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**DYING TO BE MASCULINE: THE BARRIERS MEN FACE TO ACCESSING
GENETIC COUNSELING**

**A thesis submitted to
Regis College
The Honors Program
in partial fulfillment of the requirements
for Graduation with Honors**

by

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May 2022

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ABSTRACT

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DYING TO BE MASCULINE: THE BARRIERS MEN FACE TO ACCESSING GENETIC COUNSELING

Advisor's Name: Dr. Erin Winterrowd

Reader's Name: Dr. Michael Ghedotti

There is a crisis in healthcare that is often not discussed: men's health. Men die younger, are more burdened by illness during life, fall ill at a younger age, and have more chronic illnesses than women. Contradictory concepts of health, struggles with help-seeking, and worse healthcare outcomes and life expectancies for men can be traced back to attempts to conform to hegemonic masculine ideals or social norms. Although researchers have studied the stigma of help-seeking in men, these ideas have yet to be extended to the field of genetic counseling. This review outlines the barriers that men face when accessing genetic counseling, using a socioecological conceptual framework. Through pursuing genetic counseling, men are supported through their healthcare decisions, empowered to seek personalized care, and taught the skills to communicate their health challenges to healthcare providers and important people in their lives. Accessing genetic counseling presents an opportunity to challenge narratives of hegemonic masculinity to improve healthcare for men.

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CHAPTER ONE: INTRODUCTION

1.1 The Field of Genetic Counseling

Many traits, physical characteristics, and medical conditions are partly or entirely determined by DNA, the molecule that carries the instructions for many living things. People and other organisms pass down genes, sections of DNA that affect characteristics by producing a protein or other molecules, generationally. Genes can increase one's risk of developing certain health conditions including cancer, neurological disorders, and heart disease. Genetics is the scientific study of genes and heredity ("About Genetic Counselors", n.d.). Over the past 30 years, the field of genetics has rapidly advanced due to new technologies, new genetic testing options, advances in analytical approaches, and landmark studies such as the Human Genome Project. Because of these advancements, many of the genes and variants that cause genetic disease have been identified. In a relatively short time frame, this knowledge has been applied to clinical care. Genomic medicine, which was previously uncommon and usually expensive, has become mainstream (Claussnitzer et al., 2020). Since disease heritability is complicated, many patients seek support in understanding their risk for certain genetic conditions. Oftentimes, doctors refer patients to genetic counselors to assess their risk and treatment options.

While concerns about passing on hereditary conditions dates back thousands of years, formal counseling about the recurrence of hereditary conditions began in the 1940s when medical centers began to open hereditary clinics. The field of genetic counseling is a relatively new medical specialty, evolving over time alongside advances in medical genetics and genomics (Cohen, 2020). Genetic counselors are medical professionals that receive training in both medical genetics and counseling. Patients pursue genetic counseling to learn about how genetic conditions might affect them or their family. By working alongside clients, genetic counselors

work towards understanding and adapting to the psychological, medical, and familial effects of the genetic contributions to disease. Genetic counselors interpret family and medical histories to assess the risk of disease occurrence or recurrence. The responsibilities of genetic counselors also include educating clients about testing, inheritance, management, prevention, research, and other resources. In addition to knowledge about medical genetics, genetic counselors use counseling techniques to help their clients make informed choices and to adapt to a risk or condition (Resta, 2006). Doctors refer patients to genetic counselors for support through planning for pregnancy, during pregnancy, caring for children, or managing personal health (“Genetic Counseling”, 2020). Specialties include prenatal, pediatric, oncology, neurology, ophthalmology, psychiatry, and other areas (“About Genetic Counselors”, n.d.).

1.2 My Reasons for Pursuing a Career in Genetic Counseling

I hope to pursue a career in genetic counseling and was drawn to the field of genetic counseling because of the field’s emphasis on client autonomy. Genetic counselors work with their clients during some of the most difficult times of their lives, helping them to make informed choices about their healthcare. From helping couples understand family histories of genetic conditions when engaging in their own family planning to determining the most suitable cancer treatments for patients with cancer to communicating insurance coverage, or lack thereof, genetic counselors work to empower their clients to seek personalized care.

My experience of working with a victim advocate made me realize the power of occupations that help people navigate complicated systems and experiences much like genetic counseling. I have faced personal experiences with hardships in which I felt like I had little control over the situation. I survived multiple sexual assaults in high school. When I started college, I had not dealt with the trauma of my past assaults. Then, during my first year of college,

I was date-rape drugged. This experience was especially difficult to navigate because of prior sexual assaults. I worked with my university's Title IX office as well as a victim advocate provided through the school. My relationship with a victim advocate was essential for helping me not only make decisions regarding the Title IX process, but to also begin to acknowledge what had happened to me before coming to Regis.

When I was faced with great adversity, my victim advocate guided me through the confusion to make healing possible. When he sexually assaulted me, he took control over my body, and denied me control over my own body. Following these experiences, I wanted to focus on healing. Instead, I was bombarded by investigations, reporting, doctors' appointments, and paperwork. My victim advocate was my guide, holding my hand through all the processes so I could focus on surviving. She empowered me by giving me back control over my life and explaining the choices I had available to me. Victim advocates and genetic counselors fill similar roles; they give their clients their sense of control back when they feel like they have no control.

Enduring sexual assaults inspired me to work with my university's Victim Advocacy and Violence Prevention (VAVP) department to plan programming, trainings, and events to normalize healthy relationships on campus. One of the most impactful experiences from this job was developing and leading a book club about Chanel Miller's story of surviving sexual assault with other survivors and allies. By facilitating discussions, book club members heard the stories of others, asked questions, and shared their own experiences. Through this process, I was able to guide people through the healing process. During meetings, I worked to translate difficult concepts of the cultural elements that perpetuate gender-based violence while also navigating the emotions that arose during discussions. For example, we discussed the psychology of trauma and how the process of going to court was retraumatizing instead of healing for Miller. Although

running this book club was difficult, it was highly rewarding and gave me a glimpse of the role of a genetic counselor.

Through my work at VAVP, I also learned about masculinity in the context of healthy relationships, sexual assault, intimate partner violence, and stalking. One of the greatest challenges I faced in this role as a peer educator was training male athletes. These trainings covered Title IX, our university's sexual misconduct policy, consent, and healthy relationships. During these trainings, I faced pushback from the trainees. These experiences motivated me to learn more about masculinity and how it contributes to gender-based oppression. While learning about masculinity in the context of VAVP, I began to extend what I was learning to my career aspirations of pursuing genetic counseling and wonder about how our narratives about masculinity contribute to men's health outcomes.

1.3 Genetic Counseling & Improving Men's Healthcare

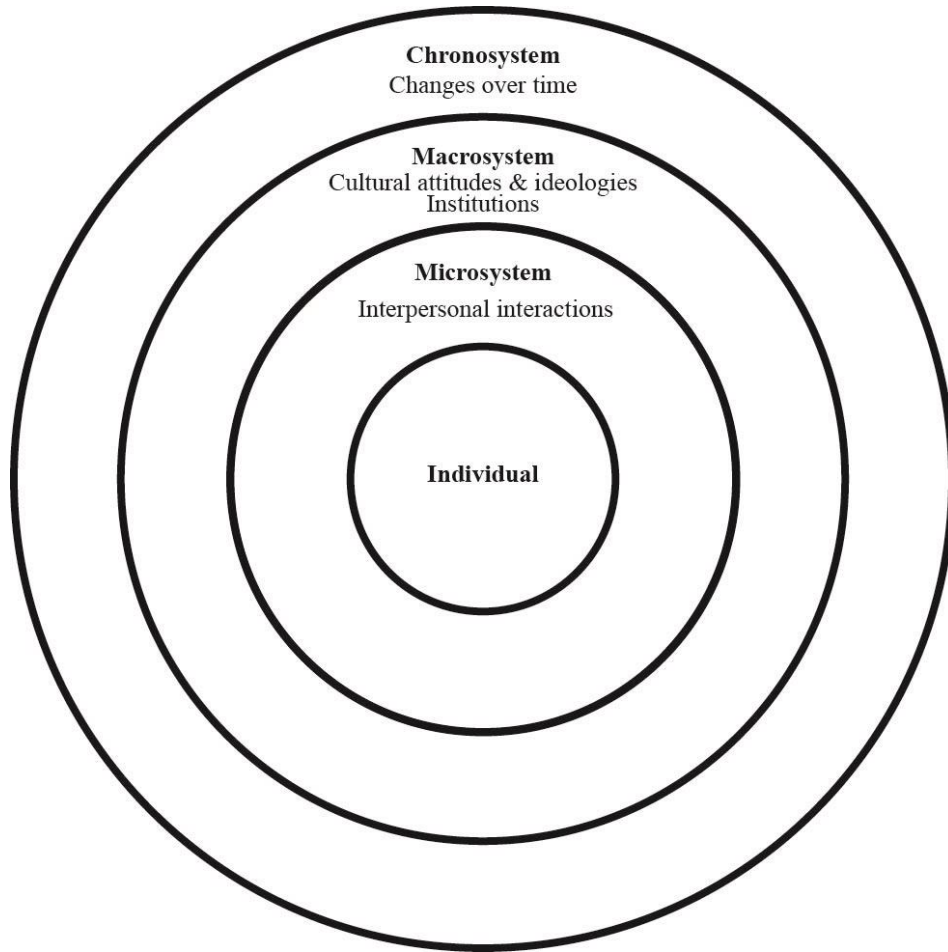
Genomics and personalized medicine allow for better health outcomes for patients facing many kinds of medical conditions. As genomics becomes more integrated with clinical practice, the medical field faces the issue of exacerbating the existing health disparities if genomic services are not accessible to all populations equitably (Jooma et al., 2019). High costs and variable insurance coverage for genetic tests, the need for more provider knowledge about genomics, availability of technology in low-resource areas, and a shortage of genetic counselors indicate that access to genomic services is still a significant barrier. To equitably advance genomic medicine in a way that can improve the health of all populations, we must begin by looking at those who are facing the worst health outcomes. Men are one such group.

Pressure to adhere to masculine norms can explain the challenges that men face when it comes to seeking healthcare. This assertion connects to the title of my thesis: “Dying to Be Masculine.” Men desire to maintain masculine gender norms, and in doing so, put their health and well-being at risk. Research exists within the field of psychology surrounding the stigma of help-seeking in men (Davis, & Liang, 2015; Good et al., 2004; Herron et al., 2020; Kaya, Iwamoto, & Brady, 2019; Kimmel, 1997), yet these ideas have yet to be extended to the field of genetic counseling. Through pursuing genetic counseling, men are supported through their healthcare decisions, empowered to seek personalized care, and taught the skills to communicate their health challenges to healthcare providers and important people in their lives. Accessing genetic counseling presents an opportunity to challenge social norms surrounding masculinity to improve healthcare for men.

Men face barriers to accessing genetic counseling services at various levels. To exhibit the psychosocial factors that prevent men from utilizing healthcare services, I employ Bronfenbrenner’s Ecological Systems Theory. Bronfenbrenner’s theory, originally developed in the context of child development, postulates that individuals are affected by a complex system of relationships consisting of multiple levels of the surrounding environment including interpersonal interactions, cultural values, laws, institutions, and changes that occur over time. To improve issues of access for men and to improve men’s health outcomes through genetic counseling, it is important to understand the various barriers that exist at various interacting systems. Bronfenbrenner divided an individual’s environment into five different systems: the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem (Bronfenbrenner, 1979, Figure 1). In this analysis, I focus on four levels of Bronfenbrenner’s model.

Figure 1

Bronfenbrenner's Ecological Systems Theory



(Bronfenbrenner, 1979)

CHAPTER TWO: THE MACROSYSTEM

The macro level of Bronfenbrenner's Ecological Systems Theory includes social norms and beliefs, cultural elements, and structural influences (Bronfenbrenner, 1979). This can include many identities that individuals hold including socioeconomic status, race, and gender. Gender, as defined as whatever a culture at a particular time in history prescribes as masculine and feminine, can act as a barrier for people seeking healthcare and support. Gender is a feature of society as well as a characteristic of an individual; that is, it is socially constructed. Gender identity refers to an individual's personal sense of having a particular gender. Gender expression is how a person expresses their gender identity through their appearance, clothing, behavior, and other forms of expression. With gender identity and expression comes certain gender societal expectations. Gender also acts as a social marker and places individuals in a social hierarchy. While men hold the power in most societies, men also face social pressures that come with their gender identity. Masculinity exists in many forms, varying by culture. Hegemonic masculinity, or the dominant masculinity over different competing types of local masculinities, prescribes how men are expected to behave. Hegemonic masculinity is characterized by attributes such as having power, dominance, aggressiveness, courage, independency, efficiency, rationality, competitiveness, success, activity, control, and invulnerability (Connell, 1995, Figure 2). Gender expectations can affect people's behaviors and conceptions of self.

Figure 2*Defining Hegemonic Masculinity*

2.1 Cultural Beliefs Surrounding Masculinity in the United States

Manhood is a precarious identity, meaning it must be earned and can be taken away and threatened. Womanhood is not as precarious of an identity for women. While some circumstances, such as infertility, could pose a threat to women's gender identity, manhood is only earned by men who adhere to socially accepted characteristics of masculinity (Kimmel, 1997). For example, if a man cries and this goes against the expectation that men are not supposed to cry, this man is deemed to be less "manly" or masculine. Men must consistently demonstrate their masculinity through engaging in displays of masculine characteristics, such as aggression, and avoiding these kinds of displays of femininity (Vandello & Bosson, 2013).

Masculinity within a patriarchal society is the antithesis of femininity (Kimmel, 1997). Because of this, male dominance is oppressive and abusive of the feminine—not only of women but also of the virtues and characteristics associated with femininity including love, relatedness, and gentleness. Feminism has largely focused on the negative effects of patriarchy on women's lives, but patriarchy is an attack on masculinity as well as femininity in its fullness (Moore & Gillette, 1991). In other words, patriarchy harms men in addition to women because it pressures men to behave in prescribed ways and limits their opportunities to be fully themselves.

Men's socialization presents a crisis when men face challenges to their sense of power in control (Solomon & Levy, 1987). When men face certain genetic diagnoses, this could be perceived as a threat to their social power because a genetic difference that may be perceived as a disability is viewed as a loss of power. Gender-role conflict exists when gender roles have negative consequences for people. For men, researchers have identified six patterns of strain resulting from gender-role conflict, the fear of femininity, and male socialization (Figure 3). Three gender-role conflicts that men face are especially relevant to genetic counseling: restrictive emotionality, socialized control and power issues, and health care problems (Solomon & Levy, 1982). These gender expectations can prevent men from seeking healthcare and emotional support through genetic diagnoses and associated counseling offered through genetic counselors.

Figure 3*Male Gender-Role Conflict Patterns*

Note. Patterns of gender-role conflict and issues arising from male socialization and fear of femininity (Solomon & Levy, 1982).

Men oftentimes struggle to live up to hegemonic ideals and feel inadequate and shameful when they cannot do so. It is important for men to maintain separate emotional performances from women because femininity in emotionality signifies subordination within patriarchy. These norms are reinforced as male emotional behavior is policed by other men, and sometimes women. Although breaking gender norms can be protective for mental health, going against norms can cause psychological distress. Since hegemonic masculinity is viewed as the “natural” state of masculinity, a divergent or subordinated masculinity, such as being gay, transgender, bisexual, or not adhering to traditional masculinity may create gender-role conflict or increase risk for mental health issues including suicide (Canetto & Cleary, 2012).

Gender-role conflict can result in severe strain that can cause psychological distress. For example, men represent the majority of those who die by suicide worldwide. Paradoxically, boys and men are less likely than girls and women to engage in nonfatal suicidal behavior (i.e., “attempt suicide”) but more likely to die as a result of a suicidal act. There are possible gendered reasons for this paradox. One possible reason could be that men choose more lethal means such as using guns. This tendency to use more lethal means can be tied back to gender expectations. Hegemonic masculinity’s valuation of efficiency, aggressiveness, and success could pressure men to use means that are more likely to kill themselves, thereby saving them from the potential shame of “failing” at suicide (Canetto & Cleary, 2012). In this example, gender is central to the analysis of suicidal behavior because gender influences the way we view suicide and determines our social power.

Facing a medical diagnosis can be especially challenging for men and can put men at higher risk for suicide. Older European American male adults face high rates of suicide in the U.S. Cultural narratives around gender and suicide could contribute to this high rate. A survey conducted by researchers at the University of Wisconsin Oshkosh in collaboration with Colorado State University (Winterrowd, Canetto, & Benoit, 2015) utilized fictionalized scenarios about older adult suicide to investigate how people view others’ reasons for engaging in suicidal behavior. Health problems were the most endorsed older adult suicide precipitants and were seen as the most likely stressor to cause suicidal ideation, and suicide precipitated by health problems was also rated most positively and seen as courageous or rational. This was in comparison to other precipitants such as financial stress or interpersonal problems. Older adults, people with more education, and people who did not identify with a religion expressed the most favorable attitudes about older adult suicide across suicide precipitants. Men viewed older adult suicide as

more permissible whereas women viewed older adult suicide with more sympathy. The apparent cultural belief among European Americans that suicide is triggered by health problems, in addition to favorable attitudes about older adult suicide, suggest cultural normalization of adult suicide with implications for suicide risk and prevention (Winterrowd, Canetto, & Benoit, 2015). Genetic counseling is a field that deals with medical diagnoses as well as the psychosocial ramifications for receiving a diagnosis. Given that men may have an increased suicide risk following genetic diagnoses, genetic counselors could potentially moderate or alleviate this risk, especially for older White men, by assessing men for their suicide risk and having conversations with their patients about mental health.

While the risk of suicide is high in White men, men of color face unique challenges due to beliefs about masculinity. Concepts of masculinity are informed by multiple social identities including race and ethnicity, so these factors are important to consider when addressing the health needs of men of color. For example, Black men's constructions of masculinity are impacted by additional sociopolitical factors such as race and socioeconomic status, as racism and poverty disproportionately affect Black American men. It is theorized that Black men adhere more strictly to hegemonic masculine ideals to compensate for perceived threats to their masculine identity stemming from experiencing racism (Wade & Rochlen, 2013). This puts Black men at an especially high risk for gender role conflict and could affect help-seeking behaviors and tendencies. On the other hand, some research suggests that Black masculinity can be protective of health. A study conducted on low-income Black men on health attitudes and behaviors showed that Black men with a self-reliant attitude towards maintaining their health were more likely to think about their health, take steps to care for themselves, and believe that they could influence their health. Because of a history of discrimination, Black men may develop

a tendency to rely on interpersonal connections or themselves rather than on larger-scale systems. Black men's reluctance to rely on society and institutions to take care of them motivates them to find it within themselves to manage their care. This, in turn, encourages them to pursue healthcare (Wade, 2009). Racialized concepts of health influence men's health and willingness to seek care.

Latino men also face racialized gender expectations. Many Latino men have different conceptions of masculinity that include machismo and caballerismo. Machismo is typically associated with hypermasculine and stereotyped behaviors including aggression, antisocial behaviors, emotional restrictiveness, and wishful thinking. Caballerismo is a more multidimensional conceptualization of Latino masculinity that includes emotional connectedness and chivalry (Arciniega et al., 2008). Latino men, like Black men, may face threats to their masculinity due to subjugation of their Latino identity because of racism. However, the more multidimensional character of caballerismo may allow Latino men to be more likely to engage in help-seeking behavior (Davis & Liang, 2014).

Asian American men face unique demands in society due to gender and racial stereotypes. Like all men, Asian American men face pressures to adhere to hegemonic masculinity, but their Asian identity complicates these gender concepts further. Unlike overly masculine and hypersexual stereotypes associated with Black men and Latino men, stereotypes of Asian American men usually characterize them as lacking masculinity (Falicov 2010; Wong & Schwing, 2014). Asian Americans are often stereotyped as "the model minority" and characterized as hard-working, intelligent, and successful. Although these stereotypes are positive, they can have detrimental effects. For example, these stereotypes are a perceived threat to White masculinity. These narratives originated historically when Chinese immigrant men were

portrayed as stealing White American's jobs and women. Consequently, to maintain the power structure and dominance of White men, Asian American men are associated with asexuality, passivity, femininity, and weakness as a method of subjugation. This also conforms to the ideas put forth by the model minority stereotype because prioritizing work implies asexuality and sacrificing personal relationships for success (Sue & Zane, 1985). These racialized concepts of gender can be internalized and could influence Asian American men's willingness to seek health care. For instance, out of fears of being perceived as feminine or weak and confirming racial stereotypes, Asian American men may avoid pursuing healthcare. For many Asian American men, racial emasculation represents an immensely shameful experience that deters them from seeking acknowledgment, validation, and support (Liao, 2020). The negative psychological impact of gendered and sexualized racism among queer Asian American men is well documented, including the internalization and reenactment of emasculated stereotypes performed to attain proximity to White hegemonic masculine ideals (Han, 2015). Racial identities, another component of the macro level, complicate gender stereotypes and expectations.

2.2 Institutional Barriers That Men Face

Differences in Life Expectancy & Barriers to Healthcare

When approaching men's healthcare, it is important to examine the cultural narratives that may inform men's approach to healthcare. Cultural beliefs surrounding men's identities can act as barriers for men seeking care. Cultural beliefs about sex/gender have effects on health and well-being. As a result of the advancement of medical diagnoses and treatment and changes to lifestyles, life expectancies have been on the rise in the United States. Despite these improvements, however, the sex longevity gap remains. Everyone is living longer, but females continue to live longer than males, and this gap is widening. In fact, the sex longevity gap is

wider now than it was a century ago (Harvard Health Publishing, 2019). Black men are of special concern in the context of healthcare because Black men have the shortest life expectancy of all race and gender groups in the United States (Wade & Rochlen, 2013). This problem, however, is not unique to men in the United States. Every country, including both developed and developing countries, with reliable health data statistics show that women have longer life expectancies than men and that this has been true throughout history (Austad & Bartke, 2015; Harvard Health Publishing, 2019).

However, this sex gap in longevity is not easily explained. There is a paradox that exists in gender differences in longevity. Women seem to face worse health outcomes globally, yet they face better survival outcomes than men (Austad & Bartke, 2015). Globally, women display higher overall rates of physical illness, “morbidity”, than men at all ages. Women also experience more disabilities and activity limitations from those illnesses. However, men die younger and fall ill at a younger age when they do fall ill. In addition, when we disaggregate the data, we see that men have more chronic illnesses, specifically, than women (Harvard Health Publishing, 2019).

Some would argue that these life expectancy differences are due to biological factors between males and females, not social reasons. For instance, differences in immune responses, sex chromosomes, or sex hormones could explain differences in susceptibility to various diseases (Ferguson et al., 2013; Oertelt, 2012). For example, differences due to males having one X chromosome and one Y chromosome can have health implications. The Y chromosome, which is only about a third as large as the X chromosome, contains far fewer genes than the X chromosome. Some of these genes may be linked to diseases that contribute to the excess male mortality throughout life. If a female has a disease-producing gene on one of their X

chromosomes, it may be counterbalanced by a normal gene on the other X, but if a male has the same disease-producing gene on their X chromosome, they lack the potential protection of an additional copy of the gene. While these biological factors play a role in survival, they do not explain the full extent of the issue. “About the difference in life expectancy, we say that one year is biological, the rest is cultural,” remarks Gilles Tremblay, PhD, a social work professor at Laval University in Quebec City (Murray-Law, 2011). A variety of cultural, environmental, and socioeconomic factors influence the magnitude of sex differences in longevity.

Many men are distanced from the healthcare system and face barriers to care. Men are less likely to visit a doctor, seek hospitalization, have a place to go for care when they are in need of medical care, and take medications when there are concerns over their health and well-being compared to women (Christensen et al., 2009; Kaiser’s Men’s Health Survey, 2015; Macintyre, Ford, & Hunt, 1999; Raghupathi & Raghupathi, 2018; Verbrugge & Wingard, 1987). These disparities have costs not only for the well-being of men, but also place burdens on the healthcare system. Although women see doctors more often than men, men cost our society much more for medical care past the age of 65. Men’s irregular contact with and avoidance of healthcare providers means that they often do not receive preventative care which consequently puts their health at risk (Sandman, Simantov, & An, 2000). Women are also more likely than men to have health insurance and a regular source of health care such as a primary physician or OBGYN (Harvard Health Publishing, 2019). A major survey conducted by the Commonwealth Fund found that one in four men did not see a physician in the year prior to the survey, three times fewer than the rate found for women. The survey found that one third of the men surveyed did not have a regular doctor that they could go to when they were sick or needed medical advice

(Sandman, Simantov, & An, 2000). Men do not have regular contact with the healthcare system, and this has consequences for their health.

Trans men especially face barriers to healthcare due to their gender identity. Studies have shown that transgender individuals access healthcare services, including genetic counseling, less than cisgender individuals. This is often attributed to feeling unsafe and experiences of stigmatization of their gender identity (Clarke et al., 2018; Giblon & Bauer, 2017; Merkel, 2017; Poteat, German, & Kerrigan, 2013; Puckett et al., 2018). We can imagine that while pursuing genetic counseling, trans men may also grapple with a perceived conflict of genetics and sex assigned at birth with gender identity. For many trans people, there is a feeling that their biology conflicts with their gender identity which can manifest as gender dysphoria. Some but not all trans people experience gender dysphoria, designated in the DSM-5 (a psychological diagnostic tool) as clinically significant distress or impairment related to a strong desire to be of another gender (American Psychological Association, 2013). These experiences may prevent trans men from pursuing care. Trans men not only must face the stigma surrounding their trans gender identity but also their masculine gender identity when seeking healthcare.

Genetic Counseling Practices & Education

Men's other identities such as sexual orientation can contribute to avoidance of seeking care, and this avoidance often stems from institutional practices or a lack of education. Sexuality and gender are "omnipresent, meaningful, and meaning-making categories" in health care (Hsieh & Shuster, 2021). In other words, gender and sexuality can influence a person's experience in the healthcare system. Bias based on gender and sexuality can create institutional barriers and restrictive cultural norms (Ridgeway & Correll, 2004). Sexual and gender minorities continue to face inequalities on an institutional and interactional level across healthcare and medicine

(Shuster, 2016). For example, gay and bisexual men can face bias while interacting with their providers in part because of the institutional lack of culturally competent training in medical education (Giffort & Underman, 2016). Lack of cultural competency education for healthcare providers has implications for other marginalized identities, as well.

The field of genetic counseling needs to prioritize issues of racial equity in training programs. A survey of genetic counseling training programs (Freeman, Arbuckle, & Petty, 2021) assessed how these programs are working towards addressing disparities in Native American professional representation and student enrollment, deliver culturally relevant curricula and clinical opportunities that serve the needs of Native Americans, and positively engage Native American communities. Training programs are not doing enough in all these areas because their efforts to meet these goals are extremely limited. This is important because Native Americans have historically been left behind in the healthcare system (Freeman, Arbuckle, & Petty, 2021). Native American men, in addition to the barriers presented by pressure to adhere to gender norms, face race-based institutional barriers to accessing quality healthcare.

Certain genetic counseling practices set by guidelines at the institutional level are exclusionary to transgender and nonbinary patients. Currently, the National Society of Genetic Counselors (NSGC) does not have guidelines for genetic counselors to adhere to regarding gender-affirming care or trans inclusive practices. Other institutions, such as the American Psychological Association (APA, 2015) and the World Professional Association for Transgender Health (WPATH, 2012) have clear guidelines and set practices to adhere to when giving gender-affirming care to trans patients. While publications exist detailing inclusive practices for genetic counselors to adhere to (Barnes, Morris, & Austin, 2020; Vaupel & Walsh, 2021), these

recommendations have not been codified into official practice guidelines. Without guidelines, proper care is not the established standard.

Other practices can also be exclusionary to trans and nonbinary clients. For example, many genetic counselors construct pedigrees to visually depict a client's family history. They are used to explain patterns of heritability, build rapport, evaluate patient needs, and provide risk assessment. Individuals are represented as symbols following a standardized set of criteria. Circles and squares are the most frequently used symbols to refer to cisgender men and women. Currently, there is no standardized practice for depicting transgender and nonbinary individuals. While sex and gender are different things, both could be important to include in a pedigree for the sake of both patients and medical professionals. Given the issues that arise when constructing a pedigree, genetic counseling could potentially feel unsafe for transgender and nonbinary individuals (Barnes, Morris, & Austin, 2019). Genetic counselors must address these issues to make their clients feel comfortable, accepted, and welcome and to get them quality care. Pedigrees are used by many health professionals to create healthcare plans. If the information included in pedigrees is inaccurate or incomplete, this can have health repercussions.

A theoretical scenario is one way to understand the potential effects of inadequate pedigree standards. For instance, below is a pedigree and scenario in which a trans man is denied adequate care because of genetic counseling practices (Figure 4):

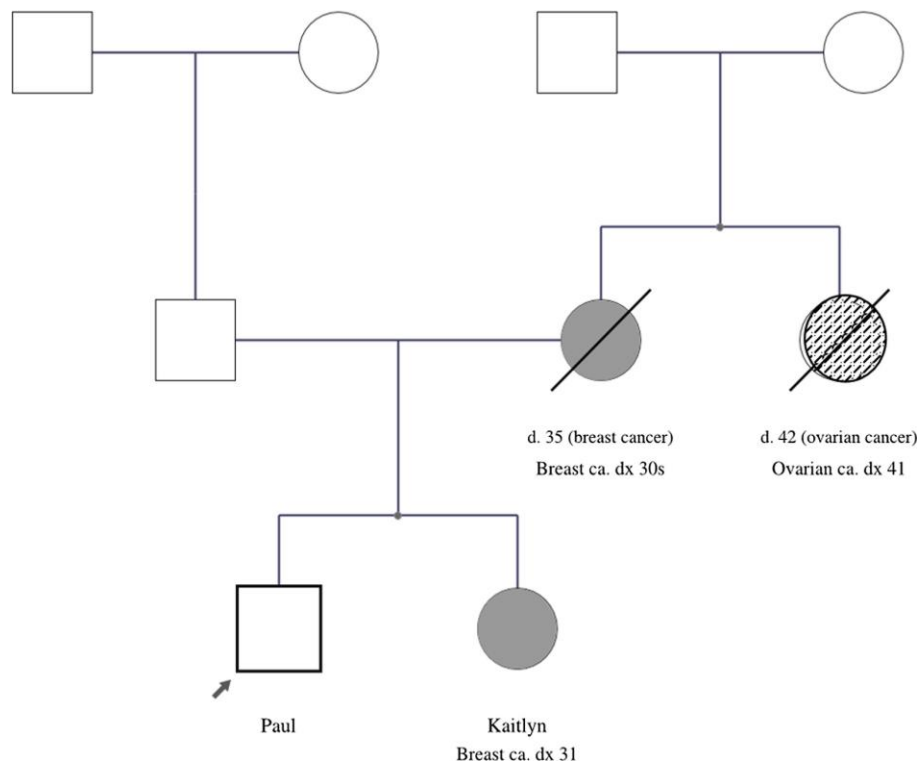
[This] scenario is based on the sex linked condition Hereditary Breast and Ovarian Cancer.

Background on the condition:

- Increased risk for female and male breast cancer, ovarian cancer and other cancers like melanoma, prostate and pancreatic cancer.
- There is increased surveillance for those who have a change in one of the genes, BRCA1 or BRCA2
- Prevention is a prophylactic bilateral mastectomy and salpingo-oophorectomy (removal of fallopian tubes and ovaries)
- Inheritance is Autosomal Dominant, which means that a parent with a change in one of these genes has a 50% chance of passing it on to a child, regardless if their child is biologically male or female

The scenario: a young transgender man named Paul attends a genetic counselling appointment for a strong family history of breast and ovarian cancer. Paul's mother died at 35 from breast cancer, his aunt died at 42 from ovarian cancer, and his sister Kaitlyn has been recently diagnosed with breast cancer at age 31.

When drawing the family history pedigree, the genetic counsellor represents Paul as a square. The family history pedigree is included here:

Figure 4*Pedigree Scenario for a Trans Man*

(Barnes, Morris, & Austin, 2020)

Genetic testing is always initiated in an individual currently or previously affected with cancer, such as Kaitlyn. She is overwhelmed with her treatment right now and declines testing at this point. She agrees to re-contact the clinic if and/or when she would like to pursue testing. As a result, Paul is currently ineligible for testing.

Two years later, Paul re-contacts the clinic. Kaitlyn is now interested in genetic testing and they attend the appointment together. The genetic counsellor who first saw Paul no longer works at the clinic and they see a different genetic counsellor. This second genetic

counsellor is not aware that Paul is transgender, as he was represented by a square on the pedigree, and does not ask him any questions about his gender identity or genotypic sex.

Kaitlyn has genetic testing, but no genetic change that would explain her cancer is found. As a result, Paul is not offered genetic testing as no familial mutation is known. Instead, he is given screening recommendations that are typically given to men with a family history of breast cancer, rather than the recommendations he should have received due to his genotypic status as female, which include a prophylactic bilateral mastectomy and a salpingo-oophorectomy (removal of fallopian tubes and ovaries).




In addition, if Paul was considering having surgery as a part of his transition, his strong family history of breast and ovarian cancer (even without a confirmed genetic change) could influence the surgical options he may choose. As Paul is not told of the screening recommendations, his decision on surgical options is not completely informed (Barnes, Morris, & Austin, 2020).

This scenario details the importance of establishing clear, medically accurate, and identity-affirming pedigree symbology. Currently, the established standard for pedigree nomenclature from the National Society of Genetic Counselors (NSGC) is to include transgender or nonbinary individuals using a diamond symbol instead of a circle or square (Bennett et al., 2008, Table 1). However, many genetic counselors adhere to the National Comprehensive Cancer Network (NCCN) for guidelines for constructing pedigrees. The NSGC and the NCCN have differing recommendations for nonbinary and transgender patients. The NCCN recommends a combination of symbols representing both gender identity and biological sex. For instance, a transgender woman would be depicted with a circle to represent gender identity with a square inside to represent biological sex (Provenzale et al., 2017). Both the NCCN and the

NSGC influence genetic counseling practices, so conflicting recommendations can create confusion.

Table 1

Pedigree symbols, definitions, and abbreviations established by the National Society of Genetic Counselors

	Male	Female	Gender not specified	Comments
1. Individual	 b. 1925	 30y	 4 mo	Assign gender by phenotype (see text for disorders of sex development, etc.). Do not write age in symbol.
















Note. NSGC recommended in 2008 to depict individuals whom their “gender is not specified, with a difference in sexual development, or identifies as transgender” using a diamond (Bennett et al., 2008).

A survey of current genetic counselors and genetic counseling students (Sheehan et al., 2020) was conducted to see which pedigree practices best fit scenarios of patients and what symbol they would choose and why. Many participants emphasized clarity, genetic appropriateness, accuracy, aligning with guidelines, and identity affirmation. There is no consensus on how to best represent transgender and nonbinary clients. Many of the participants felt conflicted about their choices to use certain symbols, and many expressed that they did not have much education or training about LGBTQ+ identities. Genetic counselors also expressed a concern with including karyotypic information or information about what chromosomes a person has. Usually when chromosomal compliments are listed on a pedigree, this signifies that a karyotype, a laboratory technique that sorts out chromosomes including sex chromosomes, has been conducted. To include sex chromosomes without conducting a karyotype could be confusing and give inaccurate information. Stacked symbols could be problematic because it implies female on

the outside, male on the inside or male on the outside, female on the inside which may reinforce transphobic narratives (Sheehan et al., 2020). Pedigree nomenclature and practices continues to be an ongoing discussion as genetic counselors attempt to be inclusive while simultaneously depicting accurate information (Table 2).

Table 2

Options of pedigree symbols for genetic counselors to represent patients

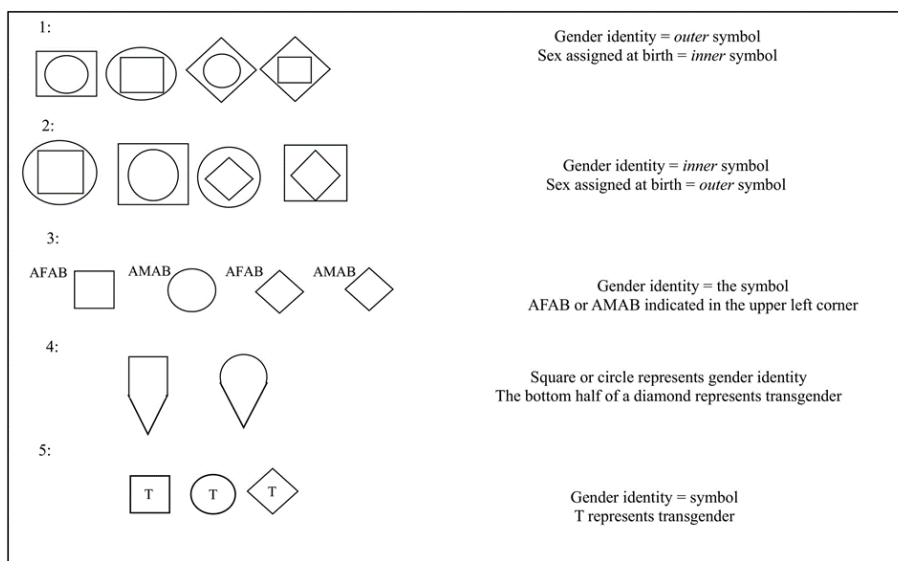
Symbol(s) and Patient Identity	Rationale
 Gender is not specified, with a difference in sexual development, or identifies as transgender	‘Unspecified’ as suggested by NSGC
 Trans man  Trans woman  Nonbinary person	Representative of gender identity
 Assigned male at birth  Assigned female at birth  Intersex person	Representative of sex assigned at birth
 Trans man  Trans woman	Representative of sex assigned at birth (inner symbol) and gender identity (outer symbol), as suggested by NCCN *No guidelines for nonbinary or intersex people, but some genetic counselors have extrapolated these guidelines when depicting nonbinary and intersex people
 XX Trans man  XY Trans woman	Representative of gender identity and sex assigned at birth by acknowledging likely/assumed karyotype, as suggested by NSGC
 GNC*, XY Nonbinary person assigned male at birth  GNC*, XX Nonbinary person assigned female at birth	Representative of gender identity while acknowledging likely/assumed karyotype based on sex assigned at birth *GNC=gender non-conforming NB=nonbinary is also commonly used
 Trans man* Trans man  Trans woman* Trans woman	Representative of gender identity while acknowledging transition and not including karyotype information *Some genetic counselors will use “Trans female” for trans women and “Trans male” for trans men

(Sheehan et al., 2020)

In response to the ongoing discourse surrounding inclusive pedigree practices, a survey was conducted with members of the transgender and nonbinary community (Barnes, Morris, & Austin, 2020). The preferred option for most participants involved the use of a single shape to represent gender identity (masculine = square, feminine = circle, nonbinary = diamond) with the annotation ‘AFAB’ or ‘AMAB’ to indicate ‘assigned female/male at birth’. Participants who chose this option explained that this was clearer and less ambiguous than the other options and they liked that gender identity is more prominently represented than sex assigned at birth (Barnes, Morris, & Austin, 2020, Figure 5). Hearing feedback directly from the transgender and nonbinary community is helpful for deciding what will be identity-affirming for clients and should be considered when determining pedigree practices of genetic counselors.

Figure 5

Pedigree symbols suggested by transgender and nonbinary study participants



AFAB – assigned female at birth
 AMAB – assigned male at birth

Note. Diamonds used to represent nonbinary or gender non-conforming individuals (Barnes, Morris, & Austin, 2020).

There are other practices that genetic counselors should implement to create a welcoming environment for their trans men clientele. Forms and documents can be adjusted to allow clients to indicate their updated name instead of their dead name as well as providing blanks, instead of boxes, to write in pronouns, gender identities, and sex. In addition to collecting this information for clients in intake forms, it is also important that family history forms include similar options. Genetic counselors should also include their pronouns in their nametags, introductions, and correspondence. Inclusive phrases during the appointment also help to make trans clients feel more included. For example, genetic counselors could say, “people who have two X chromosomes are at risk” or, “individuals who are assigned female at birth are at risk” instead of, “women are at risk.” Privacy and confidentiality concerns should also be addressed. Clients should be informed of who may have access to the pedigree in the future because some patients may not want to disclose their minoritized identity or that of a family member (Barnes, Morris, & Austin, 2020). In sum, help-seeking is stigmatized for men, and trans men face additional healthcare challenges due to their gender identity. Genetic counseling practices can worsen accessibility issues if the unique needs of trans men are not considered.

Insurance

Other institutional barriers can also deter men from seeking genetic counseling services. Many men may choose to not pursue genetic counseling because they are uninsured. Working-age men ages 18-64 are at high risk for lacking health coverage. About one out of five working-age men in the U.S. are uninsured. Men rely primarily on their jobs for health insurance in the U.S., and lower-income, working-age men have limited access to health insurance if they are not covered through their jobs. Insurance coverage can also be unstable for men. Less-educated men and young men just starting their working careers are also uninsured at a high rate. Men,

especially White men 55 and older, are more likely to be contract laborers. In surveys conducted by the Bureau of Labor Statistics, men were more likely to be independent contractors than were women; about two-thirds of independent contractors were men in May 2017. Contract laborers have less access to insurance (U.S. Bureau of Labor Statistics, 2018). Because of their increased chances of getting health coverage through more than one employer, men who are married or live with a partner are more likely to be insured compared to men who live alone or who are single (Sandman, Simantov, & An, 2000). Racial and ethnic groups face different rates of uninsurance. According to the National Health Interview Survey, as of June of 2021, Hispanic adults were the most likely to lack health insurance coverage (31.4%) followed by non-Hispanic Black (14.7%), non-Hispanic White (9.0%), and non-Hispanic Asian (6.1%) adults (Cohen et al., 2021). Lack of insurance coverage could limit access to healthcare service utilization therefore worsening health disparities that already exist. When men lack insurance, they have less financial support to pursue services that support their health and well-being including genetic counseling.

Since genetic counseling and genetic tests are new approaches to healthcare, many insurance companies have not extended their policies to cover these services. Most of the changes to insurance companies' handling of genetic conditions has been related to avoiding genetic discrimination rather than extending coverage of genetic testing and services. Some advances have been made to protect patients from health insurance discrimination. The Genetic Information Nondiscrimination Act of 2008 and other laws help protect people who undergo genetic testing against insurance discrimination ("The Genetic Nondiscrimination Act of 2008", 2008). This means that health insurers may not use genetic information to determine if someone is eligible for insurance or to make coverage, underwriting, or premium-setting decisions.

Although these protections have reduced barriers to using genetic information to make healthcare decisions, insurance companies should extend coverage of genetic testing. Improvements must be made to extend coverage of these services as personalized medicine becomes more standard in healthcare practices.

Medicare and some insurance companies are not yet paying for genetic counseling services. Currently, genetic counselors are not recognized as healthcare providers by the U.S. Centers for Medicare and Medicaid Services. Therefore, unlike nurse practitioners and physicians that provide genetic counseling services, genetic counselors are not reimbursed under Medicare. Some politicians are working to expand coverage of genetic counseling services. In June of 2019, the Access to Genetic Counselor Services Act of 2019 was introduced in the House of Representatives (“Access to Genetic Counselor Services Act of 2019,” 2019-2020). This legislation would greatly improve access to genetic counseling services including expanding insurance coverage. Not all genetic organizations support the passage of this bill. The American College of Medical Genetics withdrew its support for the legislation. Those who oppose the bill cite the concern that the current bill would allow genetic counselors to perform duties that fall out of the scope of their profession. For example, some believe that genetic counselors should not be able to order lab tests because they should not be able to practice medicine to this extent with the training they have received (Gregg & Muenke, 2020). However, in my opinion, perpetuating the requirement for involvement of a physician for coverage of genetic counseling services under Medicare creates barriers to accessing genetic counseling and minimizes the important role of genetic counselors.

Genetic counselors often receive more training in genetics than physicians. In a 2013 survey of physicians, 73.7% rated their knowledge of genetics as very/somewhat poor and 87.1%

rated their knowledge of genetic testing as very/somewhat poor (Klitzman et al., 2013). This lack of training in genetics and genetic testing can lead to inappropriate test orders, misdiagnoses, misinterpretations of results, and other errors which can worsen patient outcomes and be costly not only to individual patients but also the Medicare system (“How Medicare coverage of genetic counseling could decrease care costs and improve quality”, 2019). This gap in healthcare provider knowledge is one reason for the importance of the field of genetic counseling. Genetic counselors should be recognized appropriately as healthcare providers to increase access to genetic counseling, improve health outcomes, and reduce Medicare spending.

CHAPTER THREE: THE MICROSYSTEM

Cultural narratives inform our institutional practices and infrastructure. Hegemonic masculinity creates barriers for men at the institutional level which can reduce men's willingness to seek care, but these values can also create barriers at the interpersonal level. The micro level of Bronfenbrenner's Ecological Systems Theory includes interactions that an individual has with others (Bronfenbrenner, 1979). In the context of genetic counseling, this includes patient social interactions as well as interactions with healthcare providers.

3.1 Patient Social Interactions

Social isolation is another factor that contributes to men's well-being and is a risk for poor health outcomes. A study analyzing the data from the National Health and Aging Trends Study examined what variables are associated with social isolation in older adults (Cudjoe et al., 2020). Being unmarried, male, having low education, and low income were all independently associated with social isolation. Additionally, Black and Hispanic older adults had lower odds of social isolation compared to White older adults. Social isolation is a major and potentially modifiable risk that greatly affects the older adult population. Living arrangement, network size, religious attendance, and social participation can all contribute to one's degree of social isolation or involvement (Cudjoe et al., 2020). Partnership also has implications for one's social isolation.

A national panel study (Stronge, Overall, & Sibley, 2019) in New Zealand demonstrated that having a romantic partner has benefits for well-being, regardless of the gender of that partner, though men have more benefits from partnership than women. Single men had lower mean levels of well-being than single women, but partnered men had similar or higher levels of well-being than partnered women. Having a romantic partner was associated with higher self-

esteem, higher life satisfaction, and confidence in getting social support when needed. This gender difference has been explained theoretically by the idea that men find social support primarily through their romantic partners and do not have other reliable sources of social support whereas women tend to have broader sources of social support in addition to their partner (Stronge, Overall, & Sibley, 2019).

These findings hold true across cultures and countries. Men are consistently shown to have greater health benefits from marriage to women than women are from marriage to men. A review compiling research on the impact of social connectedness, loneliness, and support on survival concluded that relationships are crucial to health and well-being for everyone. Care and support promote health and are associated with better health outcomes. Risk of mortality is correlated with marital status because social relationships impact health and well-being. Most research has been conducted on heterosexual couples, but cultural changes have shifted cohabitation patterns, who can marry, and roles within marriage (Stronge, Overall, & Sibley, 2019; Tatangelo et al., 2017). Marital status can also have implications for the queer community.

Another study conducted using data from the Aging with Pride: National Health, Aging, and Sexuality/Gender Study (Goldsen et al., 2017) aimed to see the association between LGB legal marriage or relationship status with health outcomes. Legal marriage compared to partnership is associated with health-promoting and at-risk factors, health, and quality of life for adults over 50 living in states where same-sex marriage is legal. Participants who reported that they were legally married reported better quality of life and physical health and more economic and social resources than people who were unmarried but partnered. People who were single reported poorer health and fewer resources than partnered participants. Until recently, LGB adults were not allowed to engage in same-sex civil marriage (Goldsen et al., 2017). The benefit

of having a romantic partner not only benefits straight men but also queer men, and being in a legal marriage has even greater benefits than being unmarried but partnered.

Receiving support from a partner following a medical diagnosis or while facing health challenges is an important source of support. Genetic counselors provide a different kind of resource and can encourage clients to find additional support outside of partnerships to broaden men's social connections. Men may struggle to communicate their health challenges to their loved ones due to hegemonic masculine ideals of restricted emotionality, independency, and invulnerability (Connell, 1995). Following meetings with genetic counselors, men may encounter issues when they attempt to relay learned information to important people in their lives.

Geography can also affect men's social behaviors. Rural men's health is an especially acute crisis that must be addressed. Rural men report lower levels of stress and depression but have higher rates of suicide and substance use. This paradox could be explained by hegemonic masculinity. One study conducted in Canada (Herron et al., 2020) used interviews to examine rural men's attitudes about mental health and what it means to be a "healthy man." The study found that men expressed a desire to discuss their mental health but faced challenges when trying to talk about mental health in rural spaces. Rural spaces present a unique challenge because men can face higher levels of stigma, gossip, and competition compared to urban places. This, combined with the gender expectations that men should not show weakness or express emotionality, could explain the health paradox that rural men face (Herron et al., 2020). In addition to this struggle, limited health resources including limited access to genetic counseling could compound barriers that rural men face in their pursuit of healthcare. To improve men's health outcomes, we must make going to genetic counseling appointments more accessible.

Social interactions influenced by gender biases that people hold can reinforce the barriers that men face when seeking healthcare. In addition to interactions with community members and loved ones, men can face incidents of interpersonal bias in healthcare settings.

3.2 Patient-Provider Interactions

To make an appointment with a genetic counselor, most men will need a referral from a doctor following a diagnosis or in response to a concerning family history. Gender expectations often prevent physicians from counseling and making referrals for their male patients during visits. According to a major survey conducted by the Commonwealth Fund (Sandman, Simantov, & An, 2000), few men who recently visited a doctor reported that they received counseling including referrals on ways to improve their health or prevent illness or injury. Counseling rates between physicians and male patients were even low among men with elevated health risks. For example, only two-thirds of men who smoke reported that their doctors had discussed smoking with them. Additionally, the frequency with which sensitive topics such as emotional well-being were discussed was especially low. Despite this lack of counseling, men rated their physicians highly and reported that they trusted their doctors to care for them and their health (Sandman, Simantov, & An, 2000). This lack of counseling of male patients puts men at higher risk because they are not receiving a full range of health support.

In addition to being less likely to discuss ways to improve health with men, physicians are less likely to discuss mental health with their patients who are men. We can imagine that healthcare providers may be hesitant to broach the subject of mental health with their patients that are men because men may then be less likely to continue to seek help. Physicians are unlikely to engage in conversations surrounding mental health more generally. A study conducted on time physicians spent discussing mental health with their older adult patients found

that the median amount of time spent discussing topics of mental health lasted two minutes, and referrals to mental health specialists were rare even for severely depressed and suicidal patients (Tai-Seale, et al., 2007). By not giving adequate time to conversations about mental health, patients' mental health conditions may not be treated.

Health care professionals will regularly face patients or clients who have suicidal thoughts or die by suicide even without depression or other mental illnesses being diagnosed. Suffering from a palliative condition, or a condition which cannot be cured where only symptoms can be addressed, can have a negative impact on quality of life as a consequence of pain, increasing dependence, and need for drugs with some having severe side effects. Longer perceived or actual duration of the disease can increase risk of death by suicide because having little perspective regarding the course of the disease, decreasing social contacts, or fewer tasks in life can lead people to consider suicide. For example, following a cancer diagnosis, men may not have a clear idea of their prognosis or their chances of survival, may lessen their socializing because they are unsure of how to talk about their diagnosis, and may be unable to do previously enjoyed activities due to pain (Karasouli, Latchford, & Owens, 2014). In a study done on physical compared to mental reasons for engaging in suicidal behavior (Fegg et al., 2016), long lasting and increasing perceived burden from illness was followed by decreasing coping strategies. Adequate symptom management, relieving burdens of illness (including fear of loss of autonomy, increasing physical dependence, worry to be a burden to the family and hopelessness in awareness of the limited prognosis), and improving or restoring quality of life may decrease deaths by suicide, suicidal behavior, and suicide ideation (Fegg et al., 2016). Therefore, physician counseling must be augmented for patients that are men to improve the care they receive despite biases that healthcare providers may hold.

Patient race, according to a recent study, also affected the amount of patient-centered communication during medical interactions. Research from the University of Michigan demonstrated that Black and Hispanic/Latino men reported fewer patient-centered experiences (Mitchell & Perry, 2020). These results have implications for understanding why men of color have worse outcomes than White men in the United States. For example, Latino men experience significantly higher levels of functional limitations and related disabilities, overweight and obesity, and lower utilization of primary care compared to White males (Ai et al., 2013; Melvin et al., 2014). Health disparities impacting Black men include higher incidence and mortality rates for cardiovascular disease, hypertension, stroke, and several forms of cancer (Thorpe et al., 2013). If health care providers, due to their own biases, counsel their patients of color less, this could worsen healthcare outcomes for a group of men that face poorer health outcomes.

Healthcare providers may unwittingly interact with clients and patients of theirs that are sexual and gender minorities in a biased way because they draw on cultural norms to guide their behaviors and interpret situations (Shuster, 2016). For example, patients are often met with paternalism and suspicion because of bias held by providers (Baker & Beager, 2014). Clinical interactions that take place within a cis- and hetero-normative society will thus reflect the biases reflected in society. Because of this, there are lasting negative consequences in patients' care including avoidance of seeking care and not using preventative care (Willging et al., 2019).

Members of the queer community may also face barriers to accessing genetic counseling in addition to the barriers associated with masculinity. In a study done on men's concepts of health (Robertson, 2006), gay men and health professionals expressed during interviews that gay men care more about their health than straight men. Queer men seek out healthcare for reasons both positive and negative. While these beliefs may be beneficial to reducing the stigma for gay

men seeking healthcare, these attitudes are based in stereotypes and historical homophobia. For example, the rise of HIV/AIDS within the community served to legitimate and encourage gay men to care about their health and health issues. Although this narrative may be beneficial because queer men may be encouraged to take care of their health, classifying HIV/AIDS as a disease only impacting the queer community is problematic because the HIV/AIDS crisis has been used to justify homophobia (Robertson, 2006). These stereotypes can impact patient-provider interactions when providers assume their patients' reasons for willingness to seek healthcare based on sexual orientation.

The patient-provider relationship is further complicated by how the HIV/AIDS crisis was handled by the healthcare system. Building on the civil rights, women's rights, and gay and lesbian liberation movements in the United States, LGBTQ organizers led community-based programs geared towards providing specific types of care centered around infectious disease spread while the government and healthcare systems struggled to respond (Trapence, et al., 2012). Over time, HIV/AIDS funding incrementally shifted away from community mobilization, social support, and advocacy and toward clinics meant to make access to antiretroviral treatment easier (Aggleton & Parker, 2015). Many members of the queer community have a difficult relationship with the healthcare system because of the lack of effective response in the early years of the HIV/AIDS crisis, the shifting of funding away from community organizers to less effective clinics, and unsympathetic responses from medical providers. Access to culturally appropriate health care remains difficult for people living with and disproportionately affected by HIV, including gay and bisexual men, even with the proliferation of clinics. Discrete, sympathetic, and affordable testing and treatment was not common and continues to be difficult to access for many. The UN reported in 2020 that, "all global targets for [HIV response by] 2020

will be missed” (UNAIDS Joint United Nations Programme on HIV/AIDS, 2020). Public health responses to the HIV and overall health needs of gay and bisexual men are too often designed and enacted solely with a disease containment focus and without serious consideration for fundamental human rights principles including respect for and protection of bodily autonomy and integrity (Ayala & Spieldenner, 2021). This historical context as well as the continued unmet goals in HIV response could make queer men less trusting of the healthcare system as well as their providers.

Other stereotypes also contribute to the reduced stigma of queer men seeking healthcare. The expectations of gay men to adhere to feminine characteristics makes it more acceptable for men to care about their health. Although these beliefs surrounding gay men’s healthcare may be positive because it makes it more acceptable for gay men to care about their health, there are negative consequences that accompany these reasons. Stereotyping gay men as effeminate serves to subjugate gay men within the patriarchy in which being feminine is devalued (Robertson, 2006). These stereotypes may lessen stigma surrounding seeking healthcare, but there are consequences to this reasoning that leads to the further oppression of queer men.

Biases that individuals hold due to internalized cultural beliefs about masculinity can inform the ways that people treat men. Men internalize these beliefs and change their behavior to avoid facing additional biased incidents and to adhere to cultural beliefs surrounding masculinity and what it means to be a man.

CHAPTER FOUR: THE INDIVIDUAL LEVEL

The individual level of Bronfenbrenner's Ecological Systems Theory refers to the person in consideration (Bronfenbrenner, 1979). The individual is what the other systems interact with and influence. Individuals are affected by their environment including interpersonal interactions, cultural beliefs and attitudes, and institutional practices and structures.

4.1 Psychological Well-Being

Components of Bronfenbrenner's systems including cultural beliefs, institutions, and interpersonal interactions can have effects on one's psychological well-being. One study conducted by the University of Maryland longitudinally examined the influence of masculine norms and gender role conflict on psychological well-being among young adult college-aged men. Masculine norm conformity is how much a person adheres to the social standard of what it means to be a man (Mahalik et al., 2003). These role-maintaining behaviors can be restrictive and dysfunctional. Additionally, the psychological pressure to fulfill to these rigid gender roles can lead to gender-role conflict, or the state in which gender roles and expectations can contribute to stress and decrease well-being (Solomon & Levy, 1982). In a study done at University of Maryland ((Kaya, Iwamoto, & Brady, 2019). using assessments to quantify well-being and adherence to gender norms, findings showed masculine norm conformity and gender role conflict were predictive of both increased and decreased eudaimonic psychological well-being which includes a person's self-acceptance, purpose in life, environmental mastery, personal growth, autonomy, and positive relationships (Ryff, 2014). The masculine norms of power and sexual prowess were negatively associated with eudaimonic psychological well-being whereas the masculine norm of winning was positively correlated Gender role conflict, specifically restricted emotionality, was negatively associated with eudaimonic psychological

well-being (Kaya, Iwamoto, & Brady, 2019). These findings suggest that although adhering to certain hegemonic masculine ideals can have positive effects, adhering to others can be detrimental to men's well-being. In addition to affecting psychological well-being, gender roles can have negative impacts on other components of health including men's concepts of health.

4.2 Concepts of Health

Men have gendered conceptualizations of health. A study from the University of Central Lancashire done on men's understandings of health and well-being (Roberston, 2006) found recurrent narratives surrounding health for men. Oftentimes, men define health as the absence of illness, ability to function, fitness, looking good, feeling good, or a combination of these definitions. These narratives are often complex and contradictory. For men, health was considered a "normal" state. This concept of health was not shared by the women in the study; three times as many men as women defined health as a normal state. This gendered understanding of health connects to the idea that practices of everyday life are not fully individually-driven but also influenced by social expectations and norms. Health concepts fit into the ideas of what constitutes appropriate, gendered behaviors or expressions of belief (Roberston, 2006).

These gendered concepts of health make seeking healthcare for men more difficult. During the interviews in the study on men's concepts of health, men used rhetorical distancing as a mitigatory strategy against cognitive dissonance and gender-role conflict. For example, while describing their understandings of health, men would use third-person rather than first-person rhetoric. Men had trouble aligning themselves with illness or absence of health and exhibited a lack of concern about health that they associated with masculinity (Robertson, 2006). Rhetorical distancing can be seen as a strategy to resolve and manage conflicting discourses about what

men “should” do when it comes to their health. Two conflicting discourses exist with regards to men’s health: 1) ‘real’ men in terms of hegemonic masculinity do not care about health, and 2) pursuit of health is a moral requirement for good citizenship. Steve Robertson, a scholar on masculinity and health, terms these conflicting discourses as the ‘don’t care/should care’ dichotomy (Robertson, 2006). Men hold conflicting ideas that they should care about their health to be a good citizen and should also not care about their health to be manly. This dichotomy presents challenges for men navigating their own definitions of living a healthy life which might contribute to worse health outcomes for men.

Men’s concepts of health as a “normal” state can contribute to suicidality. Once men face being unhealthy via a diagnosis, this can be destabilizing to their identity and can lead them to feel “abnormal.” A study done at the University of Munich (Fegg et al., 2016) investigated reasons for suicidality in men and compared physical versus mental diagnoses. Suicide, medical, and police notes from men who had died by suicide revealed that mental disorders and physical illnesses may lead persons to die by suicide. One out of five men indicated physical illness as the main reason for engaging in suicidal behavior and one out of three men indicated mental illness. Of the group indicating physical illness, one out of three men suffered from cancer and about one out of three men suffered from heart disease or chronic pain. Two thirds of the men used more fatal means to die by suicide, such as guns, thereby reducing their chances of survival (Fegg et al., 2016). Understanding suicidality is important for supporting patients following medical diagnoses. Genetic counseling is an opportunity to support men through the psychological distress from receiving a physical or mental diagnosis of a condition.

4.3 Accessing Genetic Counseling

Although genetic counseling could be beneficial to those facing difficult medical decisions, receiving genetic counseling may not be accessible. One study examined why people chose to decline genetic counseling following a cancer diagnosis. Most of the participants in this study were older men. The reasons people elected to decline genetic counseling services were: 1) concern over health insurability, 2) cost, 3) fear of potential emotional impact of difficult discussions, 4) no perceived benefit, and 5) time commitment (Geer et al., 2001).

One reason men may decline genetic counseling services is that they want to avoid the emotional impact that can come from discussing difficult topics or diagnoses. As previously discussed, masculine norms dictate that men should not express their emotions because emotionality is perceived as a feminine characteristic (Solomon & Levy, 1982). Men may avoid genetic counseling because it could prompt them to express their emotions and reactions to medical issues. This requires men to be vulnerable in the context of counseling to share what they are going through which many men may be resistant to do. However, studies have shown that refusal to express emotions following a diagnosis can be detrimental to men's psychological well-being. In a study done on men following a cancer diagnosis, social constraints and restrictive emotionality were associated with higher depressive symptoms and cancer-related intrusive thoughts (Darabos & Hoyt, 2015). Following a diagnosis, men should process their emotions despite perceived threats to their masculinity for their psychological well-being.

Another challenge to attending genetic counseling is the time commitment needed to follow through with the genetic counseling process. Although the process of attending genetic counseling can be time-consuming, the field is working to ease this burden through expanding services and delivery methods including telehealth appointments (Danylchuk, et al., 2021). Men may also avoid attending genetic counseling because they do not see the benefit of receiving

genetic counseling services. Healthcare providers should educate their patients on the potential benefits of receiving genetic counseling including exploring treatment and testing options. Clients may be more willing to commit their time to these services if they see the value in genetic counseling. Additionally, engaging in exploration with clients could ultimately save clients time in the long run. These issues of time commitment and limited awareness of the benefits of genetic counseling could be especially pressing for rural men because of limited access to genetic counseling services in rural areas.

To improve men's health by increasing use of preventative healthcare and personalized medicine, men must be able to pay for the utilization of these health services and navigate health insurance coverage. Men's lack of health-care utilization may be attributed to their health insurance status, difficulty in paying medical bills, and health insurance literacy level (Edward et al., 2019; Kaiser's Men's Health Survey, 2015). A study examining men's confidence in understanding medical bills and insurance showed that difficulty in paying medical bills increased as confidence in understanding health insurance decreased (Dean et al., 2020). This demonstrates that better understanding of health insurance could prevent difficult experiences with paying medical bills. Men's lack of knowledge about navigating the healthcare system may contribute to their decreased longevity and worse healthcare outcomes.

Other masculine values are also likely to interfere with men's healing following an appointment with a genetic counselor. As men feel pressure to adhere to hegemonic masculine ideals, help-seeking implies loss of status, loss of control and autonomy, incompetence, dependence, and damage of identity. Since masculinity is a precarious identity, men may attempt to compensate for their perceived loss of masculinity. Consequently, men may refuse drugs and treatments and may instead turn to alcohol as a means of 'self-care' or to maintain their

masculine identity in a way that is socially compatible and acceptable (Riska & Ettore, 1999). Men's predisposition to use substances to self-medicate and cope with stressors due to gender expectations should be considered when genetic counselors work their clients that are men.

Considering the factors that influence individual patients' health and well-being using Bronfenbrenner's Ecological Systems Theory is a useful way that genetic counselors can better serve the men they counsel. Moving forward, I present potential suggestions for addressing the needs of men using the Bronfenbrenner's systems to address access barriers at various levels.

CHAPTER FIVE: PROPOSED SOLUTIONS, CONCLUSIONS, AND THE CHRONOSYSTEM

Bronfenbrenner's outermost system is the chronosystem or the changes that occur over time in an individual's life. Examining barriers that men face at various other levels of Bronfenbrenner's Ecological Systems Theory can inform changes within healthcare generally and genetic counseling specifically to improve the well-being of men over time. Men's struggles with setting up an appointment, seeking help, paying for services, receiving quality and identity-affirming care, and attending appointments in a convenient way must be addressed to improve healthcare outcomes.

5.1 The Individual Level

Masculinity at the individual level can be used to improve men's health without having to challenge the beliefs about masculinity that men hold. Certain hegemonic masculine values can promote health instead of acting as a barrier to men's access to healthcare services. One characteristic of hegemonic masculinity is problem-solving. A study done at the University of Missouri investigated how men's perception of their own problem-solving skills contributed to gender-role conflict. Weak self-appraisal of problem-solving skills was associated with psychological distress (Good et al., 2004). Although problem-solving can contribute to men's decreased well-being, men's valuation of this skill could be used to improve their healthcare outcomes. For example, in a study done on the effects of psychosocial interventions on adult cancer patients, problem solving played a role in disease progression of cancer patients (Meyer & Mark, 1995). If health issues can be contextualized as problems to be solved and seeking assistance as part of the path to the solution, then men may be more likely to seek support in addressing their health challenges. In addition, if men feel that they are adequately addressing

their healthcare problems, this could improve their psychological well-being by resolving issues of gender-role conflict.

5.2 The Microsystem

Genetic counselors should be aware of how their interactions with patients that are men could be threatening to their patients' identities. Genetic counselors should use specific counseling strategies during appointments with men that adhere strictly to hegemonic masculine ideals. Genetic counselors can adjust their practices to help men feel more comfortable with seeking healthcare services. For example, genetic counselors could employ psychoeducational efforts, or teaching clients about emotions and feelings, to educate their clients with difficulties expressing their emotions. By anticipating barriers in the treatment process and using research-backed techniques for counseling men, genetic counselors can better engage men in treatment by being aware of the factors that influence why men have worse healthcare outcomes and are more hesitant to seek help. For example, the Substance Abuse and Mental Health Services Administration created a guide to help providers address the specific behavioral health needs of men (U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration, 2013). Although healthcare providers addressing men with substance abuse disorders may face unique challenges, many of the recommendations provided can be relevant to genetic counselors as well. The National Society of Genetic Counselors should work to publish a similar manual specific to the field of genetic counselors.

Strengthening interpersonal relationships of genetic counseling patients can be used to facilitate a support network. Oftentimes, genetic counselors connect clients to resources such as support groups and mental health services following a diagnosis. Support groups provide valuable information and education, assist people in their decision-making, and structure peer

networking to clients and their families (Manne, 2002). While research has shown that men do not typically engage with self-health or acknowledge illness, research with men in support groups such as prostate cancer has countered the narrative that men fall short when it comes to engaging in their health. Men in these groups used humor and reformulated and rekindled men's sexuality to enhance group interactions. Humor was used to improve inclusiveness, mark the boundaries for providing and receiving mutual help, and develop masculine group norms (Oliffe et al., 2009).

5.3 The Macrosystem

Improving appointment delivery methods and genetic counseling practices are potential ways to alleviate institutional issues of access that men face when seeking genetic counseling. Telehealth is a potential way that genetic counseling can be more accessible. Using a systematic evidence review to compare telehealth delivery to in-person delivery of genetic counseling, a study concluded that patients were satisfied with virtual appointments because there were comparable rates of trust and rapport, confidence in privacy, health behavior changes, and psychosocial outcomes to in-person appointments. There was also reduced cost, higher convenience, and reduced travel time. Telehealth could be a promising option for populations with limited access to in-person genetic counseling (Danylchuk, et al., 2021). Telehealth is not only an effective appointment delivery method for clients but also providers.

In a different study on telehealth appointment delivery, researchers conducted interviews with practicing genetic counselors who use a variety of appointment delivery methods. Similar to the study done from the client perspective, genetic counselors who used virtual appointments appreciated that this appointment format reduced travel distance and wait time and increased convenience. Some limitations to virtual formats identified by the participants included logistical

issues such as billing and reimbursement, equipment set up, making arrangements for genetic testing, and the inability to see the patient. Despite these challenges, many of the genetic counselors believed that the benefits outweighed the costs (Cohen et al., 2016). Telehealth appointment delivery could be a potential way to alleviate barriers of access to genetic counseling to improve men's health, especially for men living in rural areas.

5.4 Integration of Bronfenbrenner's Systems

Men may face challenges due to adherence to gender expectations when it comes to communicating the topics discussed with a genetic counselor. I faced this a similar struggle when my dad was in a major skiing accident that caused a compound fracture of his tibia and fibula. As his caretaker, I had difficulties navigating his treatment process. One of the most useful tools that I was given was an informational packet that outlined his medications, his prognosis, upcoming appointments, warning signs to pay attention to, and next steps to support the healing of his leg. After an emotionally difficult stay at the hospital, it was reassuring to know that I had this resource to take home and refer to rather than having to find that information myself or call a provider when questions inevitably arose. Similarly, my Victim Advocate provided me with handouts as resources to connect me with support groups, organizations on campus, and local organizations specifically geared towards survivors of sexual assault. Following a difficult experience, I was grateful to have knowledge of resources without having to conduct the research on my own. These experiences demonstrate the importance of giving patients and their caretakers the necessary information they may need to heal properly.

Genetic counselors should consider compiling similar resources for their clients. By providing informational packets, clients can augment their autonomy and have more control over and understanding of the health challenges they face. These packets could also present an

opportunity to connect clients with educational resources, support groups, and other healthcare providers. Since many doctors do not receive much training in genetics and many healthcare providers may be less likely to start meaningful conversations with men about their health, these packets could help to initiate conversations between men and their healthcare providers. These packets could improve healthcare outcomes through bettering individuals' microsystems and macrosystems.

Since the field of genetic counseling is centralized and connected to the National Society of Genetic Counselors (NSGC), this organization could develop a website open to genetic counselors and members of NSGC that has an editable template that is easily manipulated so that handouts can be quickly and uniformly developed. The packets could be shared virtually and searchable. This feature could save genetic counselors time because they could have access to previously made handouts. The already established network of NSGC could be utilized to improve patient outcomes.

Although these packets would be helpful for many genetic counseling clients, men could especially benefit from this resource. This proposed solution aligns with the hegemonic masculine ideals of independency, efficiency, rationality, success, activity, control, and invulnerability (Connell, 1995). By providing this resource, men can feel that they have more control over their health issues, have the tools to efficiently and effectively address the health struggles they face, use reasoning to determine the best course of treatment, and take action to address their health concerns. A packet is also a tool that connects men to resources in a way that seems to the men like they are addressing their health needs independently. Although a genetic counselor provides the information, clients use that information to make their own healthcare decisions. These packets could also save emotional labor for clients because they could share this

resource with family or others that are asking for more information about the diagnosis without having to explain the details of their healthcare themselves. This helps with men's struggles with invulnerability because it allows them to communicate the health issues they are facing without having to facilitate these conversations on their own. My proposed solution of informational packets can address some of the issues that contribute to the current crisis of men's healthcare and well-being.

5.5 Conclusion

Gender expectations affect us all, however, men face certain pressures that can act as barriers to receiving proper healthcare. By acknowledging these challenges, healthcare professionals including genetic counselors can improve the crisis of men's healthcare by making services more accessible and removing barriers that prevent men from seeking and utilizing help and support. By understanding the various obstacles that men may face at the various levels outlined by Bronfenbrenner's Ecological Systems Theory, genetic counselors can work towards making their practices more inclusive and comprehensive. Genetic counseling empowers men to take ownership of their health and well-being, and in doing so, addresses inequities that affect men's quality of life and health. The field of genetic counseling has a powerful opportunity to enact change and improve men's wellness. Understanding masculinity and its effects on health and well-being is a useful tool in combating the crisis of men's healthcare and the barriers that men specifically face.

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