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Comparing Efficiency, Empowerment, and Satisfaction Between Individual and Group Genetic Counseling for Prostate Cancer

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COMPARING EFFICIENCY, EMPOWERMENT, AND SATISFACTION BETWEEN INDIVIDUAL AND GROUP GENETIC COUNSELING FOR PROSTATE CANCER

by

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ABSTRACT

A hereditary cause for prostate cancer can be identified in 5-17% of cases, which can impact treatment and cancer screening recommendations for patients and their families. Increased demand for genetic testing has necessitated consideration of alternative genetic counseling service delivery models to meet needs. Studies have shown that group genetic counseling increases efficiency while maintaining the same patient benefits as individual genetic counseling, but research has mainly focused on patients who were assigned female at birth (AFAB). The purpose of this study was to evaluate the utility of group genetic counseling for prostate cancer by assessing participants' satisfaction and feelings of empowerment, as well as the efficiency and acceptability of this model. Sixteen prostate cancer patients were randomly assigned to receive individual (n=7) or group (n=9) genetic counseling and were surveyed before and after their appointments. Genetic counselors saved 21 minutes per patient with group genetic counseling compared to individual genetic counseling ($p<0.001$). Participants reported high satisfaction with their appointment, with no statistically significant differences between cohorts ($p=0.12$). Empowerment scores significantly increased following genetic counseling in both individual ($p=0.04$) and group ($p=0.04$) cohorts. However, after their appointment, 71% of participants who received individual genetic counseling indicated they would not have wanted to receive group genetic counseling. To our knowledge, this study is the first to evaluate the utility of group genetic counseling for prostate cancer and to assess outcomes specific to patients who were assigned male at birth (AMAB).

Overall, results are consistent with prior group genetic counseling studies and provide preliminary evidence that group genetic counseling for prostate cancer reduces time spent per patient while maintaining high satisfaction and empowerment.

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LITERATURE REVIEW

1.1 Overview of Prostate Cancer and the Association with Hereditary Causes

Cancer is the second leading cause of death in the United States. In American males, prostate cancer is the leading diagnosis in new cases of cancer (27%) and the second leading cause of cancer-related death (11%) (Siegel et al., 2022). According to the American Cancer Society (ACS, 2023), 1 in 8 people with a prostate will develop prostate cancer. Early detection and treatment led to a 52% decrease in prostate cancer-related deaths from 1993-2018, but the current estimate is still a 1 in 41 mortality rate (ACS, 2023; Negoita et al., 2018). Most prostate cancer is sporadic, but germline pathogenic variants have been found in 5% of localized prostate cancer cases and in 12-17% of metastatic disease (Cheng et al., 2019; Giri et al., 2020). Pathogenic variants in prostate cancer patients are most often found in homologous recombination repair (HRR) genes associated with hereditary breast and ovarian cancer (HBOC) syndrome and DNA mismatch repair (MMR) genes associated with Lynch syndrome (Giri et al., 2020). Approximately 11.8% of patients with metastatic prostate cancer have pathogenic variants in HRR genes, 5% of which are *BRCA2* variants (National Comprehensive Cancer Network (NCCN), 2023; Pritchard et al., 2016). Around 1% of prostate cancer patients have a pathogenic variant in an MMR gene, most commonly *MSH2* and *MSH6* (Sedhom & Antonarakis, 2019).

1.2 Rationale of Germline Genetic Testing for Prostate Cancer

Detection of pathogenic variants can change management for patients with prostate cancer and surveillance recommendations for their families. Patients with metastatic prostate cancer who carry a pathogenic variant may be eligible for precision therapies or clinical trials (Russo et al., 2021). In 2020, the U.S. Food and Drug Administration (FDA) approved two poly(ADP-ribose) polymerase (PARP) inhibitors for those with metastatic, castration-resistant prostate cancer who have certain HRR variants. Rucaparib is approved for those with pathogenic variants in *BRCA1* or *BRCA2* (de Bono et al., 2020). Olaparib is approved for those with *BRCA1/2* pathogenic variants and has also shown utility in those with *ATM, CHEK2,* and *PALB2* (Abida et al., 2020). In addition, patients who have metastatic prostate cancer and *BRCA1/2* pathogenic variants can benefit from early platinum-based chemotherapy use (Giri et al., 2019). Prostate cancer patients with pathogenic variants in MMR genes are candidates for immune checkpoint inhibitors (Giri et al., 2019). The FDA has approved pembrolizumab, an anti–programmed cell death protein 1 (PD-1) antibody, to treat microsatellite instability–high or mismatch repair–deficient tumors (Abida et al., 2019).

Aside from therapeutic benefits to the patient, germline testing can also benefit family members. Variants in HRR and MMR genes are inherited in an autosomal dominant fashion, meaning that siblings and children of a patient with hereditary prostate cancer have a 50% chance of carrying the same variant. If a germline HRR pathogenic variant is identified, family members could be at increased risk for breast, ovarian, prostate, and pancreatic cancers, as well as melanoma (NCCN, 2023). If a germline MMR pathogenic variant is identified, family members could be at increased risk for

colorectal and endometrial cancers as well as a wide range of other Lynch-associated cancers (NCCN, 2023). Identified germline variants can inform cascade genetic testing and cancer screening recommendations for at-risk family members.

Since germline testing results have been shown to influence therapeutic strategies and benefit families, demand for genetic testing for prostate cancer has increased. Concurrently, the development of next-generation sequencing (NGS) has allowed for more efficient and practical genetic testing through availability of commercial panels (Zhen et al., 2018). The NCCN has developed criteria to determine which patients with prostate cancer should consider germline testing (NCCN Guidelines Version 1.2023: Prostate Cancer). Testing is recommended for all prostate cancer patients with high or very high risk localized, regional, or metastatic disease, intraductal or cribriform histology, or who are of Ashkenazi Jewish ancestry. Germline testing is also recommended for those with prostate cancer at any stage who also have a family history of prostate cancer or cancers related to HBOC Syndrome or Lynch Syndrome meeting specified criteria (NCCN, 2023). At a minimum, panels should include *MLH1, MSH2, MSH6, PMS2, BRCA1, BRCA2, ATM, PALB2, CHEK2,* as well as additional genes like *HOXB13* depending on the clinical context (NCCN, 2023). Best practice dictates that patients seeking genetic testing should receive pre-test genetic counseling to promote informed decision-making and consent (Riley et al., 2012). Thus, increased demand for germline testing for prostate cancer has increased the need for genetic counseling services.

1.3 Pre-Test Genetic Counseling for Prostate Cancer: Service Delivery Models

1.3.1 Traditional Pre-Test Genetic Counseling

The primary aim of pre-test genetic counseling is to assess a patient's risk for cancer and the likelihood of a germline gene mutation in the patient or their family, and to facilitate informed decision-making about genetic testing (Hyatt et al., 2021). The genetic counselor obtains a complete medical history, draws a three-generation pedigree, provides a cancer risk assessment, educates about hereditary cancer, assesses psychosocial needs, and discusses genetic testing options (Riley et al., 2012). Elements of informed consent for genetic testing include providing information about the purpose of the test and genes included, possible test results (positive, negative, or variant of uncertain significance), accuracy and cost of the test, possibility of genetic information discrimination, patient confidentiality, and alternatives to genetic testing (Riley et al., 2012). Traditionally, patients are offered pre-test genetic counseling during a one-on-one, in-person session with a genetic counselor, and subsequent results disclosure and post-test counseling occurs either over the phone or in-person (Cohen et al., 2013). It has been demonstrated that individual genetic counseling is highly effective and results in high patient satisfaction, improved accuracy of risk perception, decreased anxiety, increase in patient knowledge, and adherence to screening and prevention behaviors (Hyatt et al., 2021).

Many barriers to accessing traditional genetic counseling services exist, including lack of geographically distributed genetic counselors and long wait times (Boothe et al., 2021). Though the field of genetic counseling is expanding, there exists only one certified genetic counselor per 71,842 people in the United States (Triebold et al., 2021). There are

fewer genetic counselors in rural areas compared to larger urban areas with academic medical centers (Szymaniak et al., 2020). It is estimated that the number of genetic counselors will not reach demand until 2024-2030 (Hoskovec et al., 2018). Lack of timely access to genetics services has led both genetic counselors and physicians to seek out additional methods of delivering pre-test genetic counseling. According to a 2017 survey of service delivery models (SDM) use by genetic counselors, over 90% of clinical genetic counselors used a traditional model such as individual, in-person counseling, but over half (54%) of respondents felt that it did not sufficiently meet needs in their clinic (Boothe et al., 2021). A total of 65% reported exploring the possibility of alternative SDM to increase the number of patients, decrease wait times, and improve the quality of care (Boothe et al., 2021).

1.3.2 Telegenetic Counseling

One way to address geographic access barriers is telegenetic counseling, where video conferencing or telephone are used to provide services remotely (Gorrie et al., 2021). Use of telegenetic service delivery models by genetic counselors has significantly increased since the COVID-19 pandemic. Recent research shows that use of telegenetics among genetic counselors increased to 87% in Fall 2020, compared to 70% immediately prior to COVID-19 and 44% prior to 2017 (Mills et al., 2021). According to the 2022 Professional Status Survey (PSS) of the National Society of Genetic Counselors (NSGC), cancer genetic counselors use multiple SDMs, spending 37% of their time providing direct patient care in-person, 33% using telephone, and 29% using video conferencing (NSGC, 2022). Several studies have reported high patient satisfaction and no observable difference in distress with telephone and audiovisual telegenetics compared to in-person

cancer genetic counseling, citing improved access in rural communities, reduced wait times, and decreased costs to both clinics and patients (Arenas-Gallo et al., 2022; Kinney et al., 2016; Schwartz et al., 2014). Prior to COVID-19, a study by the Service Delivery Model Task Force of the NSGC identified limitations of implementing telegenetics in practice, including lack of support for equipment set-up, logistics of coordinating sample collection, inability to bill for services, and difficulty seeing visual cues from a patient or utilizing visual aids (Cohen et al., 2016; Zierhut et al., 2018). Following widespread implementation of telegenetics during COVID-19, waivers were implemented to remove reimbursement barriers and private insurance coverage increased (Green et al., 2023). Ma et al. (2021) found that most genetic counselors no longer reported lack of institutional support as a barrier and twice as many reported being able to bill for telehealth after the onset of the pandemic. However, this study did find that genetic counselors were concerned that the changes allowing for improved access to telehealth would not be permanent. Genetic counselors also identified barriers to equitable access, including poor internet connection in rural areas, lack of access to devices, and lack of technological literacy among elderly patients (Ma et al., 2021). The NSGC has developed telegenetics practice guidelines to anticipate and address some of these barriers (Green et al., 2023).

1.3.3 Clinician-Led Genetic Testing

Due to high demand for genetic testing and insufficient numbers of genetic counselors, some oncologists order germline genetic testing for prostate cancer patients (Russo et al., 2021). The process of "mainstreaming" genetic testing by ordering testing at the point of care by non-genetics providers has been studied among patients with various cancers, but there is a paucity of data in the prostate cancer realm. Bokkers et al.

(2022) developed a genetics training module that was shown to increase gynecologic oncologists' knowledge about genetic testing for ovarian cancer and motivation to order testing for their patients. Ramsey et al. (2023) found that mainstreaming germline genetic testing for pancreatic cancer patients led to a 6.5-fold increase in testing. With prostate cancer, studies report that 15% of oncologists performed pre-test counseling, and 45% reported taking a combination approach of ordering testing and then referring for genetic counseling (Loeb et al., 2020; Paller et al., 2019). Recently published studies reported that clinicians and prostate cancer patients are both highly satisfied with a mainstreaming approach, and that uptake of genetic testing remains high when pre-test counseling is offered by an oncologist (Abusamra et al., 2022; Scheinberg et al., 2021). However, numerous barriers to this approach have been identified, including poor physician knowledge of germline test selection, financial considerations of testing, and coordination of care between providers (Loeb et al., 2021). Following a survey of 56 urologists and oncologists, Giri et al. (2022) reported gaps in provider knowledge about genes associated with prostate cancer risk and genetic discrimination laws. Furthermore, they found that only 66% of providers felt it was important to obtain maternal family history, and only 46% regularly asked about cancer history in patients' grandparents. In response to the survey, Giri et al. (2022) piloted a web-based provider education and clinical family history tool (Helix) and found that the modules improved clinicians' knowledge about specific genes associated with increased risk for prostate cancer and increased understanding of appropriate genetic testing strategies. Providers found the tool easy to use and reported that it was helpful for family history collection. However, there was no increase in provider knowledge regarding life insurance and genetic discrimination laws

after completing training through the Helix modules (Giri et al., 2022). More research is needed to evaluate provider understanding and patient needs before this model can be widely utilized (Russo et al., 2021; Schmidlen et al., 2019).

1.3.4 Video Pre-Test Genetic Education

Pre-test genetic counseling videos have been used to address some of the barriers associated with clinician-initiated genetic testing. Urologists or oncologists can distribute a short video to their prostate cancer patients who meet NCCN criteria for genetic evaluation (Giri et al., 2020). Russo et al. (2021) piloted an 11-minute video that educated prostate cancer patients about cancer inheritance, benefits, limitations, and risks of genetic testing, multigene panel options, potential result types and their implications for individuals and families, and genetic discrimination laws. The majority of men elected to view the pre-test video over in-person genetic counseling, citing convenience and lesser time commitment. The study showed no difference in decisional conflict and satisfaction between participants who viewed the video and those who received traditional genetic counseling, as well as increased cancer genetics knowledge in both study groups (Russo et al., 2021). The authors identified several limitations of implementing the video, including finding time and private space to view the video during a non-genetics appointment, lack of provider expertise if patients had questions about video contents, and need for follow-up with genetic counselors to address questions and coordinate ordering of tests. Based on available research, collaboration and coordination with genetic counselors may still be necessary for informed consent and psychosocial considerations if videos are utilized for pre-test cancer genetic counseling (Giri et al., 2020). Two ongoing clinical trials, TARGET (NCT04447703) and ProGen

(NCT03328091), are piloting pre-test video education followed by post-test genetic counseling to prostate cancer patients to evaluate genetic testing uptake, genetics knowledge, satisfaction, and family communication among participants (Loeb et al., 2022).

1.3.5 Group Genetic Counseling

Group genetic counseling has emerged as a solution to improve efficiency of genetic counseling by increasing the number of patients that can be seen at once (Greenberg et al., 2020). In this model, groups of patients with a common indication are seen together for genetic counseling. A short individual session may or may not follow the group session (Cohen et al., 2012). Early studies proposed that group education models have an advantage over pretest education pamphlets or videos because of peer contribution and support (Lepore et al., 2003; Wilson, 1997). The NSGC PSS (2022) found that 4% of all genetic counselor survey respondents, but only 1% of cancer genetic counselor respondents, deliver services through group counseling. In clinics that use group counseling for cancer education followed by a short individual session, the group portion lasts an average of 31-60 minutes and the individual portion lasts less than thirty minutes (Greenberg et al., 2020). Limitations to widely implementing group genetic counseling include lack of physical space to accommodate a group, referral and scheduling concerns, and inability to bill for services (Greenberg et al., 2020).

In the cancer setting, research on group genetic counseling has focused primarily on breast cancer patients. Identified benefits of group genetic counseling from a patient perspective include exchange of personal experiences, a larger feeling of support, and the ability to hear others' questions or concerns (Benusiglio et al., 2016; Hynes et al., 2020).

In a 2005 pilot study, Calzone et al. randomized high-risk breast and ovarian cancer patients to either individual-only counseling or group education followed by brief individual counseling. The study not only showed that group counseling was more efficient but also that patients gained and retained equal knowledge and reported high satisfaction with both methods. Neither method generated any significant psychological distress in patients (Calzone et al., 2005). Following this, additional studies in groups of high-risk breast cancer patients demonstrated similar findings, with no difference in knowledge (Benusiglio et al., 2016), satisfaction with genetic counseling (Benusiglio et al., 2016; Gates, 2019; Ridge et al., 2009; Rothwell et al., 2012), or perceived personal control (Rothwell et al., 2012) when receiving group versus individual counseling. The scope of research on group counseling has expanded with studies involving groups of patients with mixed hereditary cancer indications (Hynes et al., 2020; Lohn et al., 2022), cardiomyopathy patients (Otten et al., 2015), and patients with positive prenatal screening results (Cloutier et al., 2017). Regardless of the patient's indication, these studies have demonstrated high satisfaction and positive psychological outcomes following group genetic counseling. Limitations of group genetic counseling identified in some of these studies included concern for privacy and confidentiality, as well as group influence affecting uptake of testing (Ridge et al., 2009; Rothwell et al., 2012). For these reasons, most studies involve a group education session followed by a brief individual session where patients can discuss private information and make genetic testing decisions one-on-one with a genetic counselor (Hynes et al., 2020). These studies also demonstrated that using group genetic counseling increased efficiency by reducing the amount of time

genetic counselors spend per patient (Calzone et al., 2005; Gates, 2019; Lohn et al., 2022) and allowing for decreased wait times (Hynes et al., 2020).

1.4 Needs of Patients Undergoing Cancer Genetic Counseling

1.4.1 Personalized Discussion About Genetic Testing and its Implications

Studies have shown that patients who were assigned male at birth (AMAB) consent to genetic testing just as frequently as patients who were assigned female at birth (AFAB) if they receive genetic counseling and are provided with adequate information (Fehniger et al., 2013; Graves et al., 2011). One study reported that prostate cancer patients primarily desire to learn about therapeutic benefits gained from genetic testing, the risk for additional cancers, and familial implications of pathogenic variants as part of their genetic counseling appointments (Greenberg et al., 2020). A study focused on developing web-based education for AMAB individuals in *BRCA1/2*-positive families reported that most participants felt that providers and internet resources provide inadequate information about their specific *BRCA1/2*-related cancer risks, including male breast, prostate, and pancreatic cancers. Participants desired pre-test genetic counseling to include statistics on *BRCA1/2*-associated cancers for AMAB patients, cancer prevention and screening options, and information for children and relatives (Peshkin et al., 2021). AMAB patients overwhelmingly report information about family members' cancer risk to be a key motivator for genetic testing (Annoni et al., 2022; Hallowell et al., 2006; Hyatt et al., 2021; Peshkin et al., 2021). D'Agincourt-Canning et al. (2006) suggest that while AFAB patients tend to share genetic information more readily with extended family, AMAB patients may need a more extensive explanation of the broad range family members who may benefit from genetic information. Furthermore, Hyatt et al. (2021)

suggest that AMAB patients without a personal cancer history may neglect to consider how genetic testing may inform their own cancer risks, so providers should consider more emphasis on education about personal risks in addition to relatives' risk during pre-test counseling. These nuanced discussions may be best facilitated through personalized and direct interaction with a provider rather than standardized web-based or video education.

1.4.2 Need for Psychosocial Assessment

According to Chambers et al. (2008), AMAB patients are less likely to pursue cancer support services compared to AFAB patients, but one-third still report a desire for additional care. Prostate cancer and associated treatments introduce physical issues such as sexual dysfunction, incontinence, and bowel dysfunction, as well as psychological concerns including stigma, fear of recurrence, and body image disturbances (Roth et al., 2008; Steginga et al., 2001). Anxiety and depression are the psychiatric symptoms most often experienced by prostate cancer patients (Watts et al., 2014). Various forms of psychotherapy are shown to improve quality of life for those with prostate cancer, but these patients are either hesitant to participate or their primary providers are not identifying psychosocial concerns and placing appropriate referrals to mental health professionals (Roth et al., 2008; Sonn et al., 2013). Several studies have demonstrated a significant difference between urologists' assessment of prostate cancer patients' quality of life compared to the patients' own self assessments (Litwin et al., 1998; Sonn et al., 2013). Urologists consistently underestimated patients' sexual, urinary, and bowel symptoms, as well as fatigue and bone pain, all of which leads to underestimation of psychological distress (Sonn et al., 2013). Roth et al. (2008) calls for mental health

practitioners to be more regularly included as part of prostate cancer patients' care team. Genetic counselors play an integral role in identifying patients who may benefit from a mental health referral, as psychosocial assessment is part of every genetic counseling session. Psychosocial aspects of genetic testing including anticipated reaction to results, coping strategies, and family concerns are all addressed as part of pre-test genetic counseling (Riley et al., 2012). Other modes of delivering pre-test genetic counseling, such as a pre-test video or clinician-led genetic testing, may not offer the psychosocial aspect needed by many prostate cancer patients.

1.4.3 Desire for Psychosocial and Community Support

Research shows that prostate cancer patients strongly desire support groups to connect with others who have similar physical and psychosocial concerns (Hyatt et al., 2021; Suttman et al., 2018). Multiple national support groups are available to those with prostate cancer, including *Us Too, Man to Man,* and *Malecare* (Roth et al., 2008). Suttman et al. (2018) found that AMAB individuals with *BRCA1/2* pathogenic variants reported a lack of male-focused support groups, especially for those with a new genetic diagnosis. The majority of respondents reported interest in such a support group, even if they had a strong family support system. They felt the primary benefit would be exchanging information and coping strategies among people with the same genetic risk factors (Suttman et al., 2018). Aside from support groups, group education interventions for those with prostate cancer have been studied in the therapeutic setting. Lepore et al. (2003) showed that education groups and peer-to-peer discussion increased prostate cancer knowledge, improved outlook on sexual dysfunction, and led to a healthier lifestyle in participants with prostate cancer compared to those who did not participate in

groups. The authors proposed implementing group discussion earlier in diagnosis when patients are still weighing treatment options. However, this study did not evaluate whether those with prostate cancer have a favorable view of group education (Lepore et al., 2003).

Most previous group genetic counseling studies have only included AFAB patients, as studies have largely involved breast and ovarian cancer patients. Although data shows that AFAB patients are satisfied with a group format, it is not yet known whether AMAB patients share this level of acceptance. Three studies have included both sexes in group genetic counseling sessions. In a study that piloted group genetic counseling for symptomatic cardiomyopathy patients, 40% of participants were AMAB (Otten et al., 2015). Patients reported higher perceived personal control, lower anxiety, and high satisfaction after receiving group genetic counseling, but no sex-specific outcomes were reported. Two other studies introduced group genetic counseling to both AMAB and AFAB patients with a variety of cancer indications, such as breast and colon cancer (Hynes et al., 2020; Lohn et al., 2022). Lohn et al. (2022) reported no significant difference in uncertainty related to genetic testing between AMAB and AFAB patients receiving group genetic counseling. However, only a small proportion of participants were AMAB: 5% of those receiving traditional genetic counseling and 10% of group participants. Group genetic counseling could be an avenue to address both the identified needs of prostate cancer patients and the lack of access to genetic counseling services, but research is needed to evaluate the acceptability of this service delivery model in wider patient populations, including AMAB patients.

1.5 Rationale of Study

To our knowledge, no research has been conducted to assess the utility of group genetic counseling for prostate cancer. As demand for cancer genetic counseling increases due to the clear benefits of genetic testing for prostate cancer patients, research into alternative service delivery models is necessary to address the high demand. Other service delivery models, such as clinician-initiated genetic testing and pre-test videos have been shown to be acceptable to these patients but may not provide the personalized discussion and psychosocial support needed in this population. Previous studies have shown that group genetic counseling can improve genetic counselor efficiency in the cancer setting while maintaining the same patient outcomes, satisfaction, and personalized discussion as traditional genetic counseling (Benusiglio et al., 2016; Calzone et al., 2005; Lohn et al., 2021). However, these studies have primarily evaluated the acceptability of group genetic counseling among AFAB patients. This current study improved on methodology from a prior group genetic counseling study at Prisma Health Midlands and broadened the understanding of the benefits and limitations of group genetic counseling by introducing it to the prostate cancer patient population (Gates, 2019).

1.6 Purpose of Study

The purpose of this study was to assess the acceptability and utility of group genetic counseling among prostate cancer patients. The objectives of this study were as follows:

1. Compare satisfaction and empowerment among prostate cancer patients who receive individual genetic counseling versus those who receive group genetic counseling;

2. Assess receptiveness to group genetic counseling among prostate cancer patients;
3. Determine the time savings per patient gained by incorporating group genetic counseling for prostate cancer.

We hypothesized that there would be no significant difference in satisfaction and empowerment between prostate cancer patients receiving group genetic counseling versus individual counseling. We also predicted that prostate cancer patients receiving individual counseling would not be receptive to receiving this service via a group counseling model. Finally, we hypothesized that group genetic counseling for prostate cancer would improve efficiency in the clinic by saving genetic counselors time per patient.

CHAPTER 2

COMPARING EFFICIENCY, EMPOWERMENT, AND SATISFACTION BETWEEN INDIVIDUAL AND GROUP GENETIC COUNSELING FOR PROSTATE CANCER[1]

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2.1 Abstract

A hereditary cause for prostate cancer can be identified in 5-17% of cases, which can impact treatment and cancer screening recommendations for patients and their families. Increased demand for genetic testing has necessitated consideration of alternative genetic counseling service delivery models to meet needs. Studies have shown that group genetic counseling increases efficiency while maintaining the same patient benefits as individual genetic counseling, but research has mainly focused on patients who were assigned female at birth (AFAB). The purpose of this study was to evaluate the utility of group genetic counseling for prostate cancer by assessing participants' satisfaction and feelings of empowerment, as well as the efficiency and acceptability of this model. Sixteen individuals with prostate cancer were randomly assigned to receive individual (n=7) or group (n=9) genetic counseling and were surveyed before and after their appointments. Genetic counselors saved 21 minutes per patient with group genetic counseling compared to individual genetic counseling model ($p<0.001$). Participants reported high satisfaction with their appointment, with no statistically significant differences between cohorts ($p=0.12$). Empowerment scores significantly increased following genetic counseling in both individual ($p=0.04$) and group ($p=0.04$) cohorts. However, after their appointment, 71% of participants who received individual genetic counseling indicated they would not have wanted to receive group genetic counseling. To our knowledge, this study is the first to evaluate the utility of group genetic counseling for prostate cancer and to assess outcomes specific to patients who were assigned male at birth (AMAB). Overall, results are consistent with prior group genetic counseling studies

and provide preliminary evidence that group genetic counseling for prostate cancer reduces time spent per patient while maintaining high satisfaction and empowerment.

2.2 Introduction

Prostate cancer is the leading diagnosis of cancer in males and the second leading cause of cancer-related death in males (Siegel et al., 2022). Most prostate cancers are sporadic, but germline pathogenic variants (PVs) have been found in 5% of localized cases and 12-17% of metastatic disease (Cheng et al., 2019; Giri et al., 2020). PVs in individuals with prostate cancer are most often found in homologous recombination repair (HRR) genes associated with Hereditary Breast and Ovarian Cancer syndrome and DNA mismatch repair (MMR) genes associated with Lynch syndrome (Giri et al., 2020). Detection of germline PVs can determine prostate cancer patients' eligibility for precision therapies such as PARP inhibitors and immune checkpoint inhibitors as well as other cancer screening recommendations (Cheng et al., 2019; Giri et al., 2019). It can also inform cascade genetic testing and cancer surveillance recommendations for family members (De Bono et al., 2020; Giri et al., 2019). Current National Comprehensive Cancer Network (NCCN) guidelines (Prostate Cancer, Version 1.2023) recommend genetic testing for all prostate cancer patients with metastatic or high-risk disease and those meeting specific histology or family history criteria. Best practice dictates that patients seeking genetic testing should receive pre-test genetic counseling to promote informed decision-making and consent (Riley et al., 2012). Thus, the need for genetic counseling services has increased with expanded eligibility for germline testing among prostate cancer patients (Russo & Giri, 2022).

The primary aim of pre-test cancer genetic counseling is to assess risk for a germline pathogenic variant and facilitate informed decision-making about genetic testing (Hyatt et al., 2021). Traditionally, patients are offered pre-test genetic counseling during a one-on-one, in-person session with a genetic counselor (Cohen et al., 2013; Riley et al., 2012). However, only one certified genetic counselor exists per 71,842 people in the United States, and the number of genetic counselors is not expected to meet demand until 2024-2030 (Hoskovec et al., 2018; Triebold et al., 2021). Lack of timely access to genetics services has led both genetic counselors and physicians to seek out alternative methods of delivering pre-test genetic counseling services to cancer patients (Russo & Giri, 2022). Mainstreaming genetic testing, with either oncologists or urologists providing pre-test counseling and ordering testing, has been shown to be an effective new model (Loeb et al., 2020; Paller et al., 2019). Still, collaboration with genetic counselors may be necessary for informed consent, psychosocial considerations, and follow-up if this model is widely utilized (Giri et al., 2020).

Group genetic counseling has emerged as a solution to address high demand by increasing the number of patients that can be seen at once (Greenberg et al., 2020). In this model, groups of patients are seen together for genetic education, usually followed by a short individual session (Cohen et al., 2012). Initial studies in groups of patients at high risk for hereditary breast and ovarian cancer demonstrated no difference in knowledge (Benusiglio et al., 2016; Calzone et al., 2005), satisfaction with genetic counseling (Benusiglio et al., 2016; Calzone et al., 2005; Gates, 2019; Ridge et al., 2009; Rothwell et al., 2012), or perceived personal control (Rothwell et al., 2012) when receiving group versus individual counseling. The scope has expanded to involve groups of patients with

mixed hereditary cancer indications (Hynes et al., 2020; Lohn et al., 2022), cardiomyopathy patients (Otten et al., 2015), and patients with positive prenatal screening results (Cloutier et al., 2017). Regardless of indication, patients report high satisfaction and positive psychological outcomes following group genetic counseling. This service delivery model also increased efficiency by reducing the amount of time spent per patient (Calzone et al., 2005; Gates, 2019; Lohn et al., 2022) and allowing for decreased wait times (Hynes et al., 2020).

Group genetic counseling could address the identified needs of prostate cancer patients and the lack of access to genetic counseling services, but no research exists regarding this model solely for patients who were assigned male at birth (AMAB). Much of the prior research is also limited by non-randomization of patients to either group or individual counseling. To our knowledge, this is the first study to assess the acceptability and utility of group genetic counseling for patients with prostate cancer. A previous study at our genetic counseling clinic at Prisma Health Midlands piloted group genetic counseling for patients with a new diagnosis of breast cancer (Gates, 2019). Our study implemented improved methodology in a novel patient population. We aimed to compare satisfaction and empowerment of prostate cancer patients randomized between individual versus group genetic counseling and to assess their overall receptiveness to group genetic counseling. This study also aimed to evaluate whether implementing group genetic counseling increased clinic efficiency compared to individual genetic counseling.

2.3 Materials and Methods

This study was reviewed by the Prisma Health Midlands Institutional Review Board and was granted an exemption (1929532).

2.3.1 Participants and Recruitment

Participants were patients with a prostate cancer diagnosis referred for cancer genetic counseling at Prisma Health Midlands. Eligible English-speaking patients had a diagnosis of prostate cancer and met NCCN criteria (Prostate Cancer Guidelines Version 4.2022) for genetic evaluation for hereditary cancer predisposition syndromes. Only English-speaking patients were enrolled because the scales used on the surveys have not been validated in other languages. Participants were enrolled from July 2022 through November 2022. Participation in the study was voluntary. Eligible prostate cancer patients were contacted via telephone, and individuals who agreed to participate were verbally consented (Appendix A). Participants were randomized to one of two cohorts: individual genetic counseling or group genetic counseling.

2.3.2 Procedure

Both cohorts received the following components in their genetic counseling session: discussion of medical and family history, hereditary cancer risk assessment, education about hereditary cancer principles, and discussion of personalized genetic testing options. The cohorts differed in the delivery method of these components. Participants in the individual genetic counseling cohort discussed all these components in a one-on-one setting with one of three board-certified Prisma Health cancer genetic counselors. In the group genetic counseling cohort, one board-certified Prisma Health cancer genetic counselor explained hereditary cancer principles and genetic testing to a group of 2-3 participants. Following group education, participants then had a one-on-one, private discussion with one of two board-certified Prisma Health cancer genetic counselors about medical and family history, hereditary cancer risk assessment, and

personalized genetic testing options. Participants in both cohorts were invited to bring one support person with them.

All participants completed a paper survey before and after their appointments (Appendix B). All Likert scale questions included five possible responses: 1= strongly disagree, 2= somewhat disagree, 3= uncertain, 4= somewhat agree, 5= strongly agree. No identifying information was collected on the surveys. Participants were assigned a unique number which was noted on their paper survey and coded into a database which was kept on a secure network drive. Additional data obtained from the medical record such as age, details on their prostate cancer, family history of cancer, and uptake of genetic testing was noted in this database.

The pre-appointment survey assessed participants' feelings of empowerment prior to genetic counseling using the Genomics Outcome Scale (GOS), a validated measure of empowerment involving six Likert scale questions (Ting et al., 2021). The scale includes items such as "I can explain what the condition means to people outside my family who may need to know" and "I can make decisions about the condition that may change my future or my child(ren)'s future." The wording "the condition" was changed to "hereditary cancer" to increase specificity; for example, Item 1 in this study reads "I can explain what hereditary cancer means to people outside my family who may need to know." The GOS scale was then repeated on the post-appointment survey. In addition to the GOS, the post-appointment survey also included the Genetic Counseling Satisfaction Scale (GCSS), a validated measure of patient satisfaction with genetic counseling involving six Likert scale questions (DeMarco et al., 2004). The post-appointment survey also included free-response questions to expand upon empowerment or satisfaction. The

post-appointment survey included one additional Likert scale question to assess information overload ("I felt that the content of the information was overwhelming"). This question was originally part of our clinic's prior group genetic counseling survey (Gates, 2019) and was included because the prior study suggested differences in feeling overwhelmed between those who had individual genetic counseling and those who had group genetic counseling.

To assess receptiveness to group genetic counseling, the individual cohort's post-appointment survey included a yes/no question asking whether participants would be willing to receive group genetic education followed by a brief individual session. Participants were asked to expand on their answer in a free-response question. The group cohort's post-appointment survey included a free response question asking if they would change anything about their group genetic counseling appointment.

The time that a genetic counselor spent in each group session and individual session was recorded. For each participant in the group cohort, length of group education and length of the one-on-one portion were both recorded. Group size was also recorded.

2.3.4 Data Analysis

Quantitative analysis was performed using Microsoft Excel and SPSS software. Descriptive statistics were used to calculate the mean and frequencies of variables. Pre-session and post-session empowerment scores were calculated by summing participants' responses to GOS items 1-6 and mean scores were calculated. GOS item 3 ("When I think about cancer in my family, I get upset") was reverse scored. The difference between the pre-session and post-session empowerment scores was also calculated by subtracting the mean pre-session score from the mean post-session score for each cohort. Satisfaction

scores were summed across the GCSS items 1-6 and mean scores were calculated. Independent t-tests were used to compare the cohorts' satisfaction and empowerment scores as well as responses to specific survey questions. Paired t-tests were used to compare pre-session and post-session mean empowerment scores across both cohorts. Correlation and regression analysis were performed to evaluate effects of demographic and cancer variables on satisfaction and empowerment scores. Genetic counselor time per group cohort patient was calculated by dividing the total length of the group session by the number of participants in the group, then adding time spent in the brief individual session for each participant. Qualitative analysis was not performed due to lack of replies to free response questions.

2.4 Results

2.4.1 Enrollment and Response Rates

As shown in Figure 2.1, 19/46 eligible patients were enrolled. Of the 46 eligible patients, 59% either actively or passively declined to participate. A total of 16 participants completed both the pre- and post-appointment surveys: seven from the individual genetic counseling cohort and nine from the group genetic counseling cohort.

2.4.2 Demographic Information and Prostate Cancer Variables

Participants' demographic and cancer information is summarized in Table 2.1. Half of the participants were between the ages of 60-69 and most were married with children. The majority of participants reported African American ancestry (56%) and 69% reported non-Hispanic ethnicity. Participants had a wide range of education levels, with 44% reporting high school level education and 38% reporting either a bachelor's or postgraduate degree. All but one individual elected to proceed with genetic testing. This

individual declined genetic testing because results would not affect his prognosis, and he did not have any children.

Differences between the individual and group cohorts' demographic and cancer variables are also shown in Table 2.1. No major differences in race or ethnicity were observed between cohorts although statistical tests were not run due to the small sample size. More participants in the individual cohort had at least some college education, whereas 55% of the group cohort reported high school as their highest education level. More participants in the individual cohort brought a support person to their appointment compared to the group cohort. The one participant who did not have a family history of cancer as well as the one participant who declined genetic testing were both in the group cohort.

2.4.3 Satisfaction

The individual counseling cohort had an average satisfaction score of 28.43 (out of 30) and the group counseling cohort had an average satisfaction score of 26.44 (Figure 2.2). The difference in satisfaction scores between cohorts was not found to be statistically significant ($p=0.12$). Item 4 on the GCSS measures participants' satisfaction with the length of their appointment. The average individual cohort score was 4.7 (out of 5) and the average group cohort score was 4.4 ($p=0.48$). Correlation analysis was performed to evaluate effects of demographic or cancer-related variables on satisfaction scores, and no statistically significant correlations were observed. Regression analysis did not show Gleason score ($p=0.59$), presence of children ($p=0.80$), or presence of a support person at the appointment ($p=0.59$) to have a significant effect on satisfaction scores.

2.4.4 Empowerment

A statistically significant increase in empowerment scores after the genetic counseling session was observed in both cohorts (Figure 2.3). The individual cohort had an average pre-session empowerment score of 18.43 (out of 30) and an average post-session score of 23.57 ($p=0.04$). The group cohort had an average pre-session empowerment score of 18 and an average post-session score of 22.61 ($p=0.04$). The individual cohort experienced a greater increase in empowerment (5.14 units) compared to the group cohort (4.61 units), but this difference was not found to be statistically significant ($p=0.85$). Additionally, there was no significant difference in feelings of being overwhelmed between the two cohorts (mean individual score = 1.57, mean group score 1.41; $p=0.06$). Correlation analysis showed a moderate negative correlation between pre-session empowerment scores and presence of a support person at the appointment (Pearson's $r= -0.51$, $p<0.5$). Regression analysis showed that presence of a support person related to a greater increase in empowerment scores ($p=0.03$). There was a negative correlation between post-session empowerment scores and participants' Gleason scores ((Pearson's $r= -0.70$, $p<0.1$) as well as participants' ages (Pearson's $r= -0.57$, $p<0.5$). Gleason score was not shown to be a significant predictor of difference in empowerment scores from pre-session to post-session ($p=0.18$).

2.4.5 Acceptability of Group Genetic Counseling

Following their session, participants in the individual cohort were asked "Would you have been comfortable receiving education about hereditary cancer in a group setting with other patients, followed by an individual, private conversation about your risks and genetic testing?" The majority of participants (71%, n=5) responded that they would not

be comfortable with group genetic counseling. Participants were given the opportunity to expand on their answer, but no responses were received.

2.4.6 Efficiency

Individual genetic counseling sessions lasted an average of 37 minutes (range 30-50 minutes). In the group counseling cohort, the group education portion lasted an average of 12 minutes (range 10-15 minutes) and the individual portion lasted an average of 16 minutes (range 10-30 minutes). Genetic counselors spent an average of 21 minutes per patient in the group counseling cohort, which was found to be a statistically significant time savings ($p<0.001$).

2.5 Discussion

2.5.1 Patient Outcomes Following Group Genetic Counseling

Patient satisfaction and empowerment scores were high in the individual and group genetic counseling cohorts. Participants in both cohorts indicated that they understood the information and found it valuable for decision-making. Those who underwent group genetic counseling reported feeling empathy and understanding from their genetic counselor, leading to high satisfaction scores. Participants' empowerment scores indicate an increase in decisional and behavioral control, emotional regulation, and hope following both group and individual genetic counseling (Ting et al., 2021). This is congruent with our clinic's prior group genetic counseling study involving breast cancer patients, where no statistically significant differences in satisfaction were observed between individual and group genetic counseling cohorts (Gates et al., 2019). This data also reflects results from prior group genetic counseling studies that included some AMAB participants (Calzone et al., 2005; Hynes et al., 2020; Lohn et al., 2022; Otten, et

al., 2015). Across these studies, patient satisfaction and empowerment scores were high, but no sex-specific outcomes were reported. Our study shows preliminary evidence that group genetic counseling does not negatively impact the education and psychosocial support received by prostate cancer patients. Future group genetic counseling studies should aim to recruit more AMAB participants so that a larger sample size can be evaluated.

It was found that those with lower pre-session empowerment scores were more likely to bring a support person with them to their appointment. Additionally, those who brought a support person tended to have a greater increase in empowerment compared to those who attended alone, such that post-session empowerment scores were equally high among those who did and did not bring a support person. It is possible that those feeling low levels of control or hope prior to a genetic counseling session were more inclined to bring a support person, but the genetic counselors provided enough relevant education and psychosocial support that the impact of a support person was felt less after the session. Analysis is limited by small sample size and the fact that more of those in the individual cohort (57%) brought a support person compared to the group cohort (33%). Future studies might consider a more extensive evaluation of a support person's impact on group genetic counseling outcomes, or on AMAB individuals' experience with genetic counseling in general.

In this study, the vast majority of prostate cancer patients reported that they did not feel overwhelmed by the session content, with no significant difference between cohorts. However, our clinic's prior study found that breast cancer patients in the group cohort felt significantly less overwhelmed by the information compared to the individual

cohort (Gates, 2019). Gates (2019) proposed that benefits of group dynamics, including a sense of community and ability to hear others' questions, contributed to decreased anxiety in the group cohort. Benusiglio et al. (2016) observed a beneficial exchange of questions and information in group genetic counseling sessions for hereditary breast and ovarian cancer. The authors hypothesized that empowerment increased because patients heard similar perspectives and gained new medically relevant information (Benusiglio et al., 2016). Several other studies noted similar beneficial group exchanges (Hynes et al., 2020; Lohn et al., 2022), while others found it difficult to encourage group interaction (Otten et al., 2015). No formal evaluation of group interaction between participants was collected in this study. Some research shows that prostate cancer patients strongly desire support groups to connect with others who have similar physical and psychosocial concerns (Hyatt et al., 2021; Suttman et al., 2018). One study showed that education groups and peer-to-peer discussion increased prostate cancer knowledge, improved outlook on sexual dysfunction, and led to a healthier lifestyle in participants with prostate cancer compared to those who did not participate in groups (Lepore et al., 2003). Perhaps those inclined to seek out prostate cancer support groups would find group genetic counseling more helpful than one-on-one counseling. Beneficial group interactions are often cited as an underlying motivation for implementing group genetic counseling, so future studies might consider focusing on presence or absence of group dynamics between prostate cancer patients.

2.5.2 Efficiency of Group Genetic Counseling

This study showed that group genetic counseling for patients with a diagnosis of prostate cancer resulted in significant time savings per patient. Additionally, those in the

group cohort overwhelmingly expressed satisfaction with the length of their genetic counseling session. Prior studies have consistently shown that group genetic counseling translates to less time spent per patient (Calzone et al., 2005; Cloutier et al., 2017; Lohn et al., 2022) and reduction of wait times (Hynes et al., 2020). Future studies should include evaluation of wait times to demonstrate improved access, including patient-reported outcomes measures to ensure quality of care is not negatively impacted.

2.5.3 Receptiveness and Acceptability of Group Genetic Counseling

Though our data shows that prostate cancer patients who received group genetic counseling were highly satisfied, the majority of participants from the individual cohort indicated they would not be comfortable receiving group education. This is consistent with our clinic's prior study, where 87% of breast cancer patients reported that they would not be willing to receive group genetic counseling (Gates, 2019). Furthermore, 59% of eligible patients contacted for this study either actively or passively declined to participate. Concerns in other studies included confidentiality and privacy in a group setting, as well as wanting to bring multiple family members and feeling intimidated by strangers (Gates et al., 2019; Hynes et al., 2020; Lohn et al., 2022; Ridge et al., 2009). Some research found that cancer patients would prefer individual over group genetic counseling for these reasons (Ridge et al., 2009; Rothwell et al., 2011), while Hynes et al. (2020) reported that 95% of patients who received group genetic counseling would recommend the model. Calzone et al. (2005) found that patients expressed a preference for whichever genetic counseling method they received. Ultimately, it is worth considering whether prostate cancer patients would accept group education in practice if it was presented as the usual method.

One group genetic counseling participant in this study mentioned that he would have preferred a virtual appointment because he had to drive a long distance. Lohn et al. (2022) also reported that the majority of those who declined to participate in group genetic counseling cited location as the primary factor. In response, the authors are currently piloting a virtual approach to group genetic counseling (Lohn et al., 2022). Given the increased implementation of telegenetic counseling during COVID-19, fewer technological and billing limitations exist and patients have become more comfortable with video visits (Allison et al., 2022; Mills et al., 2021). Future studies might consider evaluating the acceptability of telegenetic group counseling among AMAB patients.

2.5.4 Study Strengths, Limitations, and Future Research

This study was underpowered due to small sample size and small group size. Despite multiple statistically significant hypothesis tests, future studies should aim to recruit more participants to achieve a larger sample size in an effort to reduce the chances of type I error. Larger groups of prostate cancer patients could also provide more opportunity to observe group dynamics noted in existing research. Even with a small sample size, the cohorts were diverse, with majority African American participants and a range of education levels. However, the study was limited to English-speaking patients and multiple minority groups and ethnicities were not represented in the sample. Future studies should aim to maintain diversity among larger cohorts to ensure that outcomes are applicable to a wide patient population. The study was also limited to patients with a current prostate cancer diagnosis, as we found a homogenous group provided simpler coordination and minimized privacy concerns. Expanding the scope to include unaffected AMAB patients with a family history of cancer may inform more broad experiences with

group genetic counseling. Studies focusing on large-scale group genetic counseling with both AMAB and AFAB participants should consider evaluating whether any sex-specific differences in patient outcomes arise. Finally, our study demonstrated significant time savings per patient with group genetic counseling but was not designed to show whether access to genetic counseling services subsequently improved over time by allowing shorter wait times or more patients seen per genetic counselor. Future studies might consider demonstrating that time savings led to shorter wait times or an increased number of patient slots, especially if telegenetics is incorporated with group counseling.

2.6 Conclusion

Our study is the first to report outcomes for prostate cancer patients after group genetic counseling compared to individual genetic counseling. To our knowledge, it is also the first study that evaluates group genetic counseling solely for AMAB patients. Data was consistent with prior studies and demonstrated increased clinical efficiency (less time per patient) and high satisfaction and empowerment among those who received group genetic counseling. However, we found that most patients would choose individual genetic counseling over group counseling and rejection rate to participate in the study was high. Further research is needed to confirm these results in a larger sample. Future studies are warranted to expand on this preliminary data by considering different recruitment methods, evaluating more variables associated with positive patient outcomes, and by incorporating virtual group genetic counseling.

Table 2.1 Patient demographics and cancer information

Characteristic	Total (n=16)	Individual (n=7)	Group (n=9)
Age			
50-59	2 (13%)	-	2 (22%)
60-69	8 (50%)	3 (43%)	5 (56%)
70-79	4 (25%)	3 (43%)	1 (11%)
80-89	2 (13%)	1 (14%)	1 (11%)
Race			
White	6 (38%)	3 (43%)	2 (22%)
African American	9 (56%)	4 (57%)	6 (67%)
Not Specified	1 (6%)	-	1 (11%)
Ethnicity			
Non-Hispanic	11 (69%)	7 (100%)	4 (44%)
Hispanic	1 (6%)	-	1 (11%)
Not Specified	4 (25%)	-	4 (44%)
Education			
Some high school	3 (19%)	-	3 (33%)
High school/GED	4 (25%)	2 (29%)	2 (22%)
Some college	1 (6%)	1 (14%)	-
Associate/Technical degree	2 (13%)	-	2 (22%)
Bachelor's degree	3 (19%)	2 (29%)	1 (11%)
Post-graduate degree	3 (19%)	2 (29%)	1 (11%)
Relationship Status			
Single, never married	1 (6%)	-	1 (11%)
Domestic partnership	1 (6%)	1 (14%)	-
Married	10 (63%)	3 (43%)	7 (78%)
Divorced	1 (6%)	1 (14%)	-
Widowed	3 (19%)	2 (29%)	1 (11%)
Children			
Yes	12 (75%)	5 (71%)	7 (78%)
No	4 (25%)	2 (29%)	2 (22%)
Support person			
Yes	7 (44%)	4 (57%)	3 (33%)
No	9 (56%)	3 (43%)	6 (67%)
Cancer family history			
Yes	15 (94%)	7 (100%)	8 (89%)
No	1 (6%)	-	1 (11%)
Gleason score			
6	1 (6%)	1 (14%)	-
7	9 (56%)	3 (43%)	6 (67%)
8	4 (25%)	3 (43%)	1 (11%)
9	2 (13%)	-	2 (22%)
Genetic testing uptake			
Yes	15 (94%)	7 (100%)	8 (89%)
No	1 (6%)	-	1 (11%)

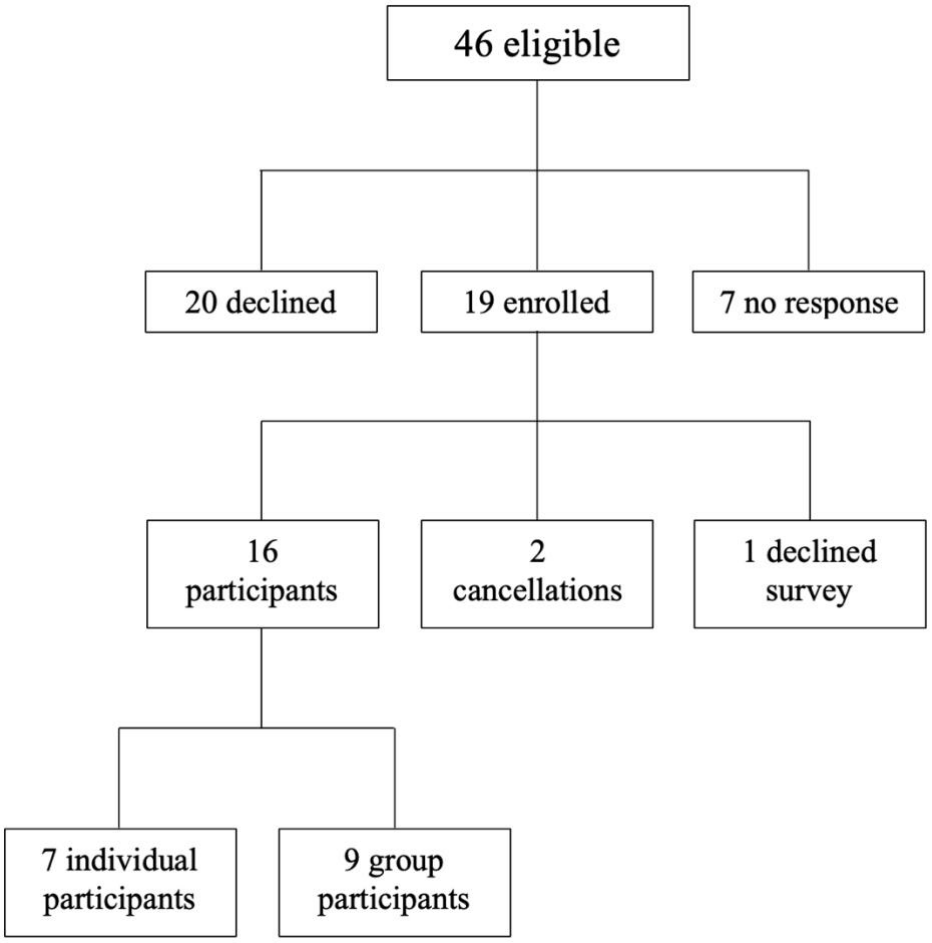

Figure 2.1 Enrollment and response rates

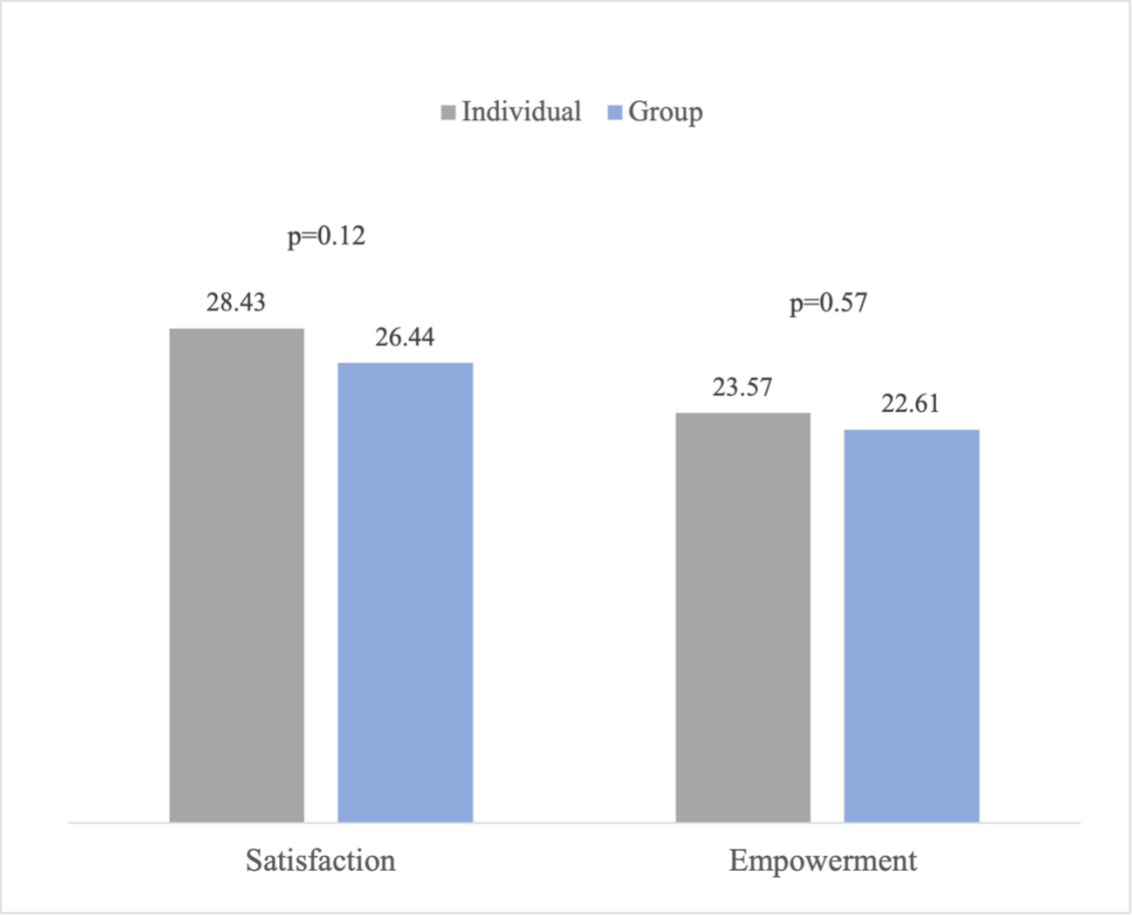

Figure 2.2 Mean satisfaction and empowerment scores following individual versus group counseling

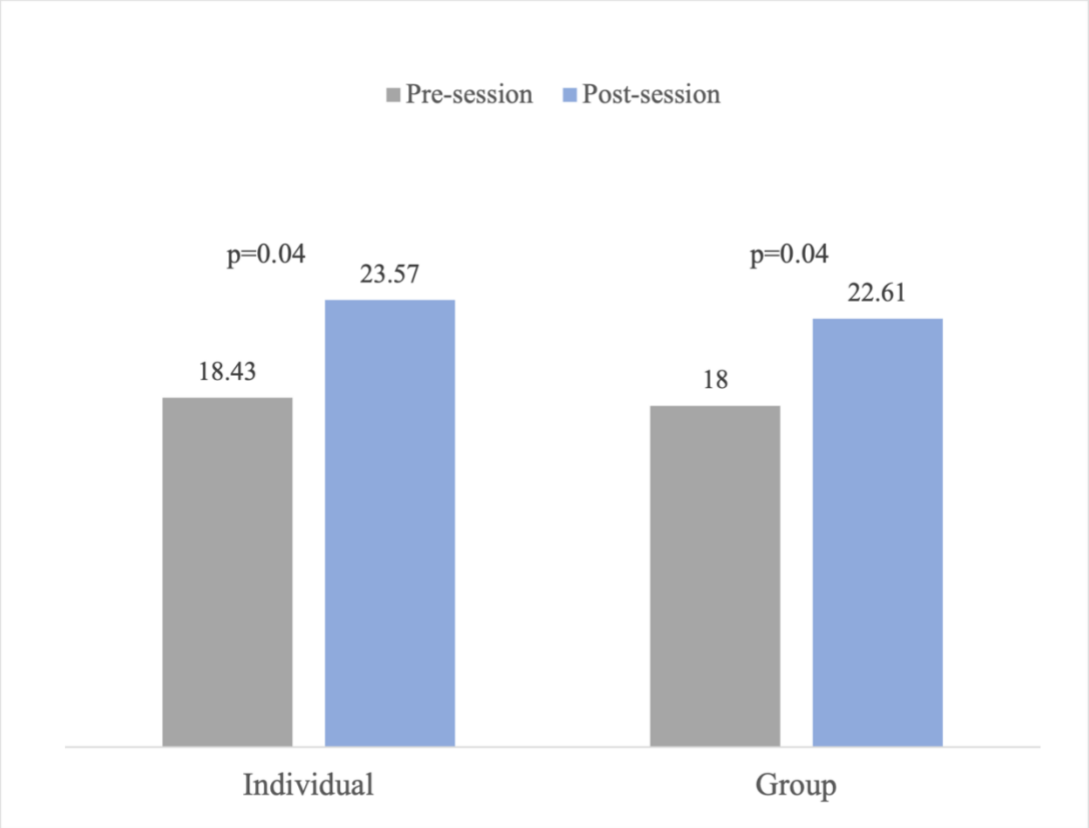

Figure 2.3 Pre-session and post-session empowerment scores between individual and group genetic counseling cohorts

CHAPTER 3

CONCLUSION

This study implemented group genetic counseling for prostate cancer and evaluated patient satisfaction and empowerment compared to traditional individual counseling. Participants were randomized to either group or individual genetic counseling and surveys with validated satisfaction and empowerment scales were used to measure patient outcomes. Sample size was small, but this data show that prostate cancer patients experienced high satisfaction and empowerment following group genetic counseling. Additionally, the study determined that the group model saved genetic counselors an average of 16 minutes per patient. While these outcomes were consistent with existing research in patients who are high-risk for hereditary cancer, rejection rate for this study was high and we found that most prostate cancer patients would prefer individual over group genetic counseling if given the choice. We identified several avenues where future studies can expand in order to further assess group genetic counseling for a wide variety of patients.

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APPENDIX A

PHONE SCRIPT

Hello, this is _____, from Prisma Health Genetic Counseling. I am calling regarding your appointment for cancer genetic counseling. We currently have you scheduled for [date]. Are you aware of this appointment? **OR** We have received a referral on you from Dr. [X]. Were you aware of this referral? [Discuss reason if needed]

We are currently looking into patient satisfaction with their genetic counseling appointment. So, we would like to invite you to participate. This will involve filling out a survey after your visit. Participating will not change the information discussed during your appointment or the genetic testing offered to you.

I have more details if you might be interested.

[If yes or maybe] Some that agree to participate, will have all of their appointment with the genetic counselor alone, and others will have a brief education session before they meet alone with a genetic counselor. This will be to discuss your personal/family history specifically. Nothing private is discussed in the group. At the beginning and end of your appointment, you will be given a survey.

You do not have to participate in this survey and chose to keep your genetic counseling appointment [as currently scheduled/scheduled in the next available slot.]

Do you have any questions?
Do you agree to be part of this study?

APPENDIX B

SURVEY

Hello,

You are being invited to participate in this research study because you have been referred for genetic counseling for hereditary cancer. The title of this study is, "Comparing efficiency, empowerment, and satisfaction between individual and group genetic counseling for prostate cancer." It has been approved by the Prisma Health IRB. The goal of this study is to evaluate your satisfaction with your genetic counseling appointment. Your participation in this study is completely voluntary. The attached survey involves answering 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 question. Doing so will not affect the service you receive as part of your clinical appointment with the genetic counselor. 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 Sarah.Dickman@uscmed.sc.edu.

Sincerely,

Sarah Dickman
Genetic Counseling Student
University of South Carolina School of Medicine

Please complete this page <u>BEFORE</u> your appointment.

Circle the response that best fits your present feelings.

	Strongly disagree	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I can explain what hereditary cancer means to people outside my family who may need to know.	1	2	3	4	5
I know who else in my family might be at risk for cancer.	1	2	3	4	5
When I think about cancer in my family, I get upset.	1	2	3	4	5
I know what I can do to change how hereditary cancer affects me/my children.	1	2	3	4	5
I am able to make plans for the future.	1	2	3	4	5
I can make decisions about hereditary cancer that may change my future or my child(ren)'s future.	1	2	3	4	5

Please complete the following pages <u>AFTER</u> your appointment.

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 felt that the content of the information was overwhelming.	1	2	3	4	5

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

	Strongly disagree	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I can explain what hereditary cancer means to people outside my family who may need to know.	1	2	3	4	5
I know who else in my family might be at risk for cancer.	1	2	3	4	5
When I think about cancer in my family, I get upset.	1	2	3	4	5
I know what I can do to change how hereditary cancer affects me/my children.	1	2	3	4	5
I am able to make plans for the future.	1	2	3	4	5
I can make decisions about hereditary cancer that may change my future or my child(ren)'s future.	1	2	3	4	5

Individual genetic counseling cohort only:

3. You received individual genetic counseling today. Would you have been comfortable receiving education about hereditary cancer in a group setting with other patients, followed by an individual, private conversation about your risks and genetic testing? (circle one)

   Yes No

4. If you would like to comment on any of your answers in Questions 1-3, please do so below:

   _____

   _____

   _____

   _____

   _____

   _____

   _____

Group genetic counseling cohort only:

5. What, if anything, would you change about your appointment?

   _____

   _____

   _____

   _____

   _____

   _____

   _____

Demographics:

Race:
Please check all that apply.

- □ White
- □ African American/Black
- □ Middle Eastern/North African
- □ American Indian/Alaskan Native

- □ East Asian/Southeast Asian
- □ South Asian
- □ Native Hawaiian/Pacific Islander
- □ Prefer not to answer
- □ Other: _____

Ethnicity:
Please check one.

- □ Non-Hispanic
- □ Hispanic/Latinx
- □ 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's degree
- □ Post-graduate degree (MD, Ph.D., MS, JD)

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 children?

- □ Yes
- □ No

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

- □ Yes If yes, whom? _____
- □ No