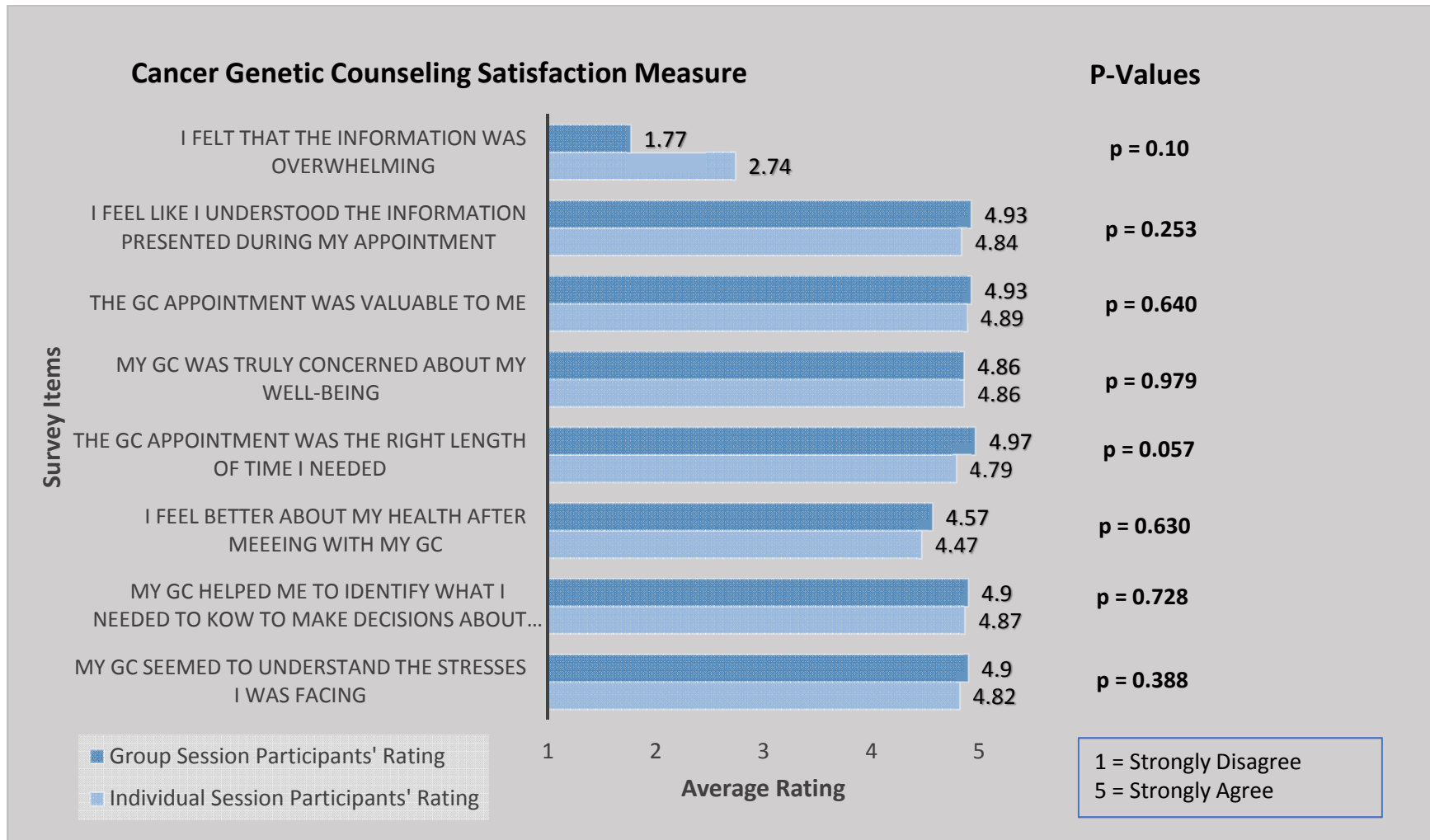


Figure 2.1 Satisfaction and distress between individual and group genetic counseling participants

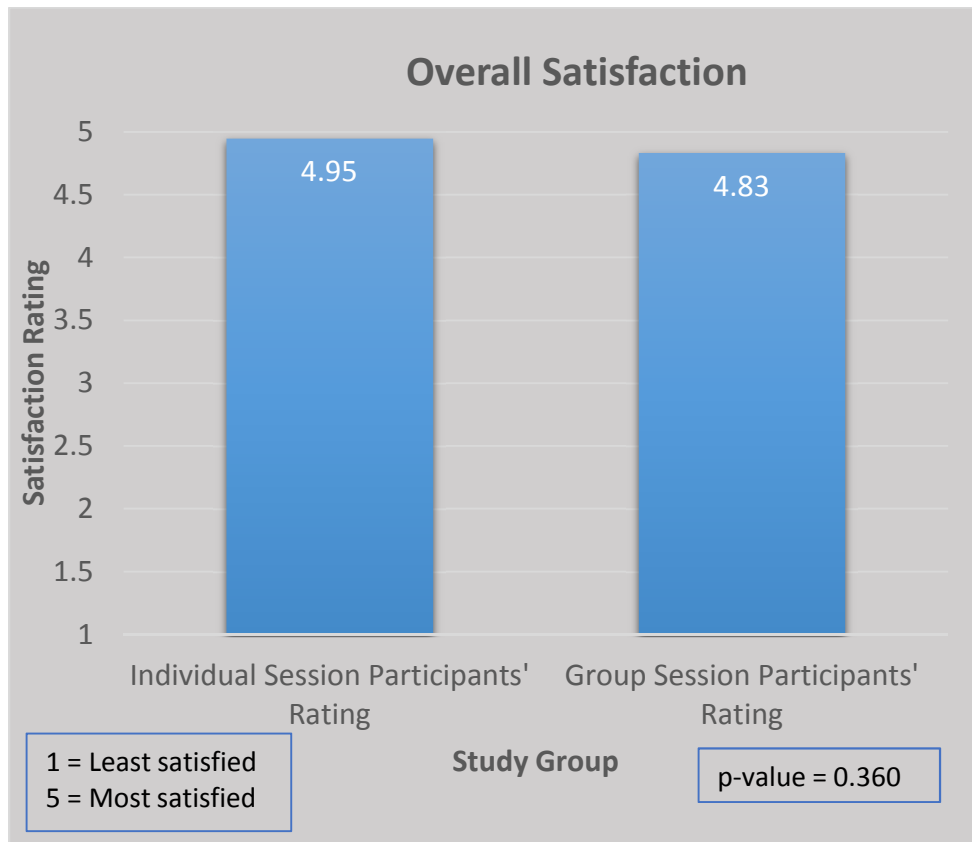


Figure 2.2 Overall satisfaction between individual and group genetic counseling participants

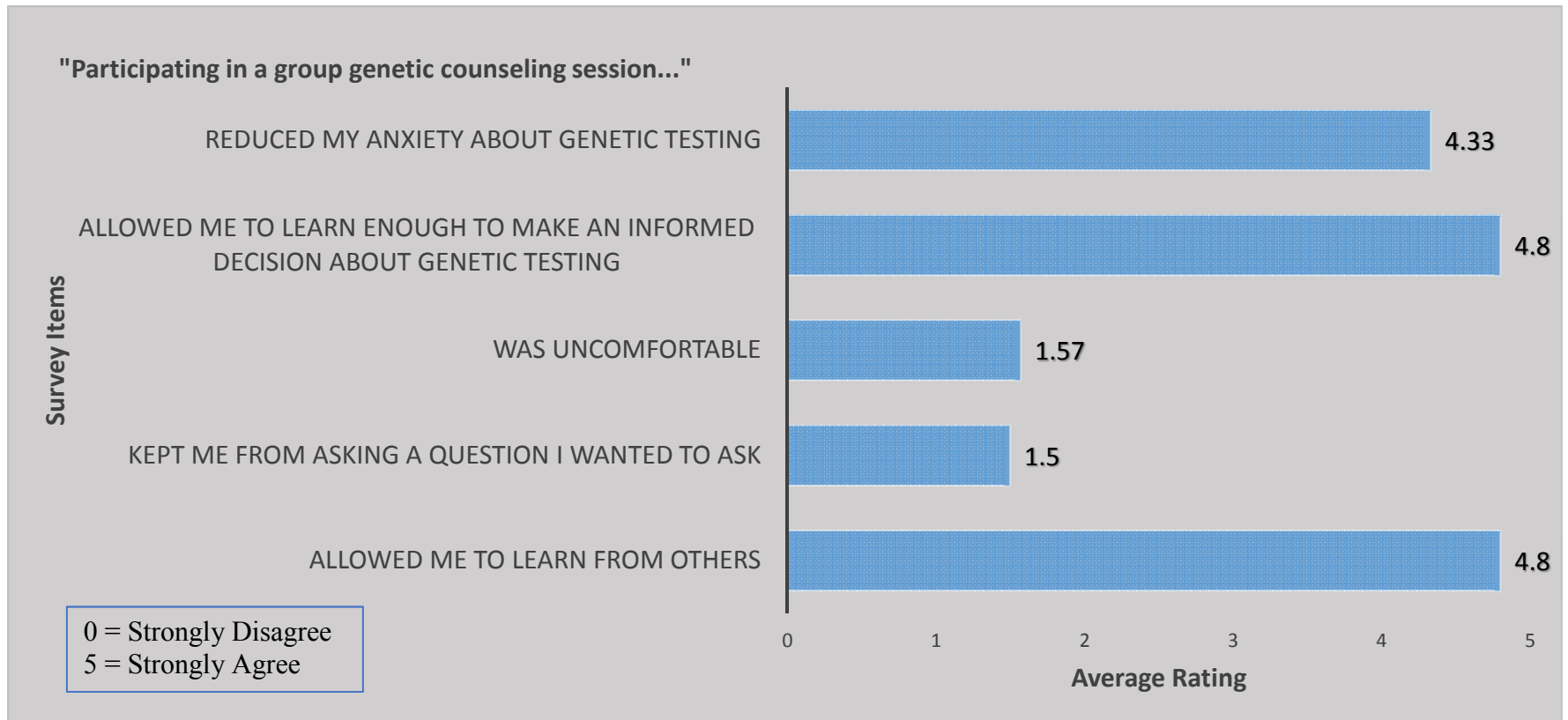


Figure 2.3 Group genetic counseling study group comfort and anxiety ratings for the group portion of their genetic counseling appointment

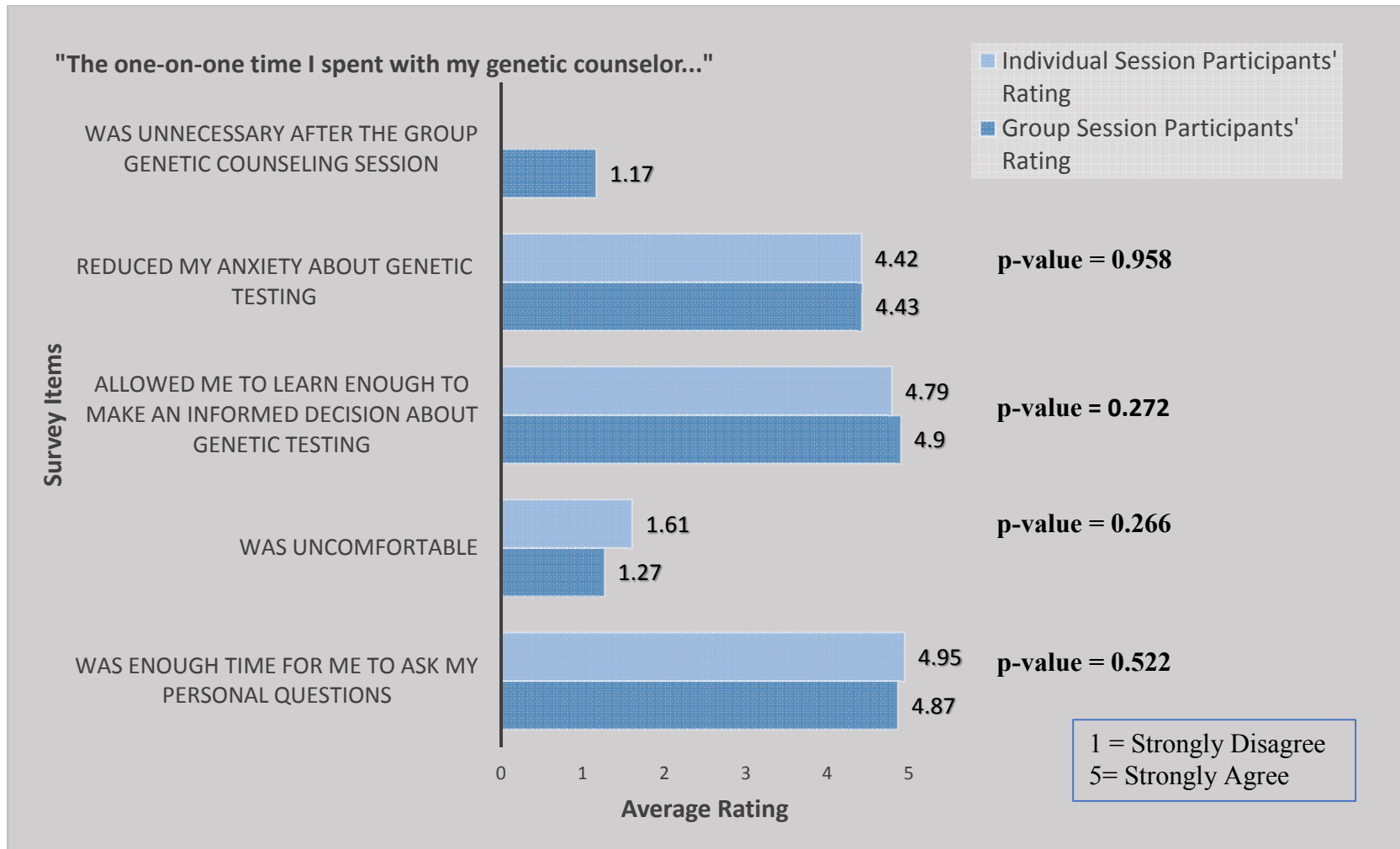


Figure 2.4 Comfort and anxiety ratings for the individual components of both study cohorts' genetic counseling experience

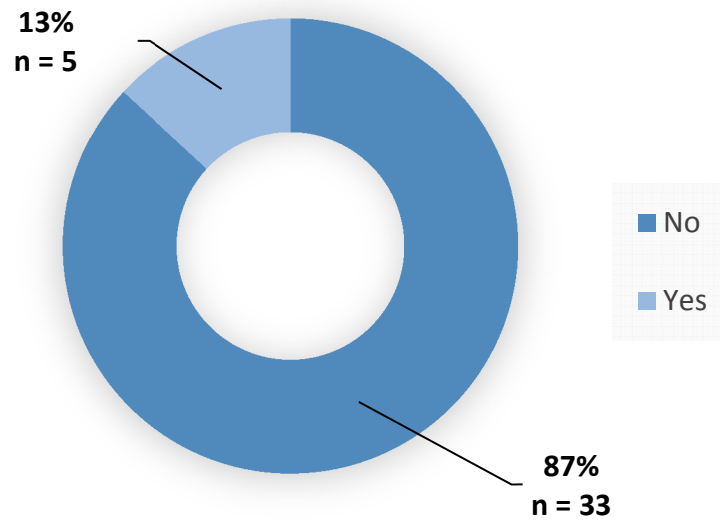


Figure 2.5 Individual genetic counseling participant theoretical willingness to receive group genetic counseling

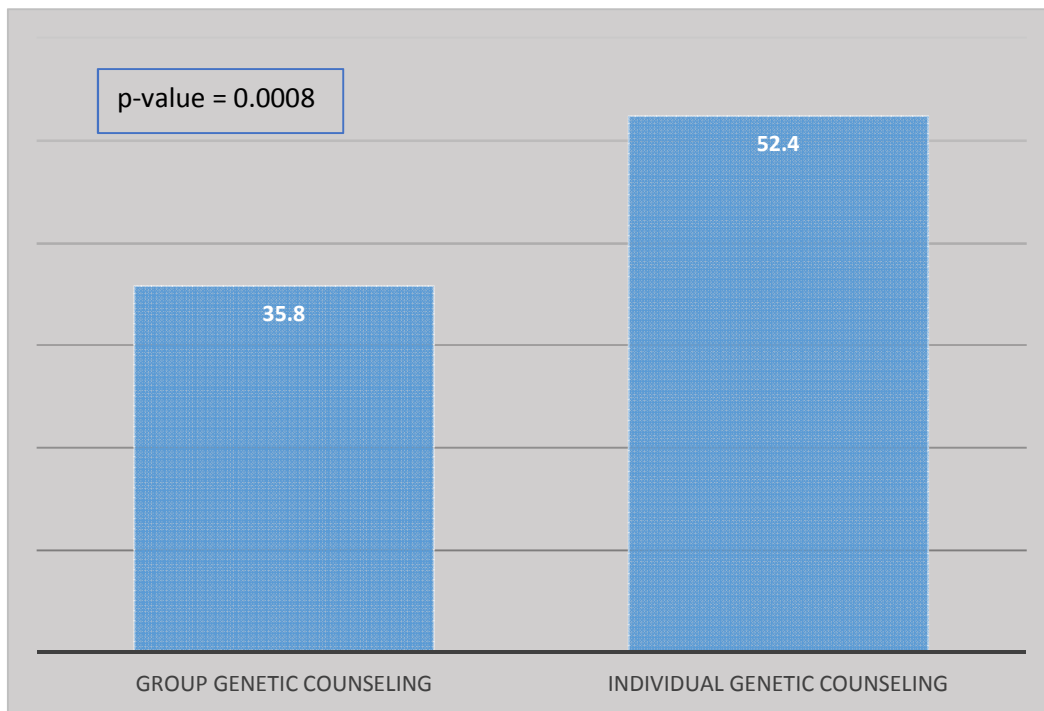


Figure 2.6 Average counselor time per patient (minutes) based on service delivery model for those with family history taken during their genetic counseling session

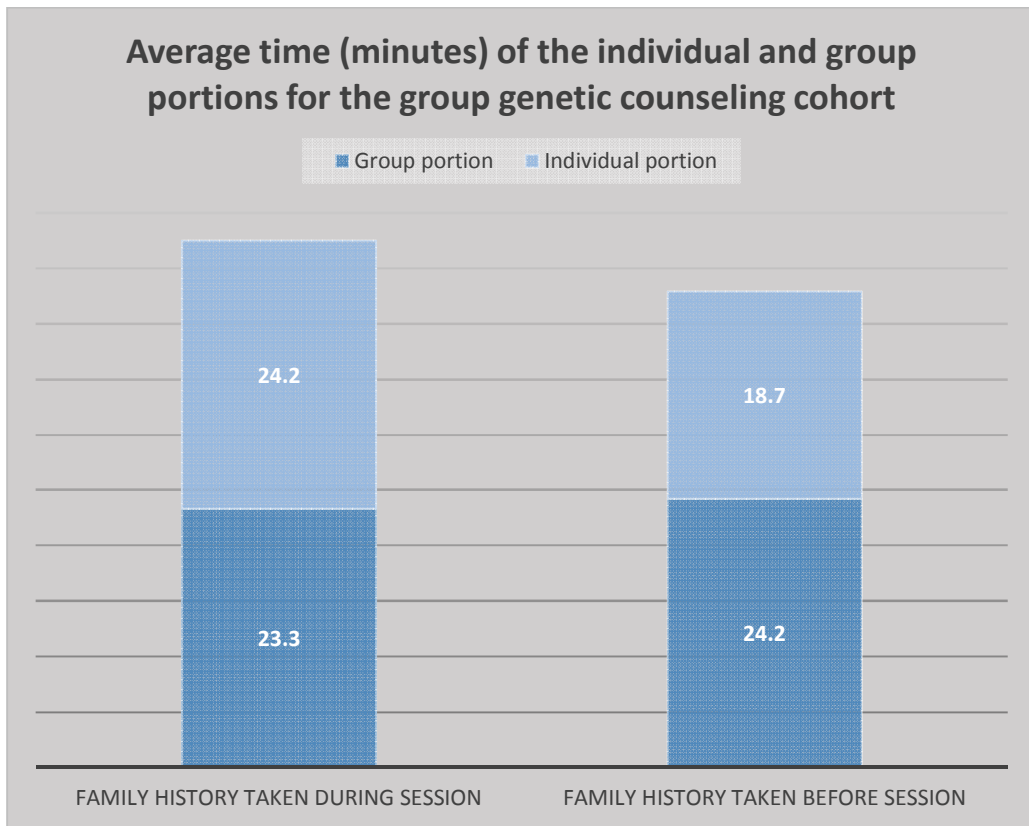


Figure 2.7 Average time (minutes) of the individual and group portions for the group genetic counseling cohort

REFERENCES

- American Cancer Society. (2017). Breast Cancer Risk Factors You Cannot Change. Retrieved from <https://www.cancer.org/cancer/breast-cancer/risk-and-prevention/breast-cancer-risk-factors-you-cannot-change.html#references>
- American Cancer Society. (2017, April). Understanding Genetic Testing For Cancer. Retrieved from <https://www.cancer.org/cancer/cancer-causes/genetics/understanding-genetic-testing-for-cancer.html>
- Benusiglio, P. R., Di Maria, M., Dorling, L., Jouinot, A., Poli, A., Villebasse, S., . . . Caron, O. (2017). Hereditary breast and ovarian cancer: successful systematic implementation of a group approach to genetic counselling. *Fam Cancer*, 16(1), 51-56. doi:10.1007/s10689-016-9929-x
- Buchanan, A. H., Datta, S. K., Skinner, C. S., Hollowell, G. P., Beresford, H. F., Freeland, T., . . . Adams, M. B. (2015). Randomized Trial of Telegenetics vs. In-Person Cancer Genetic Counseling: Cost, Patient Satisfaction and Attendance. *J Genet Couns*, 24(6), 961-970. doi:10.1007/s10897-015-9836-6
- Buchanan, A. H., Rahm, A. K., & Williams, J. L. (2016). Alternate Service Delivery Models in Cancer Genetic Counseling: A Mini-Review. *Front Oncol*, 6, 120. doi:10.3389/fonc.2016.00120
- Calzone, K. A., Prindiville, S. A., Jourkiv, O., Jenkins, J., DeCarvalho, M., Wallerstedt, D. B., . . . Kirsch, I. R. (2005). Randomized comparison of group versus individual genetic education and counseling for familial breast and/or ovarian cancer. *J Clin Oncol*, 23(15), 3455-3464. doi:10.1200/JCO.2005.04.050
- Cloutier, M., Gallagher, L., Goldsmith, C., Akiki, S., Barrowman, N., & Morrison, S. (2017). Group genetic counseling: An alternate service delivery model in a high risk prenatal screening population. *Prenat Diagn*, 37(11), 1112-1119. doi:10.1002/pd.5149
- Cohen, S. A., Huziak, R. C., Gustafson, S., & Grubs, R. E. (2016). Analysis of Advantages, Limitations, and Barriers of Genetic Counseling Service Delivery Models. *J Genet Couns*, 25(5), 1010-1018. doi:10.1007/s10897-016-9932-2
- Cohen, S. A., Marvin, M. L., Riley, B. D., Vig, H. S., Rousseau, J. A., & Gustafson, S. L. (2013). Identification of genetic counseling service delivery models in

- practice: a report from the NSGC Service Delivery Model Task Force. *J Genet Couns*, 22(4), 411-421. doi:10.1007/s10897-013-9588-0
- Crawford, B., Adams, S. B., Sittler, T., van den Akker, J., Chan, S., Leitner, O., . . . van 't Veer, L. (2017). Multi-gene panel testing for hereditary cancer predisposition in unsolved high-risk breast and ovarian cancer patients. *Breast Cancer Res Treat*, 163(2), 383-390. doi:10.1007/s10549-017-4181-0
- Dancey, J. E., Bedard, P. L., Onetto, N., & Hudson, T. J. (2012). The genetic basis for cancer treatment decisions. *Cell*, 148(3), 409-420. doi:10.1016/j.cell.2012.01.014
- Evans, D. G., Barwell, J., Eccles, D. M., Collins, A., Izatt, L., Jacobs, C., . . . Murray, A. (2014). The Angelina Jolie effect: How high celebrity profile can have a major impact on provision of cancer related services. *Breast Cancer Research*, 16(5). doi:10.1186/s13058-014-0442-6
- Guo, F., MD, Hirth, J., PhD, MPH, Lin, Y., MS, Richardson, G., MD, Levine, L., MD, Berenson, A., MD, PhD, & Kuo, Y., PhD. (2017). Authors' Response: "Angelina Jolie Effect" on the Shifting Role of BRCA Testing in the U.S. *American Journal of Preventive Medicine*, 53(5), 197-199. doi:https://doi-org.pallas2.tcl.sc.edu/10.1016/j.amepre.2017.05.015
- Hoskovec, J. M., Bennett, R. L., Carey, M. E., DaVanzo, J. E., Dougherty, M., Hahn, S. E., . . . Wicklund, C. A. (2018). Projecting the Supply and Demand for Certified Genetic Counselors: a Workforce Study. *J Genet Couns*, 27(1), 16-20. doi:10.1007/s10897-017-0158-8
- Jolie, A. (2013). My Medical Choice. *The New York Times*. Retrieved from <https://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html>
- Konecny, G. E., & Kristeleit, R. S. (2016). PARP inhibitors for BRCA1/2-mutated and sporadic ovarian cancer: current practice and future directions. *British journal of cancer*, 115(10), 1157–1173. doi:10.1038/bjc.2016.311
- Listøl, W., Høberg-Vetti, H., Eide, G. E., & Bjorvatn, C. (2017). Anxiety and depression symptoms among women attending group-based patient education courses for hereditary breast and ovarian cancer. *Hereditary Cancer in Clinical Practice*, 15(1). doi:10.1186/s13053-016-0062-5
- Speigel, D., & Classes, C. (2003). *Group therapy for cancer patients: A research-based handbook of psychosocial care*. New York, NY: Basic Books.
- McDonald, E., Lamb, A., Grillo, B., Lucas, L., & Miesfeldt, S. (2014). Acceptability of telemedicine and other cancer genetic counseling models of service delivery in

- geographically remote settings. *J Genet Couns*, 23(2), 221-228.
doi:10.1007/s10897-013-9652-9
- Meiser, B., Butow, P. N., Barratt, A. L., Schnieden, V., Gattas, M., Kirk, J., . . . Group, P. I. C. (2001). Long-term outcomes of genetic counseling in women at increased risk of developing hereditary breast cancer. *Patient Educ Couns*, 44(3), 215-225.
- National Comprehensive Cancer Network. (2018). Genetic/Familial High-Risk Assessment: Breast and Ovarian. Retrieved from:
https://www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf
- National Society of Genetic Counselors. (2018). Professional Status Survey 2018: Service Delivery & Access To Care.
- Okur, V., & Chung, W. K. (2017). The impact of hereditary cancer gene panels on clinical care and lessons learned. *Cold Spring Harb Mol Case Stud*, 3(6).
doi:10.1101/mcs.a002154
- Otten, E., Birnie, E., Ranchor, A. V., van Tintelen, J. P., & van Langen, I. M. (2015). A group approach to genetic counselling of cardiomyopathy patients: satisfaction and psychological outcomes sufficient for further implementation. *European Journal of Human Genetics*, 23(11), 1462–1467.
<http://doi.org/10.1038/ejhg.2015.10>
- Peshkin, B. N., Kelly, S., Nusbaum, R. H., Similuk, M., DeMarco, T. A., Hooker, G. W., . . . Schwartz, M. D. (2016). Patient Perceptions of Telephone vs. In-Person BRCA1/BRCA2 Genetic Counseling. *J Genet Couns*, 25(3), 472-482.
doi:10.1007/s10897-015-9897-6
- Phillips, K. A., Deverka, P. A., Hooker, G. W., & Douglas, M. P. (2018). Genetic Test Availability And Spending: Where Are We Now? Where Are We Going? *Health Affairs*, 37(5), 710-716. doi:10.1377/hlthaff.2017.1427
- Pirzadeh-Miller, S., Robinson, L. S., Read, P., & Ross, T. S. (2016). Genetic Counseling Assistants: An Integral Piece of the Evolving Genetic Counseling Service Delivery Model. *Journal of Genetic Counseling*, 26(4), 716-727.
doi:10.1007/s10897-016-0039-6
- Platten U, Rantala J, Lindblom A, Brandberg Y, Lindgren G, Arver B. The use of telephone in genetic counseling versus in-person counseling: a randomized study on counselees' outcome. *Fam Cancer* (2012) 11(3):371–9. doi:10.1007/ s10689-012-9522-
- 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. *J Genet Couns*, 18(1), 87-100. doi:10.1007/s10897-008-9189-5

- Riley, B.D., Culver, J.O., Skrzynia, C. et al. (2012). Essential elements of genetic cancer risk assessment counseling, and testing: Updated recommendations of the National Society of Genetic Counselors. *J Genet Counsel*, 21(151). <https://doi.org/10.1007/s10897-011-9462-x>
- Rothwell, E., Kohlmann, W., Jasperson, K., Gammon, A., Wong, B., & Kinney, A. (2012). Patient outcomes associated with group and individual genetic counseling formats. *Fam Cancer*, 11(1), 97-106. doi:10.1007/s10689-011-9486-2
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334-340. doi:10.1002/1098-240x(200008)23:43.0.co;2-g
- Schwartz MD, Valdimarsdottir HB, Peshkin BN, Mandelblatt J, Nusbaum R, Huang AT, et al. Randomized noninferiority trial of telephone versus in-person genetic counseling for hereditary breast and ovarian cancer. *J Clin Oncol* (2014) 32(7):618–26. doi:10.1200/JCO.2013.51.3226
- Society of Gynecologic Oncology. (2014, October). SGO Clinical Practice Statement: Genetic Testing for Ovarian Cancer. Retrieved from <https://www.sgo.org/clinical-practice/guidelines/genetic-testing-for-ovarian-cancer/>
- Taleghani, F., Babazadeh, S., Mosavi, S., & Tavazohi, H. (2012). The effects of peer support group on promoting quality of life in patients with breast cancer. *Iranian journal of nursing and midwifery research*, 17(2 Suppl 1), S125-30.
- The American College of Obstetricians and Gynecologists. (2015, June). Committee Opinion: Hereditary cancer syndromes and risk assessment. Retrieved from <https://www.acog.org/-/media/Committee-Opinions/Committee-on-Genetics/co634.pdf?dmc=1&ts=20190416T1959006496>
- Wang, Y. A., Jian, J. W., Hung, C. F., Peng, H. P., Yang, C. F., Cheng, H. S., & Yang, A. S. (2018). Germline breast cancer susceptibility gene pathogenic variants and breast cancer outcomes. *BMC Cancer*, 18(1), 315. doi:10.1186/s12885-018-4229-5
- Wham, Deborah & Vu, Thuy & Chan-Smutko, Gayun & Kobelka, Christine & Urbauer, Diana & Heald, Brandie. (2010). Assessment of clinical practices among cancer genetic counselors. *Familial cancer*. 9. 459-68. 10.1007/s10689-010-9326-9.
- Woodson, A. H., Profato, J. L., Park, M., Rizvi, S. H., Elsayegh, N., Rieber, A. G., & Arun, B. K. (2015). Service Delivery Model and Experiences in a Cancer Genetics Clinic for an Underserved Population. *J Health Care Poor Underserved*, 26(3), 784-791. doi:10.1353/hpu.2015.0090
- Zilliacus EM, Meiser B, Lobb EA, Kelly PJ, Barlow-Stewart K, Kirk JA, et al. Are video conferenced consultations as effective as face-to-face consultations for

hereditary breast and ovarian cancer genetic counseling? Genet Med (2011)
13(11):933–41. doi:10.1097/GIM.0b013e3182217a19

APPENDIX A – STUDY RECRUITMENT LETTER

The following letter was distributed to patients involved in both group and individual genetic counseling sessions at the USC Specialty Cancer Clinic.

Hello,

You are being invited to participate in this research study because you have had cancer genetic counseling due to a personal diagnosis of cancer. The goal of this study is to evaluate your satisfaction with your genetic counseling appointment. The title of this study is, "Impact of service delivery model on access and patient perceptions of genetic counseling for hereditary breast and ovarian cancer (HBOC)." It has been approved by the University of South Carolina IRB.

Your participation in this study is completely voluntary. This study involves answering some questions about your satisfaction with your genetic counseling appointment. All responses are anonymous, will be kept confidential and will not be a part of your medical record. You may stop your participation at any time or choose not to answer every questions. If you choose to complete the questionnaire, your name can be entered into a raffle to win a gift cards to Amazon. If you wish to be entered into the raffle, please leave your e-mail address or phone number at the bottom of this page. It will not be connected to your answers to these questions. Your time is greatly appreciated and we hope these results will help us to better serve future patients.

Anything that we learn from this study and present to others will not have any identifying information. If you have any questions, please do not hesitate to contact me by email at alyssa.gates@uscmed.sc.edu or phone at (219)-707-6578.

Sincerely,

Alyssa Gates
Genetic Counseling Student
University of South Carolina – Columbia

Name: _____

Email: _____

Phone Number: _____

APPENDIX B – GROUP GENETIC COUNSELING QUESTIONNAIRE

The following questionnaire was distributed to participants receiving group genetic counseling at the USC Specialty Cancer Clinic.

1. Please circle the response that best fits your present feelings about your overall appointment (including both the group and individual portions of your appointment).

	Strongly disagree	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
My genetic counselor seemed to understand the stresses I was facing.	1	2	3	4	5
My genetic counselor helped me to identify what I needed to know to make decisions about what would happen.	1	2	3	4	5
I feel better about my health after meeting with my genetic counselor.	1	2	3	4	5
The genetic counseling appointment was the right length of time I needed.	1	2	3	4	5
My genetic counselor was truly concerned about my well-being.	1	2	3	4	5
The genetic counseling appointment was valuable to me.	1	2	3	4	5
I feel like I understood the information presented during my appointment.	1	2	3	4	5
I felt that the information was overwhelming.	1	2	3	4	5

2. Please rank your overall satisfaction with your genetic counseling appointment today. (circle one).

1 2 3 4 5

3. Please circle the response that best fits your present feelings about your group genetic counseling appointment.

Participating in a group genetic counseling session...

	Strongly disagree	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
Allowed me to learn from others	1	2	3	4	5
Kept me from asking a question I wanted to ask	1	2	3	4	5
Was uncomfortable	1	2	3	4	5
Allowed me to learn enough to make an informed decision about genetic testing	1	2	3	4	5
Reduced my anxiety about genetic testing	1	2	3	4	5

Please explain or elaborate on any of your ratings for the group counseling session above:

4. Please circle the response that best fits your present feelings about your one-on-one time spent with a genetic counselor.

The one-on-one time I spent with my genetic counselor...

	Strongly disagree	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
Was enough time for me to ask my personal questions	1	2	3	4	5
Was unnecessary after the group genetic counseling session	1	2	3	4	5
Was uncomfortable	1	2	3	4	5
Allowed me to learn enough to make an informed decision about genetic testing	1	2	3	4	5
Reduced my anxiety about genetic testing	1	2	3	4	5

Please explain or elaborate on any of your ratings for your one-on-one time:

Please leave any additional thoughts/comments/feelings you had about your appointment below:

Demographics:

Age: I am _____ years old.

What is your race?:
Please check one.

- White
- African American/Black
- American Indian/Alaskan Native
- Asian
- Native Hawaiian/Other Pacific Islander
- Two or more races
- Prefer not to answer
- Other: _____

What is your ethnicity?
Please check one.

- Non-Hispanic
- Hispanic
- Prefer not to answer

Education:
Please check the highest level of education you have received.

- Some high school
- High school degree/GED
- Some college
- Associate degree/Technical degree or certificate
- Bachelor degree

Post-graduate degree (MD, Ph.D., MS, JD)

Health Insurance:

Please check one.

Private/Employer-based insurance

Medicaid

Medicare

TRICARE

I do not currently have health insurance

Other

Income:

Please check your current level of income.

<\$25,000

\$25,000-\$50,000

\$50,000-\$75,000

\$75,000-\$100,000

\$100,000-\$125,000

>\$125,000

Prefer not to answer

Current Relationship Status:

Please check one.

Single, never married

Single, but living with significant other

Married

Widowed

Divorced

Separated

Domestic Partnership or civil union

Do you have a family history of cancer?

Please check one.

Yes

No

Did you bring anyone with you to your appointment?

Please check one.

Yes If yes, whom? _____

No

APPENDIX C – INDIVIDUAL GENETIC COUNSELING QUESTIONNAIRE

The following questionnaire was distributed to participants receiving group genetic counseling at the USC Specialty Cancer Clinic.

1. Please circle the response that best fits your present feelings.

	Strongly disagree	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
My genetic counselor seemed to understand the stresses I was facing.	1	2	3	4	5
My genetic counselor helped me to identify what I needed to know to make decisions about what would happen.	1	2	3	4	5
I feel better about my health after meeting with my genetic counselor.	1	2	3	4	5
The genetic counseling session was the right length of time I needed.	1	2	3	4	5
My genetic counselor was truly concerned about my well-being.	1	2	3	4	5
The genetic counseling session was valuable to me.	1	2	3	4	5
I feel like I understood the information presented during my session	1	2	3	4	5
I felt that the information was overwhelming	1	2	3	4	5

2. Please rank your overall satisfaction with your genetic counseling appointment today. (circle one).

1 2 3 4 5

3. You received individual genetic counseling today. Do you think you would have been comfortable with receiving this information in a group setting with other patients? (circle one)

Yes No

Please explain below:

4. Please circle the response that best fits your present feelings about your genetic counseling appointment

The genetic counseling session I had today...

	Strongly disagree	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
Was enough time for me to ask my personal questions	1	2	3	4	5
Was uncomfortable	1	2	3	4	5
Allowed me to learn enough to make an informed decision about genetic testing	1	2	3	4	5

Reduced my
anxiety about
genetic testing

1

2

3

4

5

Please leave any thoughts/comments/feelings you had about your appointment below:

Demographics:

Age: I am _____ years old.

What is your race?:

Please check one.

White

African American/Black

American Indian/Alaskan Native

Asian

Native Hawaiian/Other Pacific Islander

Two or more races

Prefer not to answer

Other: _____

What is your ethnicity?

Please check one.

Non-Hispanic

Hispanic

Prefer not to answer

Education:

Please check the highest level of education you have received.

- Some high school
- High school degree/GED
- Some college
- Associate degree/Technical degree or certificate
- Bachelor degree
- Post-graduate degree (MD, Ph.D., MS, JD)

Health Insurance:

Please check one.

- Private/Employer-based insurance
- Medicaid
- Medicare
- TRICARE
- I do not currently have health insurance
- Other

Income:

Please check your current level of income.

- <\$25,000
- \$25,000-\$50,000
- \$50,000-\$75,000
- \$75,000-\$100,000
- \$100,000-\$125,000
- >\$125,000
- Prefer not to answer

Current Relationship Status:

Please check one.

- Single, never married
- Single, but living with significant other
- Married
- Widowed
- Divorced
- Separated
- Domestic Partnership or civil union

Do you have a family history of cancer?
Please check one.

Yes
No

Did you bring anyone with you to your appointment?
Please check one.

Yes If yes, whom? _____
No