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Measuring Awareness and Identifying Misconceptions About Genetic Counseling Services and Utilizing Television to Educate

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Measuring Awareness and Identifying Misconceptions About Genetic Counseling Services and Utilizing Television to Educate

THESIS

submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

Dena Goldberg

Thesis Committee:

Professor Maureen Bocian, Chair
Assistant Professor Kathryn Singh
Professor Kathryn Osann
Professor Wayne W. Grody
Professor Jehannine Austin

2015

DEDICATION

To

my parents, family, and friends

in recognition of their love and support

and especially to my sister Ellie for inspiring me to choose this path

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ACKNOWLEDGMENTS

My committee members have given me so much support. It means a lot that people so important and experienced in the field of medical genetics believe in my talents.

Dr. Maureen Bocian is an excellent role model and a meticulous editor. I wish I had the way with words that she does. I will definitely be utilizing her editing skills and picking her brain for my future media endeavors.

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ABSTRACT OF THE THESIS

Measuring Awareness and Identifying Misconceptions Towards Genetic Counseling Services and Utilizing Television to Educate

By

Dena Marah Goldberg

Master of Science in Genetic Counseling

University of California, Irvine, 2015

Professor Maureen Bocian, Chair

Understanding awareness and perceptions of genetic counseling (GC) is important in identifying and overcoming potential barriers to GC services. However, there are relatively few empirical data regarding these factors among US-based populations. To address this, we attended various community events for the general public, disability community, and new parents and recruited participants for a survey-based study comprising demographic questions, closed-ended knowledge-based and awareness questions, and open text sections. We applied descriptive statistics to responses about demographics, awareness of GC, purposes of GC, and perceptions of GC practice. In total, 320 individuals participated, including 69 from the general public, 209 from the disability community, and 42 from the new parent community. Slightly more than half of respondents (n =173, 54%) had heard of GC. Risk assessment and counseling were among the most frequently cited activities attributed to genetic counselors; a few felt that GC was related to eugenics. Respondents thought that GC aims to prevent genetic disorders (n=82, 74%), helps people find their ethnic origins and understand their ancestry (n=176, 55%), advises people whether to have children (n=140, 44%), and helps couples have children with desirable characteristics (n=126, 39%). Our data showed the majority of participants preferred to watch a medical thriller involving genetic counseling, followed by documentary series; comedy was rated the lowest. These data revealed gaps in awareness of GC and misperceptions about its purpose and can be useful in devising targeted interventions by developing entertainment-based education to improve public knowledge of genetic health and the roles of GCs.

CHAPTER 1: INTRODUCTION

Genetic counseling has come a long way since its inception in 1947. When Sheldon Reed first coined the term, he was the first to recognize the necessity to provide not only genetic information, but also the "genuine respect and concern for the emotional and psychological well-being of the families he worked with" (Resta, 1997).

According to the National Society of Genetic Counselors;

> *Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following: interpretation of family and medical histories to assess the chance of disease occurrence or recurrence, education about inheritance, testing, management, prevention, resources and research, and counseling to promote informed choices and adaptation to the risk or condition* (Resta, 2006).

In the past, genetic counseling focused mainly on prenatal, pediatric, and some specialty areas. As knowledge of genetic disorders increases, the scope of practice of genetic counselors expands with it. In 2014, 35% of genetic counselors worked in a prenatal clinic, 29% in a cancer clinic, 12% in a pediatric setting, and 24% in another specialty setting, including adult complex disease, cardiogenetics, neurogenetics, hematology, psychiatry, metabolic disease, specialty disease, infertility, assisted reproductive technology (ART)/in vitro fertilization (IVF), preimplantation genetic diagnosis (PGD)/preconception, newborn screening, genomic medicine, molecular/cytogenetics/biochemical testing, personal genomics/genomic profiling, support group/advocacy, pharmacogenetics, and public health (NSGC, 2014). Genetic counselors often address conditions that are not solely, and sometimes not at all, genetic. “Genetic counselors now provide information about potentially teratogenic or mutagenic exposures; about birth defects that may have little if any genetic basis; and about common diseases of adulthood that have complex and heterogeneous causes” (Uhlmann, Schuette, & Yashar, 2009). Today, genetic counselors may even discuss interventions such as chemoprevention, prophylactic surgery, or other strategies, enabling patients to make choices that may reduce future disease risk (Phillips, 2001). With rapidly increasing genetic and genomic technologies, the utilization of genetic testing within every specialty of medicine will expand, and genetic counseling will be an essential part of this care (Guttmacher, McGuire, Ponder, & Stefansson, 2010; Harris, Kelly, & Wyatt, 2013; O'Shea et al., 2011).

Awareness of Genetic Counseling

Throughout the evolution of the field of genetic medicine, genetic counseling has adapted to the times, but what lags behind are the perceptions and opinions of the general public…that is, if they have even heard of genetic counseling at all. Two recent studies of general population perceptions of genetic counseling—one in Canada and the other in a US Midwestern rural area—showed that awareness of genetic counseling among the general population is fairly low (Maio, Carrion, Yaremco, & Austin, 2013; Riesgraf, Veach, MacFarlane, & LeRoy, 2014). In both studies, only a minority of participants had heard of genetic counseling. Of those who had heard of genetic counseling, many had misconceptions about its purpose.

Genetic counselors provide services to individuals from preconception to old age. In theory, anyone could be referred to a genetic counselor at some point in his or her life (Maio et al., 2013). However, if people are unaware of the services available to them, they are not likely to access them. Furthermore, people tend to be more comfortable engaging in activities with which they are familiar and that they view as being in concordance with their personal values (Michie, Marteau, & Bobrow, 1997). The broader the perceived scope of genetic counseling, the more likely people are to identify circumstances in which it may be of personal benefit. Therefore, it would be helpful both to potential patients and to genetics service providers to identify ways in which to improve public education and to increase awareness while dispelling misconceptions.

Negative Attitudes and Misconceptions

Before attempting to identify educational interventions, it is important to explore the possible reasons for a knowledge deficit. In the history of medical genetics, it is apparent that many misconceptions stem from the century-old historical legacy that made medical genetics what it is today—eugenics. This darker aspect of the history of the profession most likely contributed to "attitudes about disability and abnormality" as well as to the "demographic profile of the profession" (Stern, 2012).

In 1885, Sir Francis Galton coined the term "eugenics," meaning "well-born," in reference to the study of "agencies under social control that may improve or impair racial qualities of future generations, either physically or mentally" (Uhlmann et al., 2009). The practice of advising individuals and couples about inherited traits began in 1906, when William Bateson named the new study of heredity "genetics." It was thought that genetics might be able to identify hereditary factors contributing not only to medical diseases, including mental retardation, but also to social issues and behavioral disorders such as poverty, crime, and mental illness (Uhlmann et al., 2009).

Scientists collected data on human traits and provided information to affected families— usually with the intention of persuading them not to reproduce. The eugenics movement, although initially well intentioned, ultimately had disastrous consequences. By 1926, 23 of the 48 U.S. states had laws mandating sterilization of the “mentally defective,” and over 6,000 people had been sterilized (most involuntarily) (Uhlmann et al., 2009). Startlingly, this practice continued into the 1970s in some countries (Wooldridge, 1997). In 1924, the United States Congress passed the Immigration Restriction Act, instituting quotas to limit immigration by various “inferior” ethnic groups. In Germany, euthanasia for the “genetically defective” was legalized in 1939—ultimately leading to the deaths of over 70,000 people with hereditary disorders in addition to the Jews, Gypsies, and others who were killed in the holocaust (Neel, 1994). The horror of these historical examples paved the path for the development of the “nondirective” approach to genetic counseling that is so ingrained in today’s practice.

The Principle of Nondirectiveness

Nondirective counseling is the idea that information that is important for decision-making should be presented without attempting to steer the patient in a particular direction. In theory, if a counselor only gives the facts and does not express his or her opinions or give advice, then the counseling will be lacking in any eugenic motivation (Uhlmann et al., 2009). Although not necessarily appropriate for all settings, nondirectiveness is considered a defining feature of genetic counseling.

In the 1970s, Seymour Kessler defined nondirectiveness in the practice of genetic counseling as “procedures aimed at promoting the autonomy and self-directedness of the client” (Uhlmann et al., 2009). However, nondirectiveness may prove impossible when the provision of information or recommendations related to health-protective behaviors is an essential part of the session (Rees, Young, Gaff, & Martin, 2006). Although important as a basic tenet of genetic counseling, nondirectiveness may not always be applicable. Interpreting nondirectiveness narrowly or rigidly can lead to being perceived as aloof or disinterested. In fact, it is quite appropriate for a genetics professional to recommend, for example, surveillance for complications of a disorder, or sharing information with relatives. Also, in guiding patients through a decision-making process, the counselor may help them consider the potential consequences of various decisions, which, in turn, may involve questioning them to clarify their understanding, presenting them with what may be unwelcome information, or pointing out the possibility of unanticipated consequences to certain decisions (Elwyn, Gray, & Clarke, 2000).

The Disability Community

However distant they may be, the memories of the depressing history of eugenics echo in the opinions of those who are unaware of the current practices of genetic medicine. Some of the strongest negative feelings are held by people with disabilities. Although the disability community has a high concentration of genetic conditions, those within the community often see genetic medicine and genetic counseling in one of two ways: “On the one hand, there is a narrative of genetic intervention as a major contribution to human health, and a new way of avoiding the suffering associated with impairment. On the other hand, there is a narrative of genetics as a totalitarian conspiracy to rid the world of disabled people” (Shakespeare, 1998, 1999). Those who hold the second opinion may associate genetic counseling only with prenatal genetic testing and termination of affected pregnancies.

In 2001, Madeo et al. published a commentary on the relationship between the genetic counseling profession and the disability community. They mentioned that some members of the community feel judged by being offered prenatal genetic diagnosis that could lead to termination of a pregnancy because the fetus would have disabilities. The perception that genetic counselors are negatively biased and tend to focus more on the medical or functionally impaired aspects of disability when assessing the quality of life among persons with disabilities led to concern that genetic counselors may present a disability in a more negative light during a prenatal counseling session. It also was noted that the National Society of Genetic Counselors (NSGC) was an organization that has publically aligned itself financially with more abortion clinics than with groups for individuals with disabilities, thereby leaving itself open to a perception of bias by members of the disability community by appearing that its commitment to protecting individuals' reproductive rights was much greater than their dedication to ensuring a high quality of life among individuals with disabilities (Madeo, Biesecker, Brasington, Erby, & Peters, 2011).

Although the intentions of genetic counselors are pure, they may not always appear to be. In interviews with mothers of children with Down syndrome who had received the diagnosis prenatally, some reported feeling unsupported in their decision to continue their pregnancies. They perceived professional bias and assumptions that made them feel inadequate to make such a decision (Helm, Miranda, & Chedd, 1998). In another study, some mothers felt that genetic counselors were biased against individuals with Down syndrome when discussing the disorder in the prenatal session (Bauer, 2011). These negative opinions are not lost on genetic counselors.

A small number of studies have actually asked individuals with disabilities about their opinions regarding prenatal diagnosis and genetic counseling. In a small study of 15 adults with physical disabilities, genetic counseling and prenatal diagnosis were generally viewed favorably, with only a few of the respondents perceiving them to be eugenic (Chen & Schiffman, 2000). Other studies looked at the views of prenatal genetic testing held by those with learning disabilities (Ward, Howarth, & Rodgers, 2002), cystic fibrosis or Huntington disease (Chapman, 2002), and Down syndrome (Alderson, 2001). Overall, there were differing opinions, but each described some manner in which the availability of prenatal genetic diagnosis might have a negative impact on the lives of those with a disability and expressed concern that some genetic counselors may not provide balanced information about a newly diagnosed condition that may be associated with a disability. In looking at each of these studies, there is evidence that some individuals in the disability community perceive genetic counselors to be biased in their attitudes towards disability (Madeo et al., 2011).

Individuals who perceive genetic counseling negatively because of the history of eugenics may only be aware of the prenatal aspects of genetic counseling and not of pediatric and adult genetic counseling, which can aide in case management, personalized medical management plans, surveillance options/recommendations, prevention of complications, family support, referral to necessary services and resources, help in dealing with insurance, and finding clinical trials and possible therapies. Therefore, this population would be an ideal target audience for education interventions, since many disabled individuals and their families would benefit greatly from these types of genetics services. Although a number of studies have measured the opinions of the disability community about prenatal genetic diagnosis (Alderson, 2001; Bryant, Hewison, & Green, 2005; Chapman, 2002; Parens & Asch, 2003; Raz, 2004, 2005) or attitudes toward genetic counseling (Chen & Schiffman, 2000), no studies have surveyed the actual awareness of the scope of genetic counseling services within the disability community.

Physician Education

Another misconception about genetic counseling is the assumption that any primary care physician has the proper training to order, interpret, and explain complex genetic testing. Patients may believe that their primary care physician would be able to evaluate their genetic risks, provide referrals, or order the appropriate testing when necessary. It is true that the provision of genetic counseling services is not limited to genetic counselors and medical geneticists (Guttmacher, Jenkins, & Uhlmann, 2001), and although there are non-geneticist medical doctors who can provide adequate genetic counseling, physicians tend to be more information-driven and less psychosocially oriented than a trained genetic counselor or medical geneticist (Stern, 2012). The 2010 NSGC professional status survey reported that the majority of genetic counselors spend between 31-60 minutes in face-to-face interaction with each patient, while the majority of non-geneticist physicians spend less than 15 minutes (NSGC, 2010). With the pressure put on physicians to see a high volume of patients in a short amount of time, it is very difficult to reach the depth of psychosocial conversation that a genetic counselor would aim to reach (Stern, 2012).

There is still a lack of proper medical genetics training in medical schools. In 2007, Thurston et al. surveyed medical schools across the United States and Canada to measure how much time was spent on genetics in the curriculum and how it was taught. They found that 18% of medical school instructors devoted fewer than 20 hours to medical genetics instruction. Of those who devoted more time to medical genetics, the instruction consisted of general concepts rather than practical applications (Thurston, Wales, Bell, Torbeck, & Brokaw, 2007).

Without proper training, there is an increased chance that a physician may make an inappropriate decision. Brierley et al. described instances in which the wrong genetic test was ordered, genetic test results were misinterpreted, and inappropriate, inadequate, or lack of genetic counseling was provided when non-genetics health professionals provided genetic services (Brierley et al., 2010).

Inadequate knowledge of genetics remains a primary barrier in the integration of genetics into primary care. One reason for this may be that before a primary care physician (PCP) even sets foot in the clinic, his or her knowledge is already out of date. “Time has not stood still for the field of genetics since the completion of the HGP [Human Genome Project]. On the contrary, advances in genetic technology and the discovery of new genetic mechanisms seem to occur almost daily. Meanwhile, PCPs’ genetics training is likely decades old and rusty from lack of use” (Mikat-Stevens, Larson, & Tarini, 2014).

Until only recently, the field of medical genetics focused on rare diseases that are not frequently seen in a primary care clinic. Now that the understanding of the importance of genetics in more common diseases is increasing, the real challenge for providers is determining when and how to apply this information in their practice. The physician is not required to know all of the information necessary to identify, order, and interpret a genetic test appropriately, but he or she should know when to refer a patient for genetics evaluation and counseling. However, if the physicians themselves do not understand the indications for genetics services, they will not be equipped to identify patients needing referral.

In one study among health care professionals, a large number of providers perceived that genetic counselors give advice on when to terminate a pregnancy and, therefore, did not appear to understand the non-directive role of a genetic counselor (Guilbert & Cheater, 1990). If a physician misinterprets the services provided by a genetic counselor, he or she will not be able to refer a patient appropriately or prepare the patient for what to expect and what information to bring to the counseling appointment. It is important that all health care providers have an understanding of the basic principles of genetics, are aware of the genetic services available, and can advocate their use for clients who may benefit from a genetics referral (Guilbert & Cheater, 1990).

When a physician does decide to refer a patient to genetic counseling, it is important to inform the patient as to why he or she is being referred and what it means. Studies have shown that individuals referred for genetic counseling "would have liked more information about what to expect prior to attending the appointment" (Metcalfe, Werrett, Burgess, & Clifford, 2007). In order to ensure the best outcome from a genetic counseling session, it is important that individuals know what to expect and can prepare their questions or gather necessary information (such as medical histories of their family members) prior to the appointment. Therefore, educating physicians about genetic counseling will not only lead to more appropriate referrals but can also improve the outcome of genetic counseling sessions (Harvey et al., 2007; Hayflick, Eiff, Carpenter, & Steinberger, 1998; Powell et al., 2012).

Patient Education

Genetic counselors reported in 2010 that about 50% of their patients were self-referred (Riesgraf et al., 2014) Various studies found that the strongest motivating factor for a physician's referral for genetic counseling was when a patient expressed interest in genetic counseling services (Aalfs, Smets, de Haes, & Leschot, 2003; Hayflick et al., 1998; Vande Wydeven, Kwan, Hardan, & Bernstein, 2012). Therefore, if we direct education interventions only to health care professionals, we would miss half of the referral sources—the patients themselves. Direct education about genetic counseling and genetic services is just as important for patients as it is for their physicians.

Media

Both Maio et al. and Reisgraf et al. found that the majority of those who have heard of genetic counseling said they had heard about it in the media. Media is an important key that unlocks the door to broader awareness. Social media, the Internet, film, and television have the potential to reach the broadest audience possible (Maio et al., 2013; Riesgraf et al., 2014).

When Lee Raymond Dice and Sheldon Reed introduced the new concept of genetic counseling (unfortunately in the context of eugenics) to tens of thousands of Americans in 1948 through newspapers, magazines, and radio, they received a flood of letters requesting advice. This public introduction to human genetics sparked much interest in the inheritance of diseases and traits. Dice and Reed concluded that this was a demonstration of the common need for advice about heredity (Stern, 2012). Large-scale media interventions, even if their primary purpose is entertainment, can increase public awareness of various issues.

It is important for a profession such as genetic counseling to have a voice in the media; however, this voice is currently quiet and reserved. The majority of genetic counselors come from a background of biology or psychology and, therefore, may never have had training in self-promotion, self-marketing, networking, or public speaking. Genetic counselors may shy away from media appearance opportunities for fear that they may be misquoted or portrayed in a negative light. However, if medical geneticists and genetic counselors do not contribute important information to the media, someone else will, and accuracy may be compromised as a result.

The primary medium for entertainment education is television. “As a communications tool, TV continues to dominate, primarily because the size of its audience is unrivaled, dwarfing that of even the most popular websites” (Rideout, 2008). From 2013 to 2014, the number of viewers watching broadcast television episodes online increased by 81%. “The media and entertainment industry is moving quickly into a digital world. Online TV is changing the way we consume content…today, TV is no longer just the device, it’s the content, and viewer expectations are rising" (AdobePrimetime, 2014). Over the years, television has increased public awareness of a number of social issues including substance abuse, immunization, teen pregnancy, HIV/AIDS, cancer, and other diseases ("Entertainment Education and Health in the United States," 2004).

Entertainment education, also referred to as "edutainment" or "infotainment," is a means of informing the public about a social issue or concern. This strategy involves incorporating an educational message into popular entertainment content in order to raise awareness, increase knowledge, create favorable attitudes, and ultimately motivate people to take socially responsible actions in their own lives. In "edutainment," health-related storylines are incorporated into popular TV sitcoms, dramas, or soap operas and may originate from the outreach efforts of a special interest group or health agency ("Entertainment Education and Health in the United States," 2004).

When producers or writers want to learn more about a specific topic with intent to achieve accuracy, they may turn to the Hollywood, Health & Society (HH&S) program at the Norman Lear Center in the University of Southern California's Annenberg School for Communication. Through this organization, Hollywood writers and producers can ask physicians and other experts in their fields for information for their storylines. In a presentation by Sandra De Castro Buffington, the founder of Hollywood, Health, & Society, she quoted Charles Mingus, saying, "Anyone can make the simple complicated, creativity is making the complicated simple" and added, "We make the very complex world of health simple and accessible to Hollywood's producers." She described using doctors and experts in a particular field as "someone whose expertise is on deciphering medical jargon so that the everyday person could understand" (Buffington, 2013). Theoretically, this should work, but writers will still take liberties to enhance their stories, causing them to stray from scientific accuracy.

A well-known professor or physician may be an expert on a certain subject and yet may not know how to simplify it so that someone unfamiliar with the topic can understand it. Individuals who spend the majority of their time in research laboratories may be out of touch with the general public or have little idea of how patients should be evaluated and informed about their diagnoses. Although the medical information might be accurate, the way in which the patient receives it may not be properly portrayed in a storyline, which can sometimes be more important than the information itself. Who better to inform the writing of a medical thriller then the person who understands the scientific accuracy and the psychosocial intricacies of a person or family dealing with genetic disease—a genetic counselor.

Edutainment in Action

An excellent study of the effectiveness of edutainment relates to the rate of mother-to-child transmission of HIV when an HIV-positive mother receives proper medical treatment during her pregnancy. *Without* treatment, the risk of mother-to-child transmission is 25%, but with appropriate medication and care, the risk is less than 2%. For this study, the Kaiser Family Foundation worked with the writers from the popular television medical drama, *Grey's Anatomy,* to incorporate this issue into a storyline that aired on May 1, 2008. In the story, a couple finds out that they are pregnant and immediately asks for an abortion because the wife is HIV positive. The character, Izzie, a surgical intern, does some research and explains that the risk for the child to contract HIV if the mother is properly treated is only 2%. They argue, and later she says, "I wasn't saying there's *some* chance your baby might not be sick. I'm saying there is a 98% chance your baby will be born perfectly healthy. *Ninety-eight percent*!" Later, the pregnant woman replies, "A 98% chance?" and Izzie responds, "A 98% chance." After administering surveys before and after he telecast and 6 weeks later, the Kaiser Family Foundation found that “viewers’ knowledge about mother-to-child HIV transmission rates rose substantially after the *Grey’s Anatomy* episode aired, and the new information was still retained by many *Grey’s* viewers six weeks later” (Rideout, 2008). At the time, *Grey’s Anatomy* routinely drew an audience of about 20 million viewers. This study shows that with the proper incorporation of facts into any television drama with a large audience, we have the potential to educate millions of people at once.

The Absent Genetic Counselor on Television

Although health information is abundant in many television shows, the representation of a genetic counselor is essentially non-existent. Another report examined how shows like *Grey’s Anatomy* and *House MD* focus on doctors but exclude nurses, medical technicians, and other individuals who perform vital roles in patient care (Smith, 2013). To date, no genetic counselors have ever been portrayed in a medical drama. This absence in mainstream media may be a factor of the misconception that genetic counselors are not a necessary part of a medical care team.

In Season 11, Episodes 8-11 of *Grey’s Anatomy*, a surgeon couple, April and Jackson, are pregnant but find out that their unborn baby boy has a bone fragility disorder called osteogenesis imperfecta. Jackson tells April that if their child has type II osteogenesis imperfecta (a lethal form), he wants to terminate the pregnancy. However, April's Christian beliefs stand in the way. She goes through extreme psychological distress until she is comforted by her mother-in-law, who is also a surgeon. In this storyline, she never sees a counselor of any type, and although many issues are addressed well by the mother-in-law, a woman going through the same type of situation would not necessarily have a family member in medicine who could counsel her both accurately and in an unbiased manner. This is the type of storyline in which interaction with a genetic counselor could be very informative and still not detract from the drama.

In Season 3 of the *The Mindy Project*, Mindy, an obstetrician, decides to open her own fertility center. A role for a genetic counselor working as part of the team in an upscale New York maternal-fetal medicine clinic would be very realistic. Instead, they have roles for nurses, midwives, and administrators, but no genetic counselor. In Episode 21, Mindy is pregnant and visits an obstetrician, who tells her she is "high risk" because of "fat" and "much age." The doctor then tells her that her preeclampsia is so severe that "her numbers spun around the dial an extra time" and were "too high for the blood pressure monitor to read." Having severe preeclampsia certainly places a woman at increased risk for pregnancy and personal health complications; advanced maternal age increases the chance of having a baby with a chromosomal abnormality, such as Down syndrome. There is no mention in the dialogue of what she is at "high risk" for and what "much age" implies, and she is never referred to a genetic counselor. Although the show is a comedy, it still could have been a teachable moment.

Perhaps the best example of overdramatic genetic awareness in action was the eight-episode breast cancer-related story arc on the series *90210.* In Season 4 of *90210*, the character Silver is 19 years old and preparing for college and attends a routine appointment in which her doctor mentions that her mother and aunt died of breast cancer and that she should consider getting tested for the "BRCA gene." The doctor tells her, "If you have the BRCA 1 or 2 mutation, your future includes a chance of up to 60% of getting breast cancer. You have to consider preventative measures such as prophylactic mastectomy," to which Silver responds, "Do we have to talk about it now?" and her doctor says, "We do." The doctor does not present any other options or mention referral to a genetic counselor. Also, she is recommending preventative surgery to a 19-year-old, which is a much earlier age then necessary.

In another scene, Silver consults another doctor to obtain testing and brings her friend with her. The doctor walks in, remains standing as Silver sits on the examination table, and tells her, “It’s important to have support; if you test positive for the BRCA gene, you’re going to be facing some tough choices. Some people don’t even want to know.” Silver responds, “Yeah, I didn’t know if I did, but I watched my mom die of breast cancer, so if knowing means that it won’t happen to me…,” to which the doctor responds, “The gene also increases your risk of ovarian cancer. At some point, you’ll also have to consider removing your ovaries. Have you two talked about a plan for having children?” Silver says, “I don’t have a boyfriend or a plan for kids. I kind of just thought I’d meet somebody and fall in love,” to which her friend responds, “Well, that can still be the plan, right?” The doctor answers, “Fertility is something that we can discuss when the test results come in. You may not even have the gene.” It is possible that this doctor was supposed to be playing the role of a medical geneticist or genetic counselor, but if so, the dialogue was a poor example of genetic counseling. Although there may have been time limitations on the script, this scene was a complete distortion of the actual genetic counseling process. Then, Silver receives her BRCA test results in the mail, opens them, and begins to cry. Mailing the report directly to the individual is considered a completely unacceptable way to inform a patient of test results. Seeing this portrayal may have caused viewers to perceive the genetic testing process as unstructured and impersonal. Ideally, Silver should have seen a genetic counselor for pre-test counseling and again for discussion of her test results. Next, accompanied by three of her friends, she sees yet another doctor. The doctor’s first comment is, “So I hear you’re ready to talk about a surgery schedule,” to which she responds, “Oh, uh, well, yes, I’m not sure yet, but until I take care of this, I feel like I’m a walking time bomb.” The doctor replies, “Yeah, I understand,” with no acknowledgment of her statement about feeling like a “time bomb.”

In Season 5, after Silver decided to freeze her eggs, she runs into an old friend who also has a BRCA mutation and who tells her, “You know us BRCA gene patients, we’re always finding some reason to be at the hospital. Good news is, I lost a couple pounds, bad news is it was all boobs and ovaries…Actually, it was the scariest thing I’ve ever done. It hurts, I have scars, and I have to take pills for the rest of my life…but you will be alive and you won’t go to bed worried about cancer.” Although this may be an empowering message, it also could cause viewers unnecessary anxiety, especially important since the main demographic of *90210* viewers is teenage girls.

The Hollywood, Health, & Society Program did a study on this storyline to see if it made a difference in viewer awareness of inherited breast cancer. Rosenthal, et al. explored whether viewing a single episode affected regular television viewers and if knowledge and behavioral outcomes varied. They found that 13% of participants reported talking to a female acquaintance about the BRCA gene test as a result of having viewed this storyline, and 16.5% reported searching online for more information about breast cancer (Rosenthal, Buffington, & Cole, 2013). This demonstrates that the program proved to be a very good way to raise awareness, but it would have been even better if the storyline had included a more factual portrayal of genetic counseling and testing procedures for inherited breast cancer.

Bending the Science

Some television writers prefer to bend the truth to make a show more dramatic. However, a genetics clinic is already dramatic as it is. With patients from all walks of life being evaluated by medical geneticists for a wide variety of reasons, adequate drama can come from the patients and a more accurate portrayal of their back-stories.

In Season 5, episode 6 of the show, *House MD*, a widowed man with a young daughter has blackout periods, starts buying and using cocaine while sleepwalking, begins to sweat blood, and develops kidney failure. Neither he nor his daughter shows any emotion, and they soon realize that she is sleepwalking as well. Dr. House calls them “anhedonic” (anhedonia: the inability to gain pleasure from normally pleasurable experiences) and surmises that their dopamine receptors were “wiped,” causing the father to sleepwalk and purchase cocaine. He then claims that it would have been caused by schizophrenia if they were white, but they are hiding that they are Middle Eastern, and he concludes that they have “contracted” Familial Mediterranean Fever (FMF). He treats them with dopamine, and their emotions return. (FMF, an autosomal recessive, non-contagious disorder more common in some Middle Eastern populations, is characterized by recurrent episodes of fever and pain in the chest, abdomen, and joints; it causes neither anhedonia nor sleepwalking, and there may be strikingly red skin lesions but not “sweating blood.” There is treatment, but not with dopamine.) This episode depicts a marked distortion of FMF. The only similarities are kidney failure and Middle Eastern descent. If someone with recently-diagnosed FMF or a relative saw this episode, it could cause unnecessary anxiety. In shows like these, seeking input from a genetic counselor or medical geneticist could result in more realistic portrayals and spread fewer misconceptions about a disorder without diminishing the dramatic effect of making a diagnosis and successfully treating the patient.

Missed Opportunities

There are times when a large health education initiative could have been undertaken but, for reasons unknown, was not. In the hit show *Glee*, the one of the characters has Down syndrome.

This actress developed early dementia, providing an excellent opportunity to educate the public about Alzheimer disease in individuals with Down syndrome. Instead, they wrote her out of the show by having her character die and staged a large funeral but never mentioned anything about dementia. Individuals with Down syndrome are at increased risk to develop Alzheimer disease at an earlier age than in the general population (Zigman, 2013), but many of their families may not be aware of this possible complication.

Perhaps the best example of television impacting individuals with genetic disorders is the role of Charles “Corky” Thatcher, a young man with Down syndrome played by Chris Burke for four seasons in the ABC drama, Life Goes On. Gail Williamson, the premiere Hollywood agent for actors with disabilities—especially those with Down syndrome—is the mother of a man with Down syndrome. In an interview, she described Corky’s role as the first time an individual with Down syndrome was portrayed on television. Although Burke was likely higher functioning than many or most individuals with Down syndrome, his role changed the way the general public viewed affected individuals (Williamson, 2015). Williamson was an active parent in the Down syndrome community, and she recounted hearing stories of doctors advising abortion or automatically scheduling an abortion when a fetus was found to be affected with Down syndrome. Then, as the show became popular, she heard stories of doctors telling parents, “Your child could grow up to be like Corky,” emphasizing his capabilities instead of focusing purely on negative aspects of Down syndrome. Since then, several prime-time television series have featured actors with Down syndrome, all of which positively impacted public understanding of the disorder.

Objectives of the Present Study

By recognizing the areas in which public knowledge is lacking, we can better target specific educational initiatives to raise awareness of genetic counseling. Previous studies (Maio et al., 2013; Riesgraf et al., 2014) measured the knowledge and perceptions about genetic counseling among the general public in Canada and the rural Midwestern US. This study will be the first to examine these factors among the general public in California as well as in the disability and new parent communities. This study is designed to answer several questions:

1. How familiar is the general public with genetic counseling?
2. How accurate are public perceptions of the purpose and nature of genetic counseling?
3. How do these measures of perceptions and awareness compare among the general public, the disability community, and the new parent community?
4. What interventions can we take to increase understanding and dispel misconceptions?

We propose to answer these questions by surveying the general public, a disability community, and a new parent community and comparing their responses. We hypothesize that knowledge of genetic counseling will be low among all three groups and that a large proportion of participants will have unfounded negative opinions about the profession. We will also explore how participants watch television and what type of show they would be interested in viewing if we were to design a genetics-themed program.

CHAPTER 2: METHODS

IRB approval was obtained from University of California Irvine (HS# 2014-1553). A booth was set up at multiple expositions ("expos") and public venues on various dates between November 2014 and March 2015. These sites included the Abilities Expo in San Jose and in Los Angeles, CA, the Santa Monica Santa Run Finish Line Expo in Santa Monica, CA, the Venice Beach Boardwalk in Venice, CA, and the Baby & Kidz Expo in Orange, CA. A table and chair were set up with a poster identifying the author as a UC Irvine graduate student conducting a survey. Participants who approached the booth and inquired were asked to take the survey. The survey was administered on a laptop, tablet, or, if requested, on paper. There was a link to the survey online so that people could take it from their smart phones, but no IP addresses or identifiable data were collected. The survey took each participant between 5-10 minutes, after which they received a small gift bag and were given the opportunity to ask questions. The gift bags contained a brochure created by the author defining genetic counseling, a plastic cup with the UCI genetic counseling graduate program logo, the booklet, "Making Sense of Your Genes: A Guide to Genetic Counseling" from the Genetic Alliance, and a genetic fact sheet created by the author. The gift bags given out at the Los Angeles Abilities Expo also included several booklets about rare disorders and genetic counseling that were donated by Global Genes, a rare disease advocacy organization, as well as Global Genes rare disease awareness ribbons.

Participants

Individuals were eligible to participate if they were able to understand and speak English and were 18 years or older. These participants were placed into one of three categories: general public, disability community, or new parent community. The category was determined by the expo/location at which the individual participated in the survey; participants did not define their categories, and the categories were mutually exclusive. The disability community responses were those collected at the Abilities Expos in San Jose or Los Angeles and included affected individuals, family members, caretakers, or anyone else attending these gatherings. The general public responses were defined as those collected at the Santa Run Run Finish Line Expo or from passers-by on the Venice Beach Boardwalk. Both of these locations were open to the general public, and neither was associated with any particular agenda or philosophy. The new parent responses were collected at the Baby & Kidz expo in Orange, CA and included mothers and fathers of young children and babies, expectant parents, family members, and friends.

The Survey

The survey instrument was designed to assess participants' awareness of genetic counseling and their perceptions regarding its purpose. It was based on the survey from Maio, et al. but was adapted to relate to different aspects of genetic counseling and media. We did a pilot study with genetic counseling graduate students and with individuals who are not associated with genetics or other areas of medicine or science to test wording, clarity, and time needed. Based on the pilot study responses, on input from the thesis committee, and on advice from the last author of the Maio, et al. study, we revised and finalized the survey instrument. It consisted of four open-ended questions, 28 multiple-choice questions, and 18 true-or-false questions. The demographic section was comprised of items relating to age, gender, self-described ethnicity, religion, education level, location, occupation, household income, and marital status. The survey was administered between November 2014 and March 2015. The complete survey is available in Appendix A.

Awareness of Genetic Counseling

To assess awareness of genetic counseling, the survey began with several open-ended questions. First, we asked, “In a few words, what is the first thing that comes to mind when you hear the term, “genetic counseling?” The responses were categorized according to content after they were all collected (refer to Appendix B). The categories included DNA/genes/makeup/the body, risk/predictions/future/screening, genetic disorder/disability/rare disease, family/hereditary/inherited, counseling/helping/guidance, testing, prenatal/birth defects, lifestyle/health/prevention, preconception, laboratory/research, genealogy, desirable characteristics/eugenics, altering genetics, adult-onset disorders/pre-symptomatic testing, cancer, pediatrics, psychiatric/mental illness, ethnic prevalence/ethnicity-specific genetic disease, or not sure/no response. Each participant’s response could be categorized under multiple categories if it was deemed by the author to fit. Special attention was paid to responses that mentioned the type of genetic counseling setting (e.g., Preconception, Prenatal, Pediatric, Adult, or Cancer).

To assess the source of awareness, the second question asked, “Before coming across the phrase while participating in this study, have you heard of ‘genetic counseling’ before today?” If the respondent said no, he or she was directed to the next question. If the answer was yes, he or she was directed to the question, “How did you become familiar with genetic counseling?” Answer choices included, “I have been referred to or have seen a genetic counselor,” “A friend or acquaintance has been referred to or has seen a genetic counselor,” “A family member has been referred to or has seen a genetic counselor,” “A friend or acquaintance is a genetic counselor,” “A family member is a genetic counselor,” “I have read about genetic counseling in the news,” “I have seen a TV show in which a genetic counselor was mentioned or portrayed,” “I have read about genetic counseling on the Internet,” “I have seen a movie in which a genetic counselor was mentioned or portrayed," "I am, or am studying to be, a genetic counselor," or "other" with a write-in response. Write-in responses were also categorized (see Appendix B). After this question, the participant was directed to answer, "If you have seen a TV show or movie in which a genetic counselor was mentioned or portrayed, please write the name of the television show(s) or movie(s) here."

Assumptions about Genetic Counseling

To assess the understanding or assumptions of what a genetic counselor does, the next question asked, "What do you think genetic counselors do?" These open-ended responses were categorized according to content (see Appendix B). Response categories included risk assessment, laboratory work or evaluating/analyzing a patient's genes or DNA, counseling or emotional support, preconception, explaining results/a diagnosis/post-test counseling, teaching about genetics, inheritance/heredity, looking at family history, prenatal, personal genomics/personalized medicine/health counseling, explaining treatment options and management strategies, finding a diagnosis, surveillance or prevention, clinical trials/research/rare disease, altering DNA/designer babies, advising people what to do, pre-symptomatic testing, screening, disabilities, taking a blood sample or blood test, pediatrics, pre-test counseling or testing guidance, genealogy or finding ancestry, connecting patients to support groups/resources/referrals, cancer, not sure/no response, or other. Each response could be categorized under multiple categories if it was deemed by the author to fit. These particular categories were separated out in order to measure both the misconceptions as well as the correct roles of the genetic counselor among the responses. Special attention was paid to any mention of pre-test and post-test counseling associated with genetic testing as well as those that mentioned the type of genetic counseling setting (e.g., Preconception, Prenatal, Pediatric, Adult, or Cancer).

The next question asked, “Where do you think a genetic counselor would work?” as an open-ended question. The responses were later categorized into cancer center, clinic, counseling center/mental health center, doctor’s office, family planning/fertility clinic, health club, homeopathic center, hospital, industry, lab, media, Medical Facility/ Setting/ Office, Maternal Fetal Medicine Center/ Obstetrician, private practice, Regional Center/ Disability Center/ Organization, School/ University, Wellness Center, research, home, insurance, other, and not sure/blank (see Appendix B), and if a response mentioned multiple types of venue, it was counted in multiple categories.

Perceptions of the Purpose of Genetic Counseling

The next part of the survey consisted of 18 true-or-false questions regarding the purpose of genetic counseling and included 9 examples of reasons for genetic counseling as well as 9 common misconceptions. These questions were based on questions used in the Maio, et al. survey and were expanded upon with assistance from the thesis committee.

Participants were instructed to mark whether they believed the statements to be true or false. Each question began with, “A purpose of genetic counseling is to……” and was followed by one of true statements (provide referrals and resources for families with a genetic condition, calculate the risk a patient has of developing cancer based on family history and testing, help people understand their options for genetic testing, provide genetic testing to people with a family history of a genetic condition, provide information and support to pregnant women whose babies may be at risk for a genetic condition, provide information and support to couples planning a pregnancy that may be at risk for a genetic condition, provide an explanation of the preventative, screening and diagnostic options that are available to a patient with cancer, help families understand the condition in their family and what it means for them – even if the condition is caused by a combination of genes and environment, aid in determining if a person's autism, developmental delay, or intellectual disability was caused by genetic factors) and 9 misconceptions (fix mutated genes, help people find their ethnic origins and understand their ancestry, help couples have a child with desirable characteristics, provide information and support to ALL pregnant women, provide information and support to ALL couples planning a pregnancy, prevent genetic diseases or abnormalities, determine whether a child without symptoms is going to develop an adult-onset condition later in life, such as Huntington disease or Alzheimer disease, help police use DNA to solve crimes, advise people about whether to have children). Participants were given a knowledge score based on how many of these items they answered correctly.

To assess another aspect of awareness, the next question asked, “Which of the following specialists are the most qualified to provide genetic counseling?” Participants had the option of “YES, this person is qualified to provide genetic counseling” or “NO, this person is NOT qualified to provide genetic counseling” for each of the following: midwife, internist, obstetrician, psychologist, pediatrician, genetic counselor, primary care physician, oncologist, nurse, or social worker.

TV and Media

To asses the opportunity for media involvement, we asked, “How do you watch TV shows?” and gave the options “Mostly online,” “Online and TV equally,” “Mostly TV,” or “I don’t watch TV at all.” If the respondent answered, “I don’t watch TV at all,” he or she was guided to the last section. Otherwise, he or she was asked, “If the following TV shows were to come out next season, how likely would you be to watch?” Participants’ choices included, “I would definitely NOT watch this show,” “I would NOT be likely to watch this show,” “Not sure,” “I might watch this show," or "I would definitely watch this show" for each of the following hypothetical television shows: (1) "The Counselors: A panel of geneticists and genetic counselors answer questions about genetics in a talk show setting with a studio audience. (Similar to: The Doctors, Dr. Oz);" (2) "Chasing the Helix: A drama/thriller about a group of genetic counselors and the unique stories of their patients based on real-life cases. (Similar to: *House, Grey's Anatomy, Law and Order*);" (3) "Blue Genes: A comedy that follows a group of genetic counselors and their quirky patients. (Similar to: Scrubs);" (4) "DNA Files: A documentary series that discusses a different genetic disorder each episode and interviews experts, patients, and their families with each disorder. (Similar to: Mystery Diagnosis, Untold Stories of the ER, Extraordinary People);" or (5) "Real Genes: A reality show that follows real genetic counselors in different clinical settings and the challenges they face with patients, insurance, medical staff, etc. (Similar to: NY Med, COPS, Keeping up with the Kardashians)." To view the full survey as it was distributed, see Appendix A.

Demographics

The last section of the survey asked about demographics. Age was divided into categories (18-20, 21-29, 30-39, 40-49, 50-59, 60 or older), as was gender (male, female, other). To assess education level, participants were asked, "What is the highest level of school you have completed or the highest degree you have received?" The multiple choice answers included none, less than high school (0-8 years), some high school (9-11 years), high school graduate (12 years), some college or university, college or university graduate, some graduate school, graduate or professional degree, and other. If a participant had a graduate or professional degree, he or she was asked to enter the type of degree and the area of specialization. Race/ethnicity were combined in one question with multiple choice answers: Caucasian/non-Hispanic, Black or

African American, Asian, Hispanic/Latin, American Indian or Alaskan Native, Pacific Islander, Middle Eastern, East Indian, Prefer not to answer, or Other, with space to write in an answer. Several categories were given for occupation (Administration, Art/Music/Writing, Banking/Finance, Construction, Education, Entertainment/Media, Hospitality, Law, Management, Medicine, Military, Politics/Government, Retired, Sales/Marketing, Science/Engineering, Student, Technology, Transportation, Unemployed) or "Other" with an option for a write-in response. Choices for Religion included Buddhism, Catholicism, Hinduism, Inter/Non-denominational, Islam, Judaism, Latter Day Saints (Mormonism), Native American, Other Christianity, Protestantism, no religion, prefer not to answer), and an option for free response. Categories that could be combined were combined after receiving all responses (e.g., science and engineering were combined with technology for the category science/engineering/technology).

Although all surveys were conducted in California, all participants were asked to list the state in which they currently reside. Marital status choices included "single," "married," or "not married, but living with partner." Participants were then asked questions including if they have children, if they have a disability, or if they are practicing physicians, each with "yes" and "no" response options. The last question, which assessed socioeconomic class, was, "How much total combined income did all members of your household earn last year?" Options included: less than \$25,000, \$25,000-\$49,999, \$50,000-\$74,999, \$75,000-\$99,999, \$100,000-\$149,999, \$150,000-\$199,999, \$200,000-\$499,999, more than \$500,000, and "I'd rather not say."

Analysis

The open-ended questions were coded and compared among the three population groups to determine if there were any significant differences between any of the populations. Categorical data were compared using chi-square tests, while continuous data were compared using analysis of variance and paired t-tests to compare means. P-values less than 0.05 were considered to be statistically significant. P-values have not been adjusted for multiple comparisons and, therefore, should be interpreted with caution. SPSS was used for statistical analysis of data.

In addition to applying descriptive statistics to summarize the data, we created a “knowledge score” for each participant based on his or her responses to the 18 true-or-false questions regarding the purpose of genetic counseling. These scores were created by summing the number of correct responses for each participant. The range of possible knowledge scores was 0-18. Participants were also given a score for how many true statements they correctly recognized as true (truth score), and how many misconceptions they correctly recognized as false (misconception score). Each participant’s truth and misconception scores could each range between 0 and 9.

In exploratory analyses, analysis of variance (ANOVA) with pair-wise t-tests were used to investigate differences in knowledge scores among different groups (i.e. based on gender, education, geographic location, or whether or not they had heard of genetic counseling).

CHAPTER 3: RESULTS

A total of 328 surveys were administered, and 320 were fully completed. Twenty one percent of participants fell in the 18-29 year age range (n=68), 21% were in the 30-39 age range (n=68), 20% were in the 40-49 year age range (n=64), 23% were between the ages of 50-59 (n=75), and 14% were age 60 or older (n=45). See Table 1.1. These distributions differed significantly by population group in that new parents were younger than the disability community or the general public ($p<0.0005$).

Sixty-three percent of participants were female (n=201), 36% were male (n=116), and 0.9% did not identify with either gender (n=3). These distributions did not differ significantly by population ($p=0.567$).

One percent of participants had less than a high school education level (n=4), 10% had a high school education (n=32), 26% had some college or university education (n=82), 31% were college or university graduates (n=98), 9% had some graduate school education (n=28), and 22% had a graduate or professional degree (n=71), and 2% did not answer (n=6). These distributions did not differ significantly by population ($p=0.621$).

Half of the participants considered themselves to be Caucasian (non-Hispanic) (n=161), 19% were Hispanic/Latin (n=60), 8% were Asian (n=27), 7% chose black or African American (n=23), 4% were mixed race (n=14), 2% were Middle Eastern (n=6), 2% were Pacific Islander (n=5), 2% were American Indian or Alaskan Native (n=5), and one participant (0.3%) was East Indian. Four percent of participants (n=12) preferred not to answer, and two percent (n=6) had no response. These distributions did not differ significantly by population ($p=0.296$).

TABLE 1.1 Participant demographic data

		Population							
		Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)		**Total (n=320)**	
		n	%	n	%	n	%	**n**	**%**
Age	18-29	35	17	15	36	18	26	**68**	**21**
	30-39	36	17	18	43	14	20	**68**	**21**
	40-49	39	19	7	17	18	26	**64**	**20**
	50-59	60	29	0	0	15	22	**75**	**23**
	60 or older	39	19	2	5	4	6	**45**	**14**
Gender	Female	127	61	31	74	43	62	**201**	**63**
	Male	80	38	11	26	25	36	**116**	**36**
	other	2	1	0	0	1	1	**3**	**1**
Highest Level of Education	Less than high school (0-8 years)	4	2	0	0	0	0	**4**	**1**
	High school graduate (12 years)	23	11	3	7	6	9	**32**	**10**
	Some College or University	59	28	12	29	11	16	**82**	**26**
	College or University Graduate	59	28	14	33	25	36	**98**	**31**
	Some Graduate School	18	9	4	10	6	9	**28**	**9**
	Graduate or Professional Degree	42	20	9	21	20	29	**71**	**22**
	No Answer	4	2	0	0	1	1	**5**	**2**
Race/ Ethnicity	Caucasian (Non-Hispanic)	108	52	16	38	37	54	**161**	**50**
	Hispanic / Latin	38	18	12	29	10	14	**60**	**19**
	Asian	15	7	8	19	4	6	**27**	**8**
	Black or African-American	16	8	1	2	6	9	**23**	**7**
	Middle Eastern	5	2	1	2	0	0	**6**	**2**
	Mixed	7	3	1	2	6	9	**14**	**4**
	Other	9	4	1	2	1	1	**11**	**3**
	Prefer not to answer	7	3	2	5	3	4	**12**	**4**
	No Response	4	2	0	0	2	3	**6**	**2**
Occupation	Education	22	11	7	17	10	14	**39**	**12**
	Medicine / Healthcare	21	10	5	12	6	9	**32**	**10**
	Student	15	7	1	2	9	13	**25**	**8**
	Sales / Marketing	17	8	3	7	2	3	**22**	**7**
	Science/ Engineering/ Technology	13	6	1	2	7	10	**21**	**7**
	Administration/ Management/ Hospitality	23	11	3	7	9	13	**35**	**11**
	Business/ Banking/ Finance	6	3	4	10	1	1	**11**	**3**
	Entertainment / Media	5	2	1	2	3	4	**9**	**3**
	Art / Music / Writing	4	2	2	5	3	4	**9**	**3**
	Counseling/Social Work	5	2	0	0	3	4	**8**	**3**
	Politics / Government/ Law	7	3	3	7	3	4	**13**	**4**
	Homemaker/ Caregiver/ Unemployed	28	13	7	17	3	4	**38**	**12**
	Retired	27	13	1	2	2	3	**30**	**9**
	Other	13	6	3	7	6	9	**22**	**7**
	No Response	3	1	1	2	2	3	**6**	**2**

		Population							
		Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)		**Total (n=320)**	
		n	%	n	%	n	%	**n**	**%**
Religion	Catholicism	43	21	8	19	24	35	**75**	**23**
	Other Christianity	53	25	13	31	6	9	**72**	**23**
	Protestantism	13	6	3	7	1	1	**17**	**5**
	Judaism	9	4	1	2	5	7	**15**	**5**
	Buddhism	5	2	4	10	0	0	**9**	**3**
	Latter Day Saints (Mormonism)	5	2	2	5	0	0	**7**	**2**
	Other	5	2	3	7	1	1	**9**	**3**
	Inter/Non-denominational	10	5	1	2	3	4	**14**	**4**
	No Religion/ Spiritual, Not Religious	43	21	5	12	23	33	**71**	**22**
	Prefer not to answer	21	10	2	5	4	6	**27**	**8**
	No Response	2	1	0	0	2	3	**4**	**1**
State	California	201	96	42	100	67	97	**310**	**97**
	Other US State	8	4	0	0	2	3	**10**	**3**
Marital Status	Single	130	62	20	48	40	58	**190**	**59**
	Married	79	38	22	52	29	42	**130**	**41**
Have Children	Yes	101	48	34	81	27	39	**162**	**51**
	No	108	52	8	19	42	61	**158**	**49**
Practicing Physician	No	205	98	38	90	67	97	**310**	**97**
	Yes	4	2	4	10	2	3	**10**	**3**
Disability	No	106	51	42	100	63	91	**211**	**66**
	Yes	103	49	0	0	6	9	**109**	**34**
Income	I'd rather not say	56	27	2	5	23	33	**81**	**25**
	Less than $25,000	39	19	3	7	4	6	**46**	**14**
	$25,000-$49,999	28	13	6	14	11	16	**45**	**14**
	$50,000-$74,999	22	11	6	14	7	10	**35**	**11**
	$75,000-$99,999	20	10	8	19	11	16	**39**	**12**
	$100,000-$149,999	20	10	11	26	7	10	**38**	**12**
	$150,000-$199,999	14	7	2	5	4	6	**20**	**6**
	More than $200,000	10	5	4	10	2	3	**16**	**5**

More detailed demographic data are reported in Table 1.1, including occupation, religion, state of residence, marital status, having children, being a practicing physician, having a disability, and income.

Open-Ended Responses

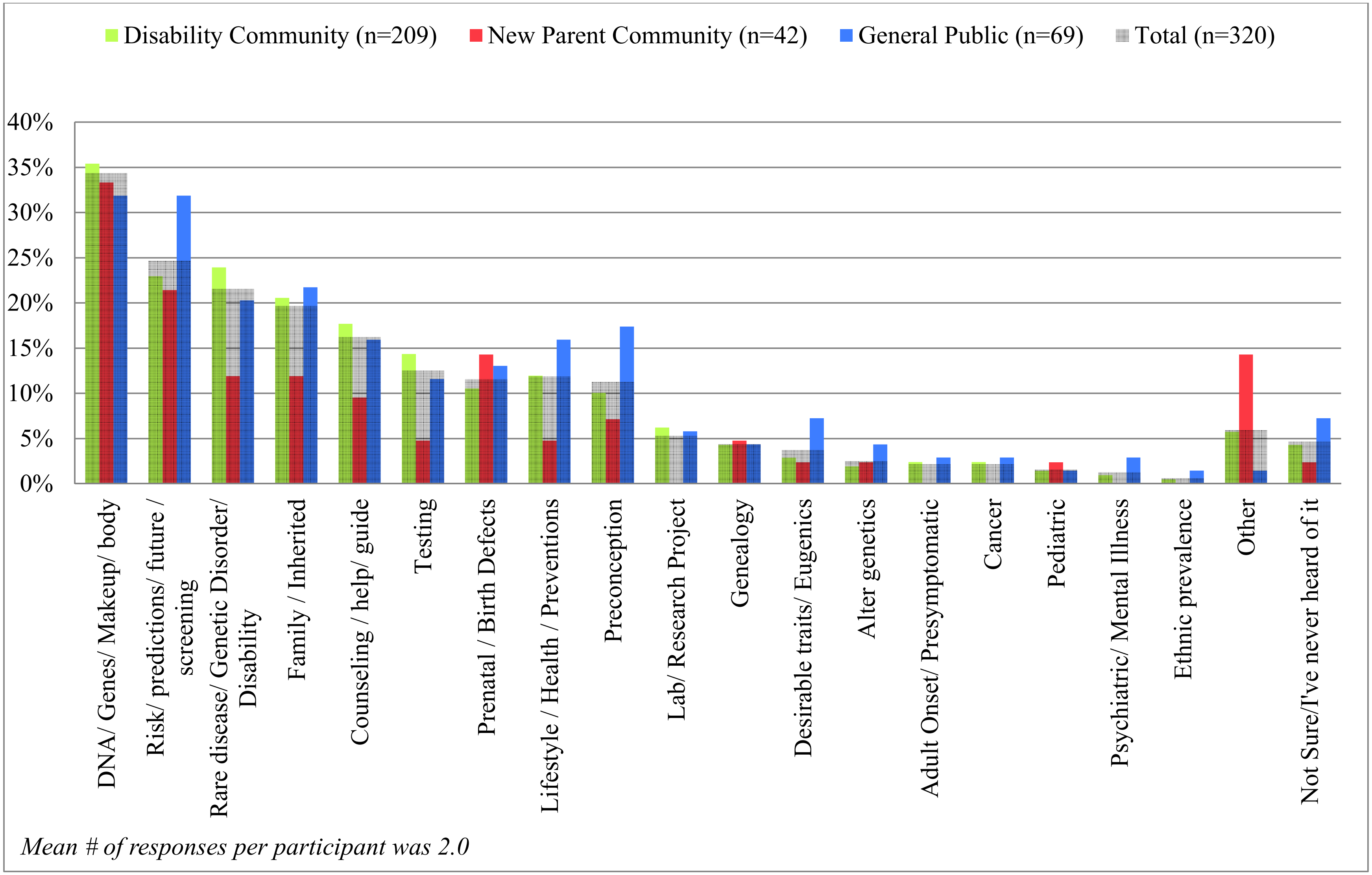
When asked what their first thoughts were when hearing the term “genetic counseling,” 34% of responses mentioned “DNA,” “genes,” “our makeup,” or “the body” (n=110), 25% mentioned “risk,” “predictions,” “future,” or “screening” (n=79), 22% mentioned “genetic disorder,” “disability,” or “rare disease” (n=69), 20% mentioned “family,” “hereditary,” or “inherited” (n=63), 16% mentioned “counseling,” “helping,” or “guidance” (n=52), 13% mentioned “testing” (n=40), 12% mentioned “prenatal” or “birth defects” (n=37), 12% mentioned “lifestyle,” “health,” or “prevention” (n=38), 11% mentioned “preconception” (n=36), 5% mentioned “lab” or “research” (n=17), 4% mentioned “genealogy” (n=14), 4% mentioned “desirable characteristics” or “eugenics” (n=12), 3% mentioned “altering genetics” (n=8), 2% mentioned “adult-onset disorders” or “pre-symptomatic testing” (n=7), 2% mentioned “cancer” (n=7), 2% mentioned “pediatrics” (n=5), 1% mentioned “psychiatric” or “mental illness” (n=4), 1% mentioned “ethnic prevalence” or “ethnicity-specific genetic disease” (n=2), and 5% were not sure or did not have any thoughts to share (n=15). Six percent of participant responses did not fit into any category and were categorized as “other” (see Table 2.1, Figure 1.1).

TABLE 2.1 Participant responses and categories for: ***"What is the first thing that comes to mind when you hear the term 'genetic counseling'?"***

	Population						Total (n=320)		
	Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)				
	n	%	n	%	n	%	n	%	p value
DNA/ Genes/ Makeup/ body	74	35	14	33	22	32	110	34	0.857
Risk/ predictions/ future / screening	48	23	9	21	22	32	79	25	0.287
Rare disease/ Genetic Disorder/ Disability	50	24	5	12	14	20	69	22	0.215
Family / Inherited	43	21	5	12	15	22	63	20	0.387
Counseling / help/ guide	37	18	4	10	11	16	52	16	0.422
Testing	30	14	2	5	8	12	40	13	0.222
Prenatal / Birth Defects	22	11	6	14	9	13	37	12	0.715
Lifestyle / Health / Preventions	25	12	2	5	11	16	38	12	0.210
Preconception	21	10	3	7	12	17	36	11	0.164
Lab/ Research Project	13	6	0	0	4	6	17	5	0.255
Genealogy	9	4	2	5	3	4	14	4	*
Desirable traits/ Eugenics	6	3	1	2	5	7	12	4	*
Alter genetics	4	2	1	2	3	4	8	3	*
Adult Onset/ Presymptomatic	5	2	0	0	2	3	7	2	*
Cancer	5	2	0	0	2	3	7	2	*
Pediatric	3	1	1	2	1	1	5	2	*
Psychiatric/ Mental Illness	2	1	0	0	2	3	4	1	*
Ethnic prevalence	1	0	0	0	1	1	2	1	*
Other	12	6	6	14	1	1	19	6	
Not Sure/I've never heard of it	9	4	1	2	5	7	15	5	

**Numbers are small, thus p-values from chi-square tests were not obtained*
Mean # of responses per participant was 2.0

(n=15). Six percent of participant responses did not fit into any category and were categorized as “other.” There were no significant differences among the three populations (p>0.164). More detailed results can be found in Table 2.1.



Mean # of responses per participant was 2.0

FIGURE 1.1 Open-ended responses to "What is the first thing that comes to mind when you hear the term, 'genetic counseling'?"

Overall, approximately half of the respondents had heard of genetic counseling (n=172, 54%). This number was consistent within each of the three population groups, (Table 3.1). Of those who had heard of genetic counseling previously, 30% had been referred to or had seen a genetic counselor (n=52), 25% had read about genetic counseling in the news (n=43), 19% had a friend or family member who was referred to or who saw a genetic counselor (n=33), 17% had read about genetic counseling on the Internet (n=29), 15% had seen a TV show in which a genetic counselor was mentioned or portrayed (n=26), and 12% said a friend or acquaintance had been referred to or had seen a genetic counselor (n=21). Many of these participants had heard about genetic counseling through multiple sources; the mean number of responses was 1.8 (Figure 2.1). See Table 3.2 for more results. Of the write-in responses, most participants claimed to have heard about genetic counseling because they work in healthcare (Table 3.3)

TABLE 3.1. Distribution of responses to "Before coming across the phrase while participating in this study, have you heard of 'genetic counseling' before today?"

	Population						Total (n=320)		
	Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)				
	n	%	n	%	n	%	n	%	p value
When I came across the phrase as part of participating in this study, it was the first time I have ever heard of genetic counseling	97	46	21	50	30	43	148	46	0.797
I have heard of genetic counseling before participating in this study	112	54	21	50	39	57	172	54	

Of the respondents who had heard of genetic counseling, 43% (n=74) selected or wrote in an option having to do with media (television, movies, news, Internet, etc). Overall, most respondents reported hearing about genetic counseling from the news (n=43, 58%), followed by the Internet (n=29, 39%), television (n=26, 35%), and the movies (n=11, 15%). One respondent mentioned hearing about it on the radio, and another mentioned reading about it in a magazine. On separating out the populations, members of the disability community and general public were much more likely to have read about it in the news than new parents (p=0.037), see Figure 2.2.

Although 26 respondents reported seeing a television show in which a genetic counselor was portrayed, only 13 were able to give examples of specific shows, and the rest could not remember or did not answer. Eleven respondents reported seeing a genetic counselor in a movie, but only six could give the name of the movie, while the rest could not remember or did not respond.

TABLE 3.2. Of those who had answered, "yes" to having heard about genetic counseling: How did you become familiar with genetic counseling?

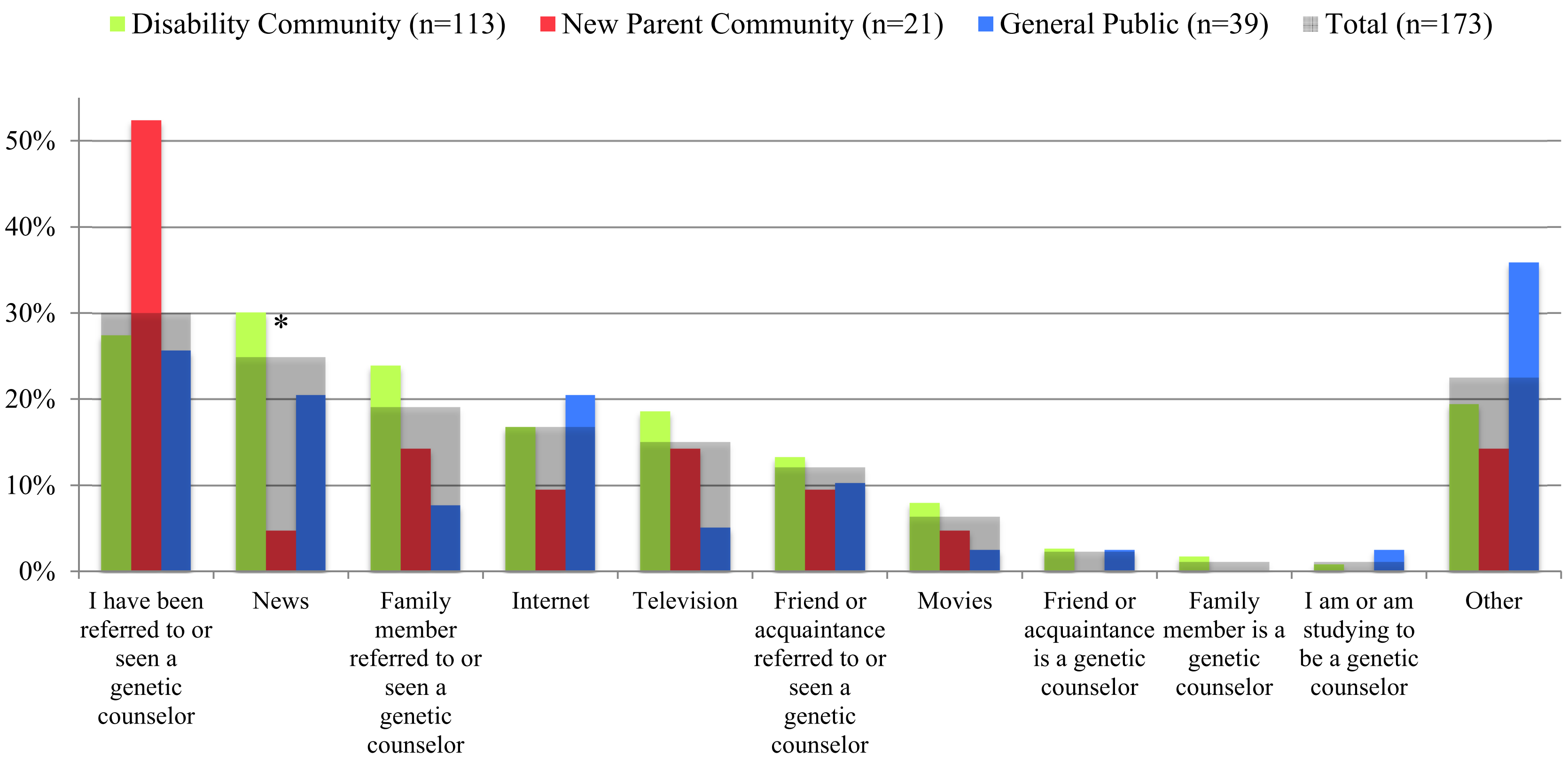
	Population						Total (n=173)		
	Disability Community (n=113)		New Parent Community (n=21)		General Public (n=39)				
	n	%	n	%	n	%	n	%	p-value
I have been referred to or seen a genetic counselor	31	27	11	52	10	26	52	30	0.058
I have read about genetic counseling in the news	34	30	1	5	8	21	43	25	0.037
A family member has been referred to or seen a genetic counselor	27	24	3	14	3	8	33	19	0.071
I have read about genetic counseling on the Internet	19	17	2	10	8	21	29	17	0.554
I have seen a TV show in which a genetic counselor was mentioned or portrayed	21	19	3	14	2	5	26	15	0.127
A friend or acquaintance has been referred to or seen a genetic counselor	15	13	2	10	4	10	21	12	0.818
I have seen a movie in which a genetic counselor was mentioned or portrayed	9	8	1	5	1	3	11	6	0.467
A friend or acquaintance is a genetic counselor	3	3	0	0	1	3	4	2	*
A family member is a genetic counselor	2	2	0	0	0	0	2	1	*
I am or am studying to be a genetic counselor	1	1	0	0	1	3	2	1	*
Other (Write-in)	22	19	3	14	14	36	39	23	0.067

**Numbers are small, thus p-values from chi-square tests were not obtained*

Mean # of responses per participant was 1.8

TABLE 3.3. Write-in responses to "How did you become familiar with genetic counseling?"

	Population							
	Disability Community (n=22)		New Parent Community (n=3)		General Public (n=14)		Total (n=39)	
	n	%	n	%	n	%	n	%
I work in healthcare	5	23	3	100	3	21	11	28
In school	6	27	1	33	3	21	10	26
Work with people who are referred	2	9	0	0	3	21	5	13
From a doctor	2	9	0	0	1	7	3	8
I work in the field of genetics	0	0	0	0	1	7	1	3
Support Group/ Organization	1	5	0	0	0	0	1	3
I know someone studying to be a GC	0	0	0	0	1	7	1	3
Know someone who works in genetics	1	5	0	0	0	0	1	3
On the radio	0	0	0	0	1	7	1	3
Nursery	1	5	0	0	0	0	1	3
Magazine	1	5	0	0	0	0	1	3
Library	1	5	0	0	0	0	1	3
Genealogist	1	5	0	0	0	0	1	3
Job Search	1	5	0	0	0	0	1	3
Not Sure	3	14	0	0	2	14	5	13
No Response	1	5	0	0	0	0	1	3



*p<0.05

Mean # of responses per participant was 1.8

FIGURE 2.1 **For those who had answered yes to having heard about genetic counseling, responses to "How did you become familiar with genetic counseling?"**

The television shows that were each mentioned twice include *Bones*, *Dr. Oz*, and *Law & Order*. The television shows *CSI*, *ER*, *Grey's Anatomy*, *House MD*, *Oprah*, and *The Big Bang Theory* were each mentioned once. The movie noted most often was *Still Alice*, mentioned by three different respondents. *Gattaca*, *Lorenzo's Oil*, and *Twitch* were each mentioned once. One respondent said, "I saw a show online that illustrated making mock babies via a computer. Each couple had to give a mouth swab. Their DNA was collected and placed in a computer program. Then the computer was able to generate the probability of having children with the mutation." Another participant responded with "brad pitt wife story."

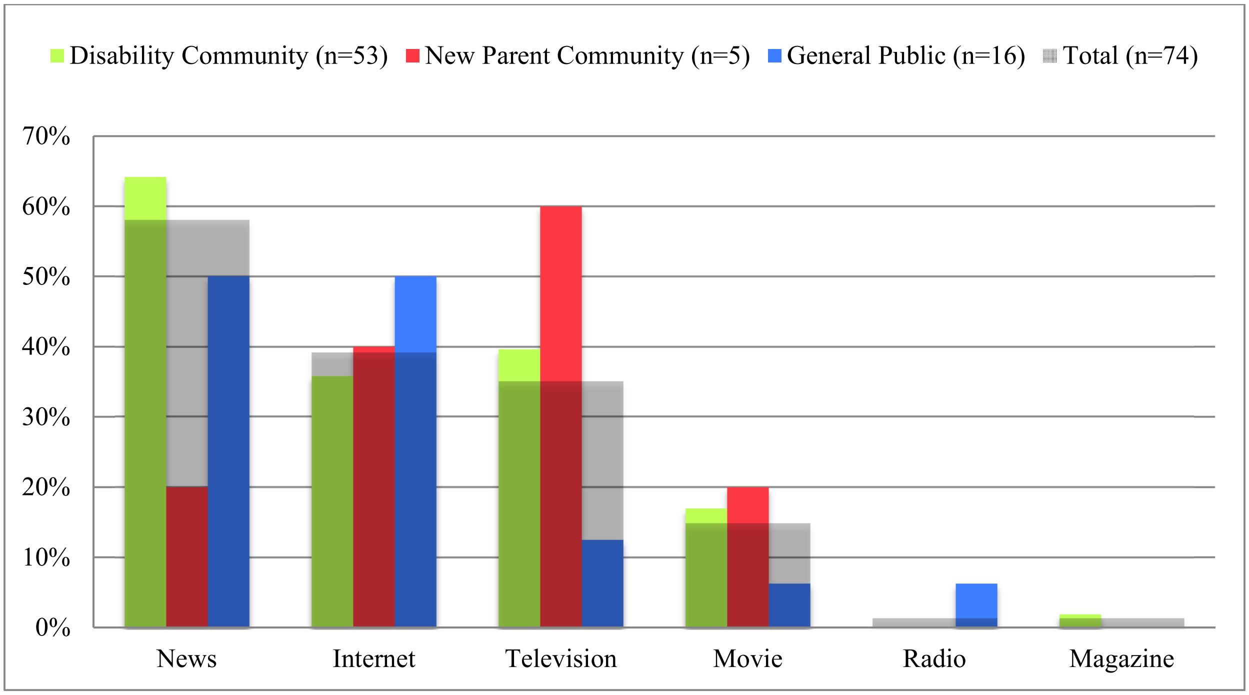


FIGURE 2.2 Of Participants who had heard about genetic counseling through Media, description of media sources

Analyses of the three population groups separately revealed that 52% (n=11) of the new parent community had been referred to or had seen a genetic counselor, while only 27% (n=31) of the disability community and 26% (n=10) of the general public chose this answer (p=0.058). See Table 3.2.

In examining referral patterns, 44% of respondents from any population who did not have a disability had never heard of genetic counseling (n=93), 36% had heard of genetic counseling but had never been referred (n=77), and 19% had been referred to or had seen a genetic counselor (n=41). Of those respondents with a disability, 50% had never heard of genetic counseling (n=54), 40% had heard of it but had never been referred (n=44), and only 10% had been referred to or had seen a genetic counselor (n=11). See Figure 2.3.

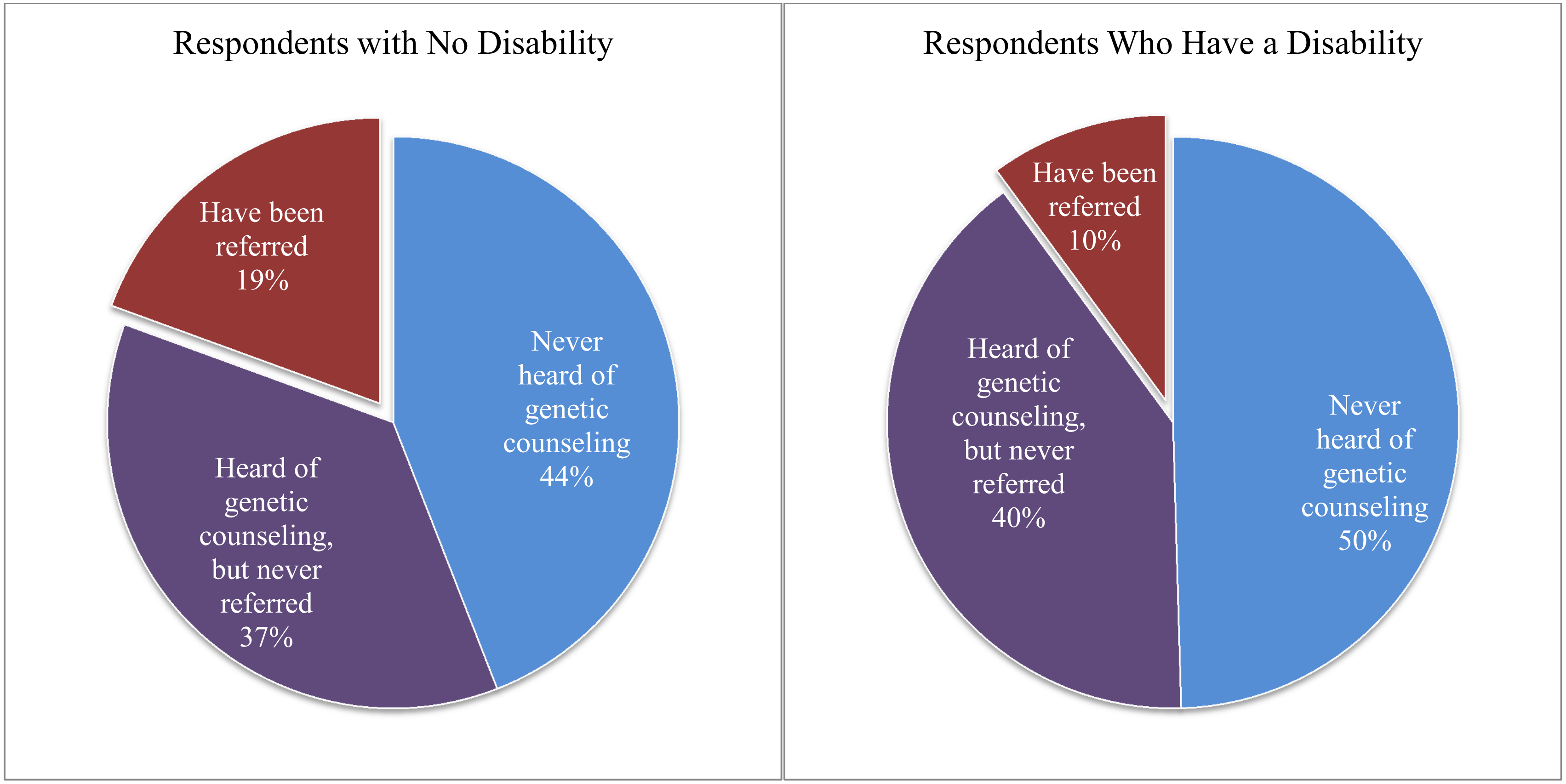


FIGURE 2.3 Referral patterns and awareness of genetic counseling services in participants with versus without disabilities

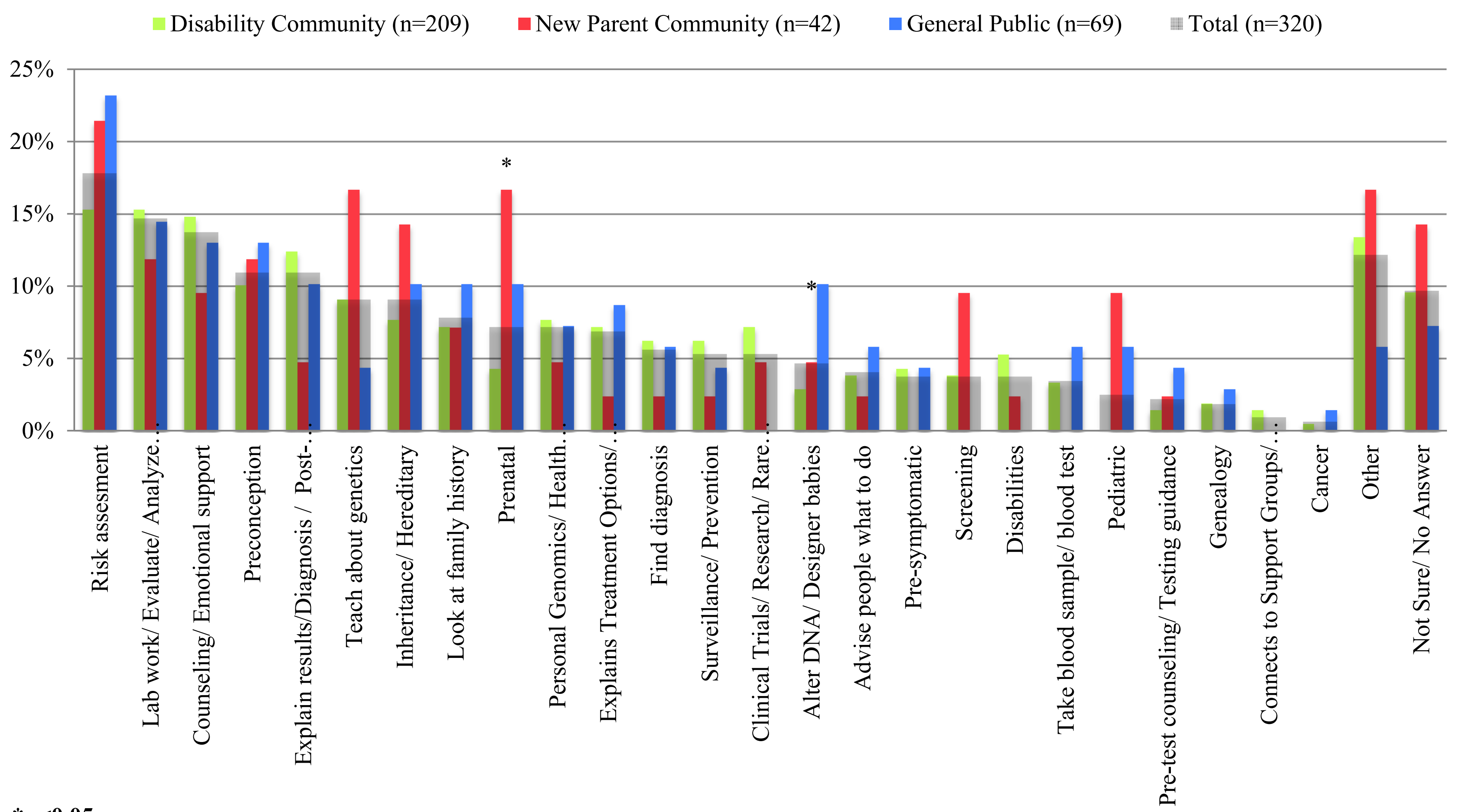
When participants were asked what they think genetic counselors do, the most common response involved risk assessment (18%, n=57). Other answers included laboratory work or evaluating/analyzing a patient's genes or DNA (n=47, 15%), counseling or emotional support (n=44, 14%), preconception (n=35, 11%), explaining results, explaining a diagnosis or post-test counseling (n=35, 11%), teaching about genetics (n=29, 9%), inheritance or heredity (n=29, 9%), looking at family history (n=25, 8%), prenatal (n=23, 7%), personal genomics, personalized medicine or health counseling (n=23, 7%), explaining treatment options and management strategies (n=22, 7%), finding a diagnosis (n=18, 6%), surveillance or prevention (n=17, 5%), clinical trials, research, or rare disease (n=17, 5%), altering DNA or designer babies (n=15, 5%), advising people what to do (n=13, 4%), pre-symptomatic testing (n=12, 4%), screening (n=12, 4%), disabilities (n=12, 4%), taking a blood sample or blood test (n=11, 3%), pediatrics (n=8, 3%), pre-test counseling or testing guidance (n=7, 2%), genealogy or finding ancestry (n=6, 2%), connecting patients to support groups, resources, or referrals (n=3, 1%), and cancer (n=2, 1%), and 10% either said they did not know or did not respond (n=31). Twelve percent (n=39) of participant responses (or parts of the responses) did not fit into any category and were categorized as "other". (See Table 4.1) The mean number of responses per person was 1.8. See Figure 3.1.

TABLE 4.1 Participant responses and categories for:" What do you think genetic counselors do'?"

	Population						Total (n=320)		
	Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)				
	n	%	n	%	n	%	n	%	p value
Risk assesment	32	15	9	21	16	23	57	18	0.268
Lab work/ Evaluate/ Analyze genetics of patient	32	15	5	12	10	14	47	15	0.849
Counseling/ Emotional support	31	15	4	10	9	13	44	14	0.648
Preconception	21	10	5	12	9	13	35	11	0.769
Explain results/Diagnosis / Post-test Counseling	26	12	2	5	7	10	35	11	0.337
Teach about genetics	19	9	7	17	3	4	29	9	0.090
Inheritance/ Hereditary	16	8	6	14	7	10	29	9	0.370
Look at family history	15	7	3	7	7	10	25	8	0.717
Prenatal	9	4	7	17	7	10	23	7	0.010
Personal Genomics/ Health Counseling	16	8	2	5	5	7	23	7	0.803
Explains Treatment Options/ Management Strategies	15	7	1	2	6	9	22	7	0.425
Find diagnosis	13	6	1	2	4	6	18	6	0.614
Surveillance/ Prevention	13	6	1	2	3	4	17	5	0.552
Clinical Trials/ Research/ Rare Disease	15	7	2	5	0	0	17	5	0.069
Alter DNA/ Designer babies	6	3	2	5	7	10	15	5	0.046
Advise people what to do	8	4	1	2	4	6	13	4	*
Pre-symptomatic	9	4	0	0	3	4	12	4	*
Screening	8	4	4	10	0	0	12	4	*
Disabilities	11	5	1	2	0	0	12	4	*
Take blood sample/ blood test	7	3	0	0	4	6	11	3	*
Pediatric	0	0	4	10	4	6	8	3	*
Pre-test counseling/ Testing guidance	3	1	1	2	3	4	7	2	*
Genealogy	4	2	0	0	2	3	6	2	*
Connects to Support Groups/ Resources/ Referrals	3	1	0	0	0	0	3	1	*
Cancer	1	0	0	0	1	1	2	1	*
Other	28	13	7	17	4	6	39	12	
Not Sure/ No Answer	20	10	6	14	5	7	31	10	

**Numbers are small, thus p-values from chi-square tests were not obtained*
Mean # of responses per participant was 1.8

When separated by population, 17% of the new parent community mentioned prenatal counseling (n=7), while only 4% of the disability community (n=9) and 10% of the general public (n=7) mentioned prenatal, with a (p= 0.010). Values can be found in Table 4.1.



***p<0.05**
Mean # of responses per participant was 1.8

FIGURE 3.1 Open-ended responses to "What do you think genetic counselors do?"

In responding to, “Where do you think a genetic counselor would work?” nearly half of the participants mentioned a medical facility, medical setting, clinic, private practice, or office (n=157, 49%) or a hospital (n=151, 47%). The mean number of responses per participant was 1.4 (Figure 4.1). More detailed results are in Table 5.1. Eleven percent of participants gave answers categorized as “other”. For a list of all open-ended responses, refer to Appendix B.

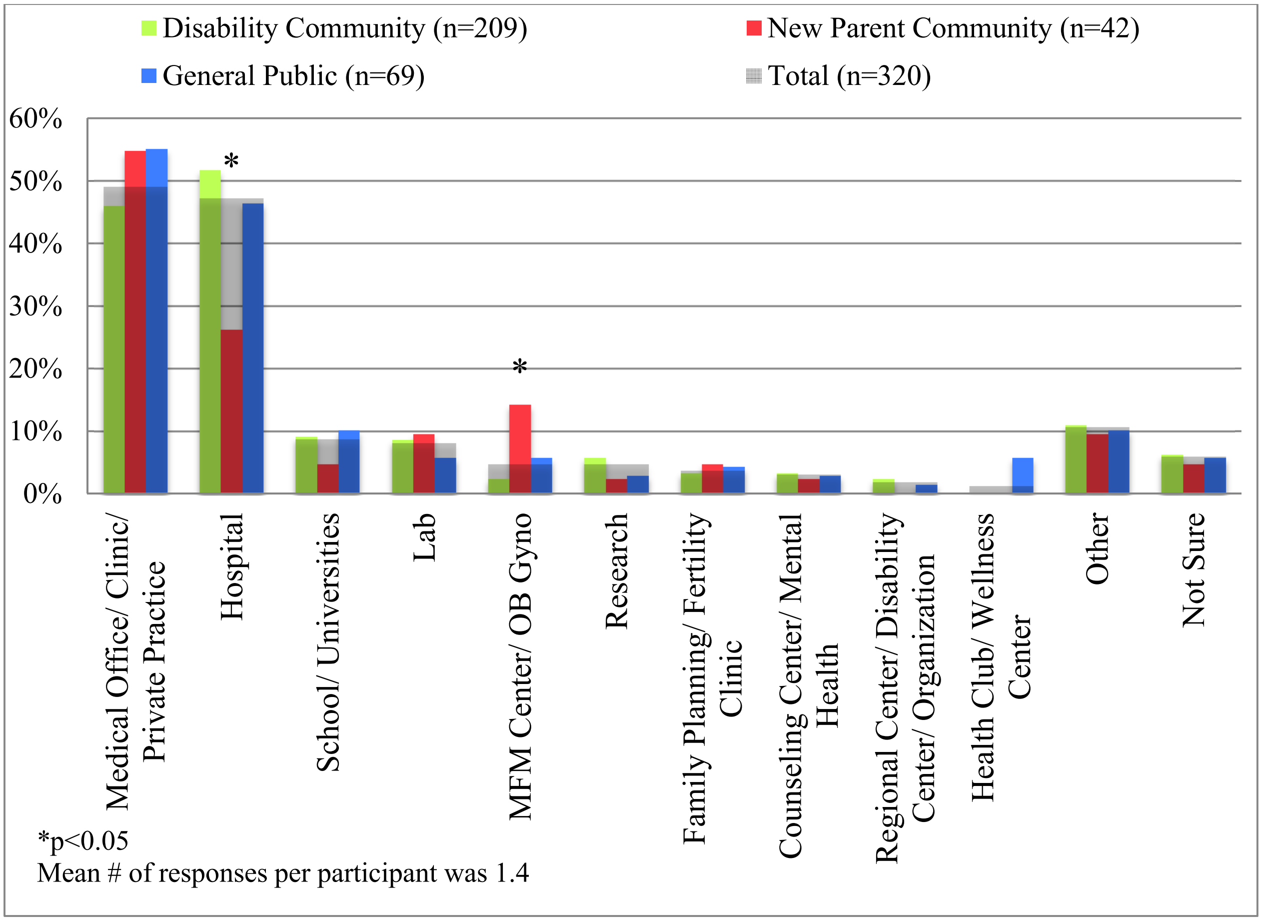
Analyses of the three populations and their responses to this question revealed that 52% of the disability community (n=108) and 46% of the general public (n=32) mentioned hospitals, while only 26% of the new parent community mentioned hospitals (n=11), with a p-value of 0.010. Among the new parent community, 14% mentioned an maternal-fetal medicine or obstetrics-gynecology center (n=6), while only 2% of the disability community (n=5) and 6% of the general public (n=4) mentioned either of these, with a p-value of 0.003. Three participants from the general public mentioned a wellness center (4%), while no one from the disability or new parent communities mentioned a wellness center (Table 5.1).

TABLE 5.1 Open-ended responses to, "Where do you think a genetic counselor would work?"

	Population						Total (n=320)		
	Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)				
	n	%	n	%	n	%	n	%	p-value
Medical Office/ Clinic/ Private Practice	96	46	23	55	38	55	157	49	0.307
Hospital	108	52	11	26	32	46	151	47	0.010
School/ Universities	19	9	2	5	7	10	28	9	0.596
Lab	18	9	4	10	4	6	26	8	0.713
MFM Center/ OB Gyn	5	2	6	14	4	6	15	5	0.003
Research	12	6	1	2	2	3	15	5	0.469
Family Planning/ Fertility Clinic	7	3	2	5	3	4	12	4	*
Counseling Center/ Mental Health	7	3	1	2	2	3	10	3	*
Regional Center/ Disability Center/ Organization	5	2	0	0	1	1	6	2	*
Health Club/ Wellness Center	0	0	0	0	4	6	4	1	*
Other	23	11	4	10	7	10	34	11	
Not Sure	13	6	2	5	4	6	19	6	

**Numbers are small, thus p-values from chi-square tests were not obtained*

Mean # of responses per participant was 1.4



*p<0.05
Mean # of responses per participant was 1.4

FIGURE 4.1 Open-ended responses to, "Where do you think a genetic counselor would work?"

Knowledge Statements

Over 90% of all respondents correctly identified *as true* that genetic counseling could provide referrals and resources for families with genetic conditions (n=306, 96%), help people understand their options for genetic testing (n=301, 94%), provide genetic testing to people with a family history of a genetic condition (n=300, 94%), provide information and support to couples planning a pregnancy that may be at risk for a genetic condition (n=296, 93%), provide information and support to pregnant women whose babies may be at risk for a genetic condition (n=294, 92%), and help families understand the condition in their families and what it means for them, even if the condition is caused by a combination of genes and environment (n=292, 91%).

See Table 6.1. Over 80% identified a purpose of genetic counseling was “to calculate the risk a patient has of developing cancer based on family history and testing” (n=264, 83%), and nearly 80% correctly identified a purpose of genetic counseling to be “to aid in determining if a person's autism, developmental delay, or intellectual disability was caused by genetic factors” (n=253, 79%) and “to provide an explanation of the preventative, screening and diagnostic options that are available to a patient with cancer” (n=245, 77%). See Figure 5.1.

TABLE 6.1 Statements about Genetic Counseling

	Population						Total (n=320)		p-value
	Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)				
TRUE STATEMENTS	n	%	n	%	n	%	n	%	
A purpose of genetic counseling is to provide referrals and resources for families with a genetic condition	200	96	41	98	65	94	306	96	0.692
A purpose of genetic counseling is to help people understand their options for genetic testing	199	95	39	93	63	91	301	94	0.462
A purpose of genetic counseling is to provide genetic testing to people with a family history of a genetic	196	94	39	93	65	94	300	94	0.960
A purpose of genetic counseling is to provide information and support to couples planning a pregnancy which may be at risk for a genetic condition	186	89	42	100	68	99	296	93	0.005
A purpose of genetic counseling is to provide information and support to pregnant women whose babies may be at risk for a genetic condition	188	90	41	98	65	94	294	92	0.183
A purpose of genetic counseling is to help families understand the condition in their families and what it means for them even if the condition is caused by a	191	91	41	98	60	87	292	91	0.155
A purpose of genetic counseling is to calculate the risk a patient has of developing cancer based on family history and testing	171	82	33	79	60	87	264	83	0.481
A purpose of genetic counseling is to aid in determining if a person's autism, developmental delay, or intellectual disability was caused by genetic factors	177	85	29	69	47	68	253	79	0.003
A purpose of genetic counseling is to provide an explanation of the preventative, screening and diagnostic options that are available to a patient with cancer	161	77	31	74	53	77	245	77	0.902
FALSE STATEMENTS									
A purpose of genetic counseling is to help police use DNA to solve crimes	149	71	31	74	55	80	235	73	0.389
A purpose of genetic counseling is to fix mutated genes	148	71	27	64	49	71	224	70	0.686
A purpose of genetic counseling is to help couples have a child with desirable characteristics	140	67	18	43	36	52	194	61	0.004
A purpose of genetic counseling is to advise people about whether to have children	114	55	24	57	42	61	180	56	0.651
A purpose of genetic counseling is to provide information and support to ALL pregnant women	100	48	11	26	34	49	145	45	0.028
A purpose of genetic counseling is to help people find their ethnic origins and understand their ancestry	94	45	14	33	36	52	144	45	0.154
A purpose of genetic counseling is to prevent genetic diseases or abnormalities	90	43	3	7	25	36	118	37	*
A purpose of genetic counseling is to provide information and support to ALL couples planning a pregnancy	76	36	9	21	25	36	110	34	0.166
A purpose of genetic counseling is to determine whether a child without symptoms is going to develop an adult-onset condition later in life such as Huntington or Alzheimer disease	53	25	10	24	19	28	82	26	0.899

**p<0.0005*

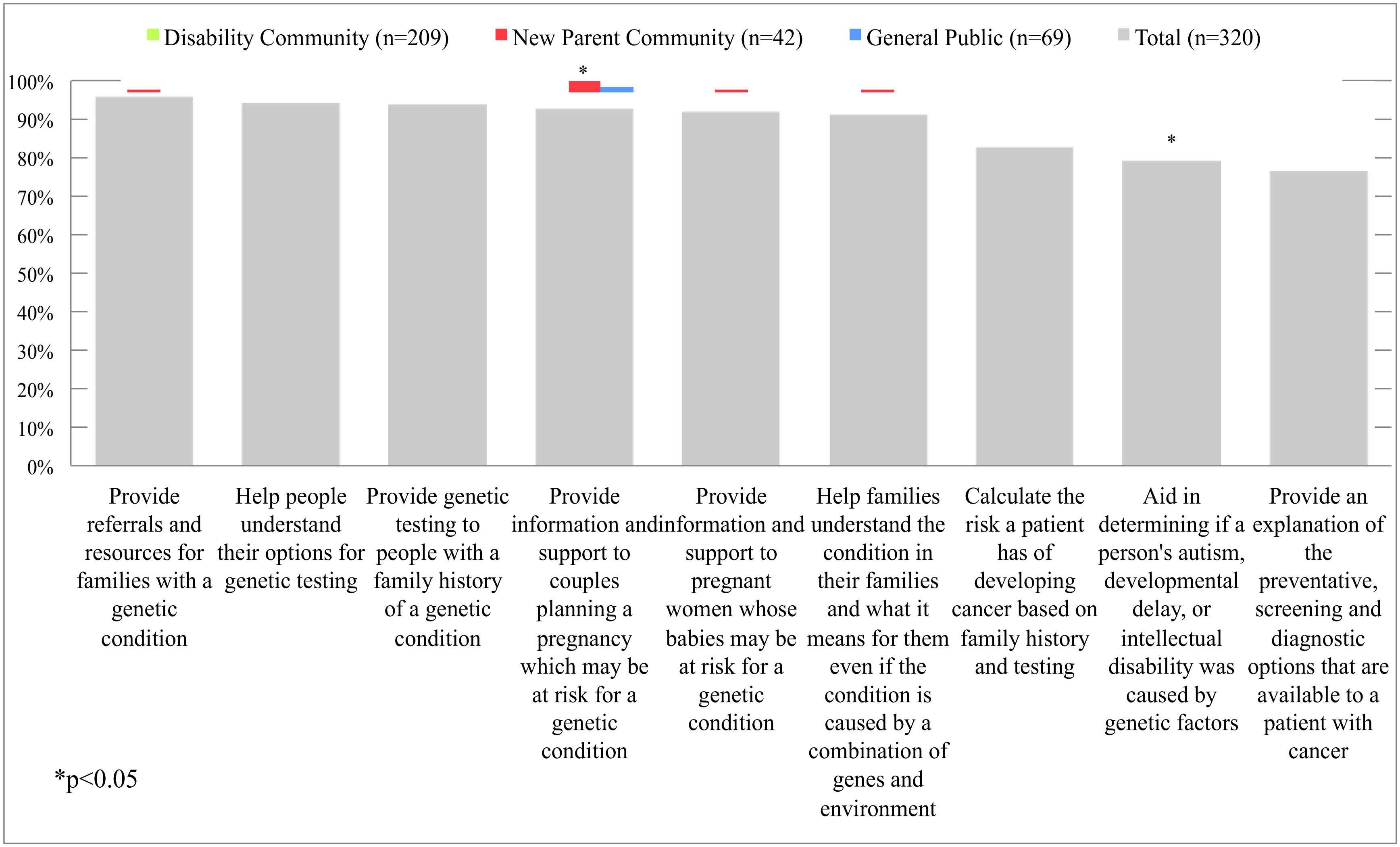


FIGURE 5.1 Correctly Identified True Statements

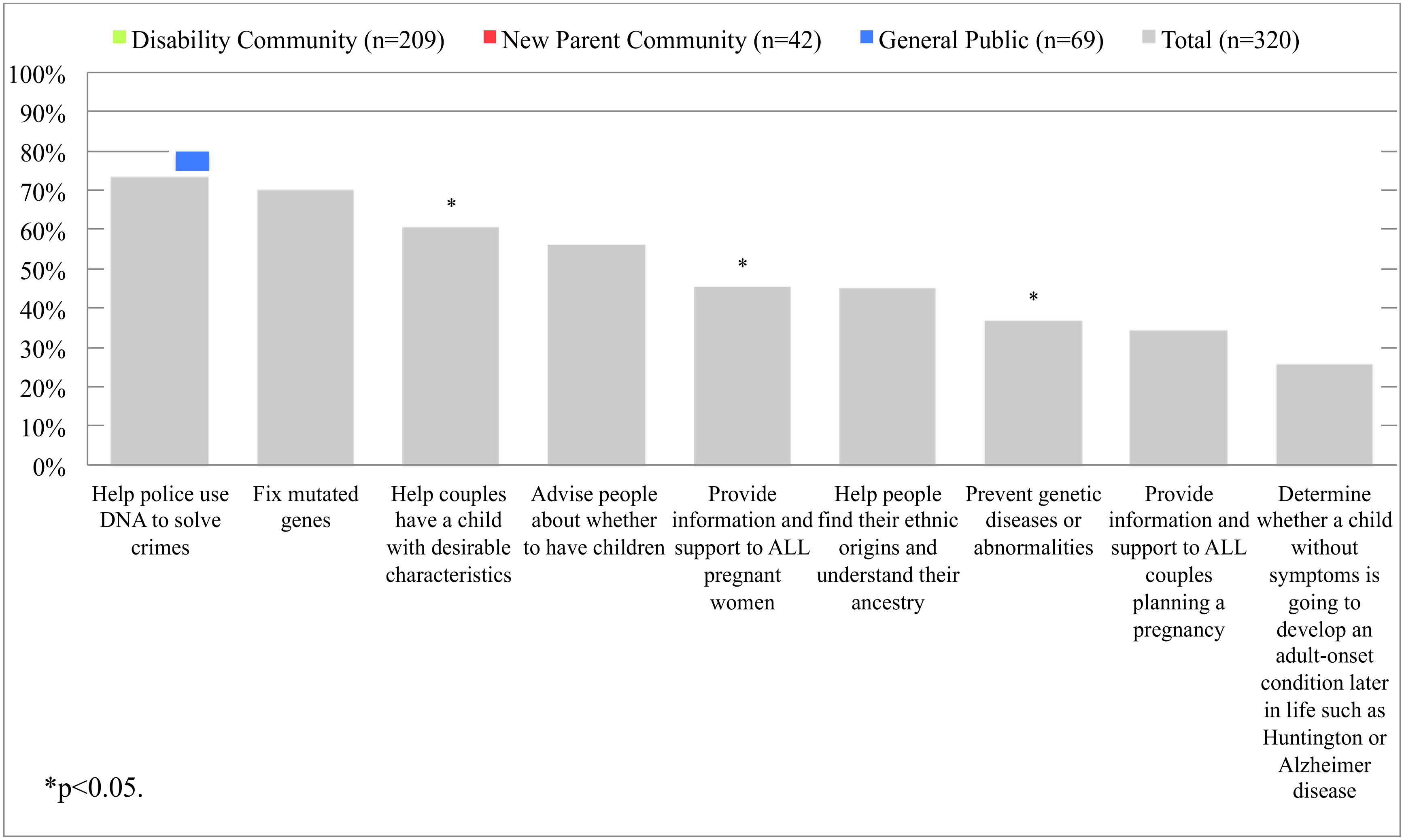


FIGURE 5.2 Correctly Identified Misconceptions

Over seventy percent of all respondents correctly identified as false the misconceptions that a purpose of genetic counseling is “to help police use DNA to solve crimes” (n=235, 73%) and “to fix mutated genes” (n=224, 70%). Over half of participants correctly identified as false the misconceptions that a purpose of genetic counseling is “to help couples have a child with desirable characteristics” (n=194, 61%) and “to advise people about whether to have children” (n=180, 56%). However, fewer than half of participants were able to correctly recognize as false that a purpose of genetic counseling is “to provide information and support to ALL pregnant women” (n=145, 45%), “to help people find their ethnic origins and understand their ancestry” (n=144 45%), “to prevent genetic diseases or abnormalities” (n=118, 37%), “to provide information and support to ALL couples planning a pregnancy” (n=110, 34%), and “to determine whether a child without symptoms is going to develop an adult-onset condition later in life such as Huntington disease or Alzheimer disease” (n=180, 56%). See Figure 5.2.

Among the individual populations, 43% of the disability community (n=90) and 36% of the general public (n=25) correctly identified “a purpose of genetic counseling is to prevent genetic diseases or abnormalities” as a misconception, but only 7% of the new parent community correctly identified this statement as incorrect (n=3) ($p<0.0005$).

Sixty-nine percent (n=29) of the new parent community and 68% (n=47) of the general public correctly identified as true that a purpose of genetic counseling is “to aid in determining if a person's autism, developmental delay, or intellectual disability was caused by genetic factors”, while 85% of the disability group correctly identified this answer as true (n=177) ($p=0.003$). Sixty-seven percent (n=140) of the disability community and 52% (n=36) of the general public correctly recognized as false the misconception that genetic counseling’s purpose is “to help couples have a child with desirable characteristics”. However, only 43% (n=18) of the new parent community correctly identified this purpose as false, with a p-value of 0.004.

Every respondent from the new parent community (n=42, 100%) and nearly every one from the general public group (n=68, 99%) correctly identified as true that a purpose of genetic counseling is “to provide information and support to couples planning a pregnancy that may be at risk for a genetic condition”. However, only 89% of the disability community thought this to be true (n=186) (p=0.005)

Fifty-two percent (n=109) of the disability community and 51% (n=35) of the general public thought that the purpose of genetic counseling was “to provide information and support to ALL pregnant women”, while 74% (n=31) from the new parent community thought this was true (p= 0.028).

No respondents answered all items incorrectly (a score of 0), only a few (n=5, 1.6%) answered the majority of items incorrectly (which would be reflected by a score of 0-8). The average “knowledge score” among participants was 12.5 (range 6-18), which represents an even distribution overall. The new parent community scored one point lower on average (mean=11.5) than the disability community (12.6) and general public (12.6) (p=0.013), see Figure 6.1.

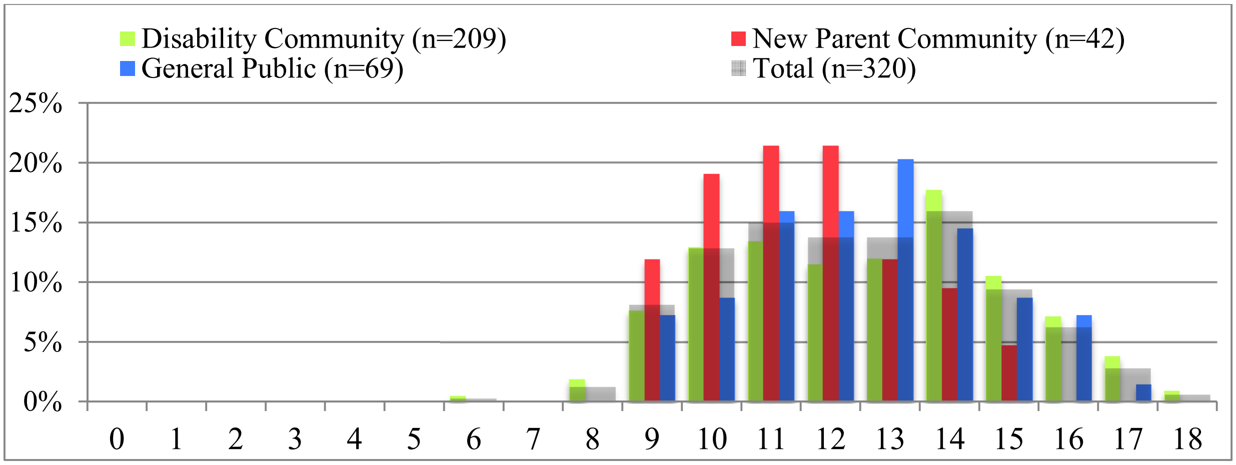
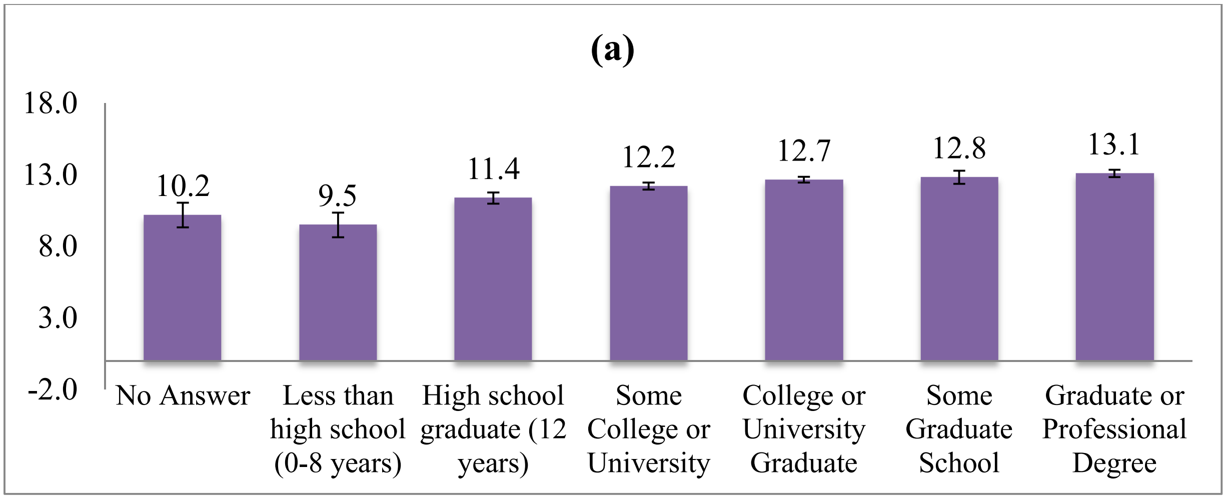
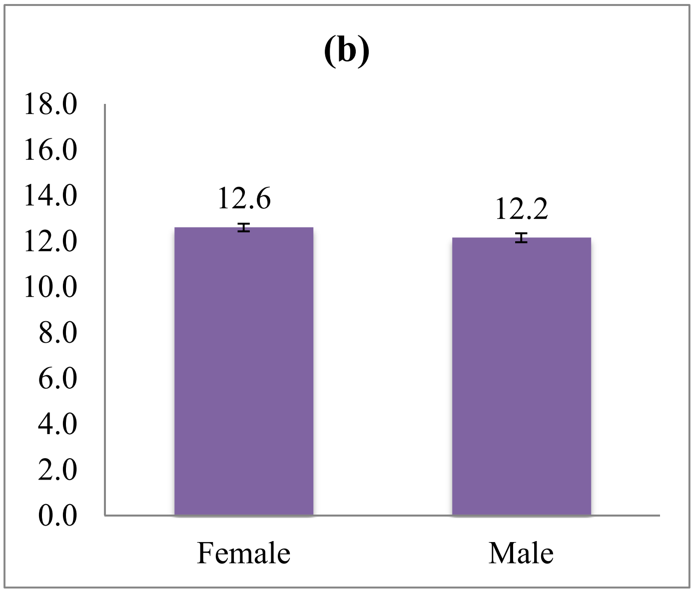


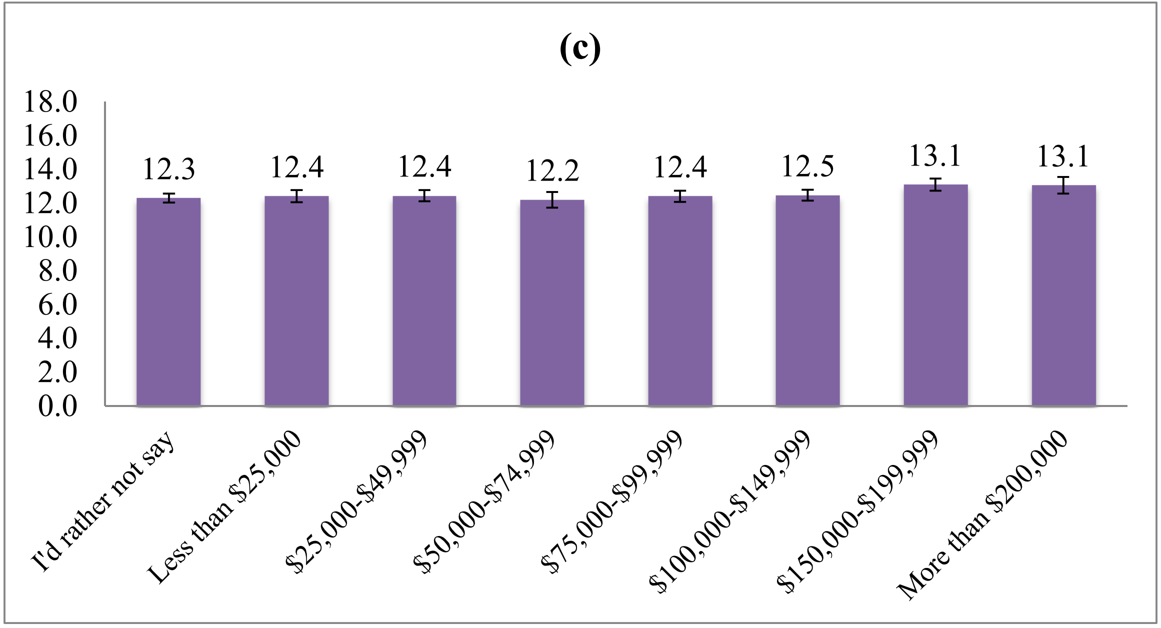
FIGURE 6.1 Distributions of Knowledge Scores by Population

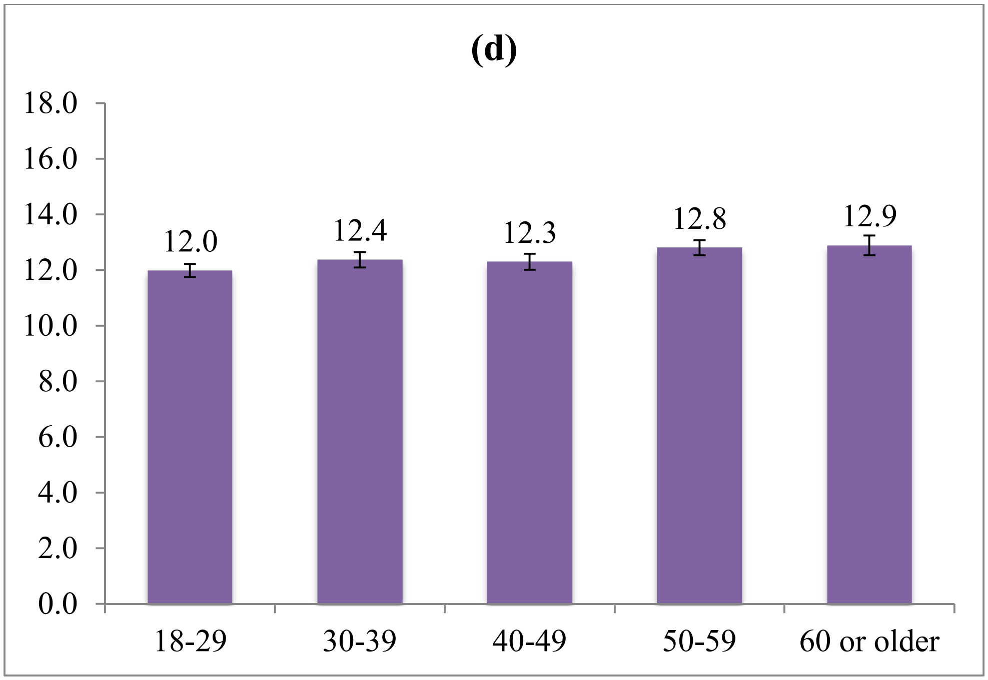
Those who had heard of genetic counseling previously (n=172, 55%) had a significantly higher average knowledge score than those who had not (n=148, 45 %), (12.9 vs. 11.9, respectively; p=0.006). Furthermore, those who had been referred to or had seen a genetic counselor had an average knowledge score of 13.1, which was higher than the score of 12.8 in those who had heard of genetic counseling but had never been referred to or seen a genetic counselor (p<0.0005).

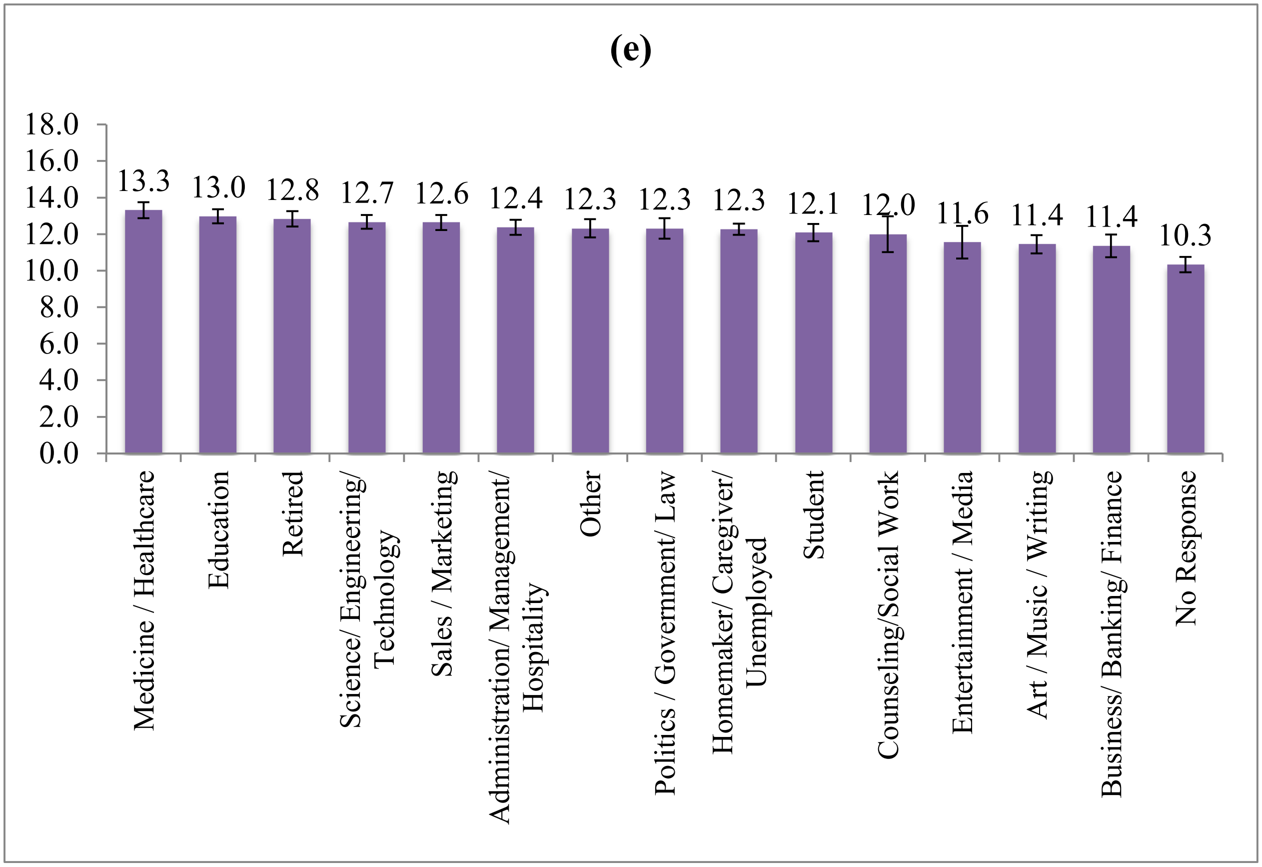
Higher education level appeared to contribute to a higher score (p<0.0005) (Figure 7.1a), as did working in healthcare (mean=13.3) (p=0.022) (Figure 7.1e). Other demographics were not significantly linked to knowledge score as shown in Figure 7.1. For data tables, refer to Appendix C.


(a)
18.0
13.0
8.0
3.0
-2.0
10.2
9.5
11.4
12.2
12.7
12.8
13.1
No Answer
Less than high school (0-8 years)
High school graduate (12 years)
Some College or University
College or University Graduate
Some Graduate School
Graduate or Professional Degree


(b)
18.0
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
12.6
12.2
Female
Male


(c)
18.0
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
12.3
12.4
12.4
12.2
12.4
12.5
13.1
13.1
I'd rather not say
Less than $25,000
$25,000-$49,999
$50,000-$74,999
$75,000-$99,999
$100,000-$149,999
$150,000-$199,999
More than $200,000


(d)
18.0
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
12.0
12.4
12.3
12.8
12.9
18-29
30-39
40-49
50-59
60 or older


(e)
18.0
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
13.3
13.0
12.8
12.7
12.6
12.4
12.3
12.3
12.3
12.1
12.0
11.6
11.4
11.4
10.3
Medicine / Healthcare
Education
Retired
Science/ Engineering/ Technology
Sales / Marketing
Administration/ Management/ Hospitality
Other
Politics / Government/ Law
Homemaker/ Caregiver/ Unemployed
Student
Counseling/Social Work
Entertainment / Media
Art / Music / Writing
Business/ Banking/ Finance
No Response

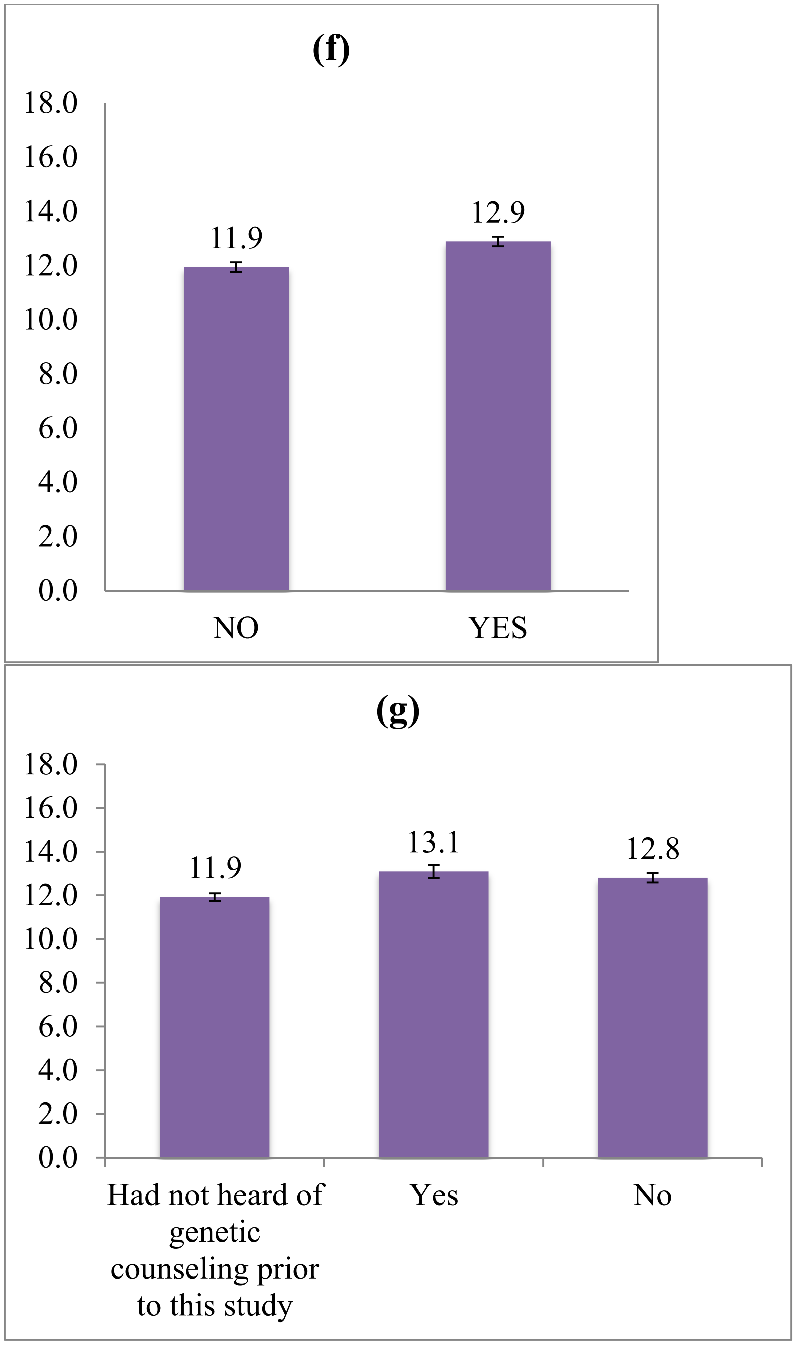


FIGURE 7.1 Mean Knowledge Scores by (a) education level (b) gender (c) income (d) age (e) occupation (f) heard of genetic counseling (g) referred to genetic counseling. The y-axis shows knowledge scores. Error bars indicate standard error of the mean.

When comparing the true statements and misconceptions in the total population, the average number of correctly identified *true* statements overall was 8/9, yet the mean number of misconceptions correctly identified as *false* was only 4.5/9. Among the individual population groups, new parents scored one point lower on average (3.5) than the disability community (4.6) or the general public (4.7) did in identifying misconceptions as false (p=0.021). However, when identifying true statements as true, all groups scored within 0.1 point of each other (8.0, 8.0, and 7.9)(p=0.909)(Figure 8.2). For data tables, see Appendix C. For the distribution of correctly identified true statements and correctly identified false statements, see Figure 8.1.

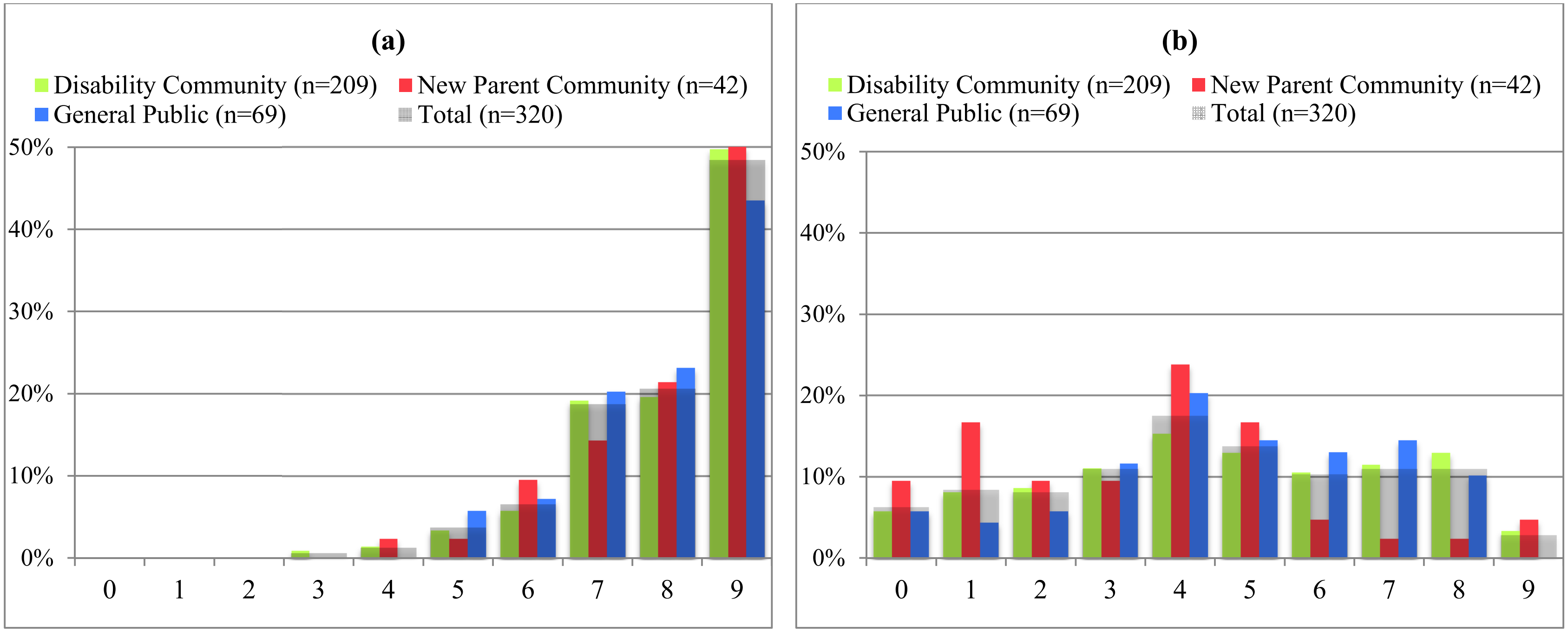


FIGURE 8.1 Distribution of (a) correctly identified true statements (b) correctly identified false statements

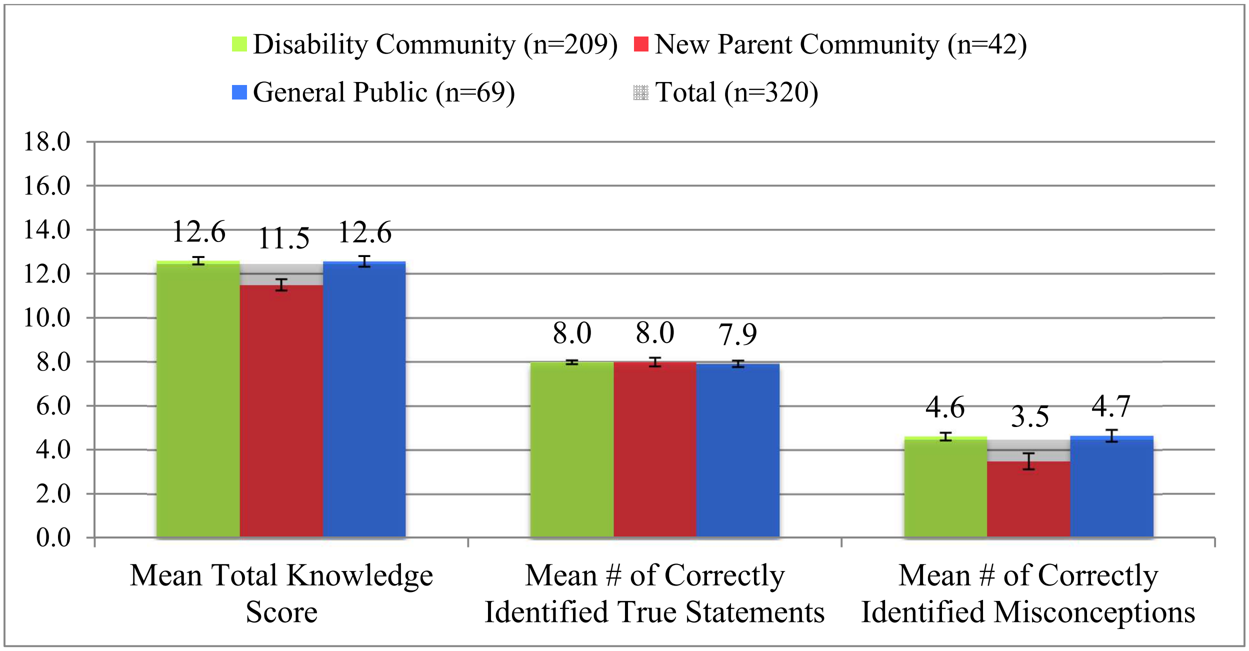


FIGURE 8.2 Mean Score Breakdown by Population. Y-axis is knowledge score. Error bars indicate standard error of the mean.

Health Care Providers

Regarding which specialists are qualified to provide genetic counseling, the majority of respondents (n=313, 98%) believed a genetic counselor is qualified to provide genetic counseling. Forty-two percent of respondents thought a pediatrician is qualified to provide genetic counseling (n=134), followed by 39% (n=126) for an obstetrician, 37% for a primary care physician (n=119), and 37% for an oncologist (n=117). These numbers were consistent across populations. (Table 7.1) (Figure 9.1).

TABLE 7.1 Are These Specialists Qualified To Provide Genetic Counseling?

	Population						Total (n=320)		
	Disability Community (n=209)		New Parent Community (n=42)		General Public (n=69)				
	n	%	n	%	n	%	n	%	p-value
Genetic Counselor	206	99	42	100	65	94	313	98	0.058
Pediatrician	79	38	23	55	32	46	134	42	0.088
Obstetrician	77	37	21	50	28	41	126	39	0.274
Primary Care Physician	75	36	19	45	25	36	119	37	0.511
Oncologist	74	35	16	38	27	39	117	37	0.836
Psychologist	57	27	9	21	19	28	85	27	0.721
Internist	53	25	12	29	19	28	84	26	0.877
Nurse	48	23	8	19	10	14	66	21	0.309
Social Worker	26	12	3	7	4	6	33	10	0.223
Midwife	15	7	4	10	6	9	25	8	0.834

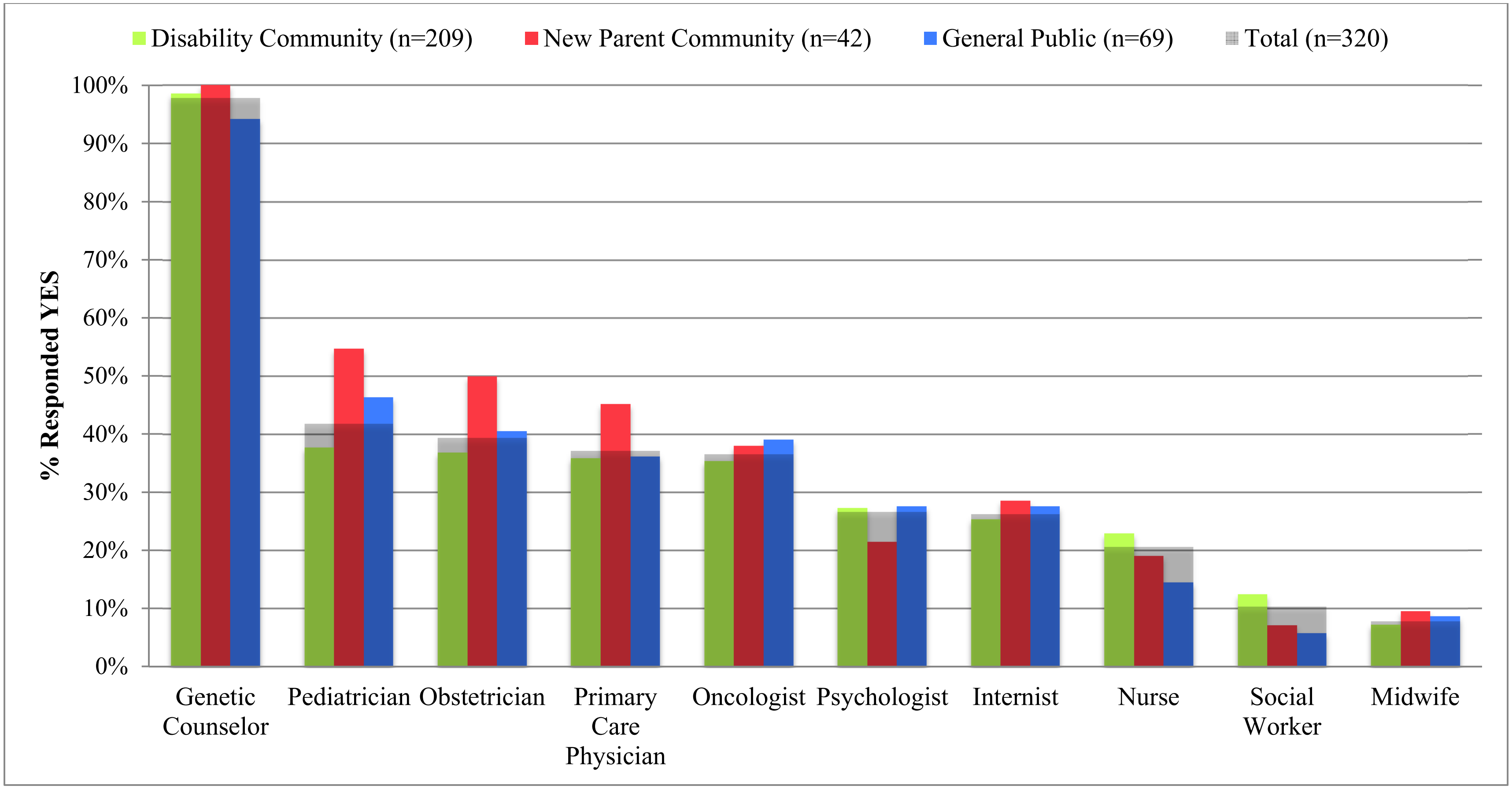


FIGURE 9.1 Are these specialists qualified to provide genetic counseling?

Television Preferences

When asked how they watch TV shows, 54% of respondents watch them on TV only (n=174), 19% watch online and on TV (n=60), 16% watch mostly online (n=52), and 11% do not watch TV at all (n=34), see Figure 10.1.

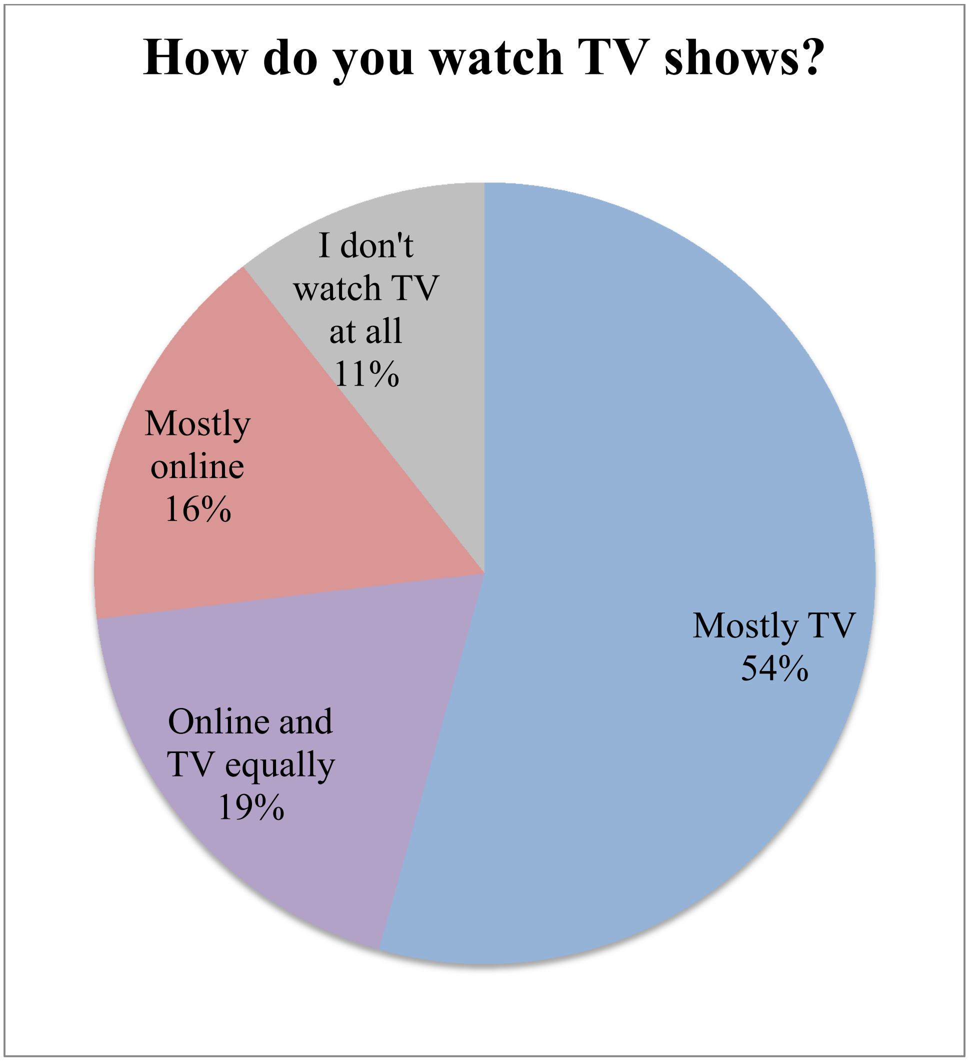


FIGURE 10.1 How Do You Watch TV Shows?

Of the hypothetical genetic TV shows, the most popular was “Chasing the Helix,” the drama/thriller option, followed by “DNA Files,” the documentary series option. The least popular option was “Blue Genes,” the comedy option. See Figure 11.1 for the ratings.

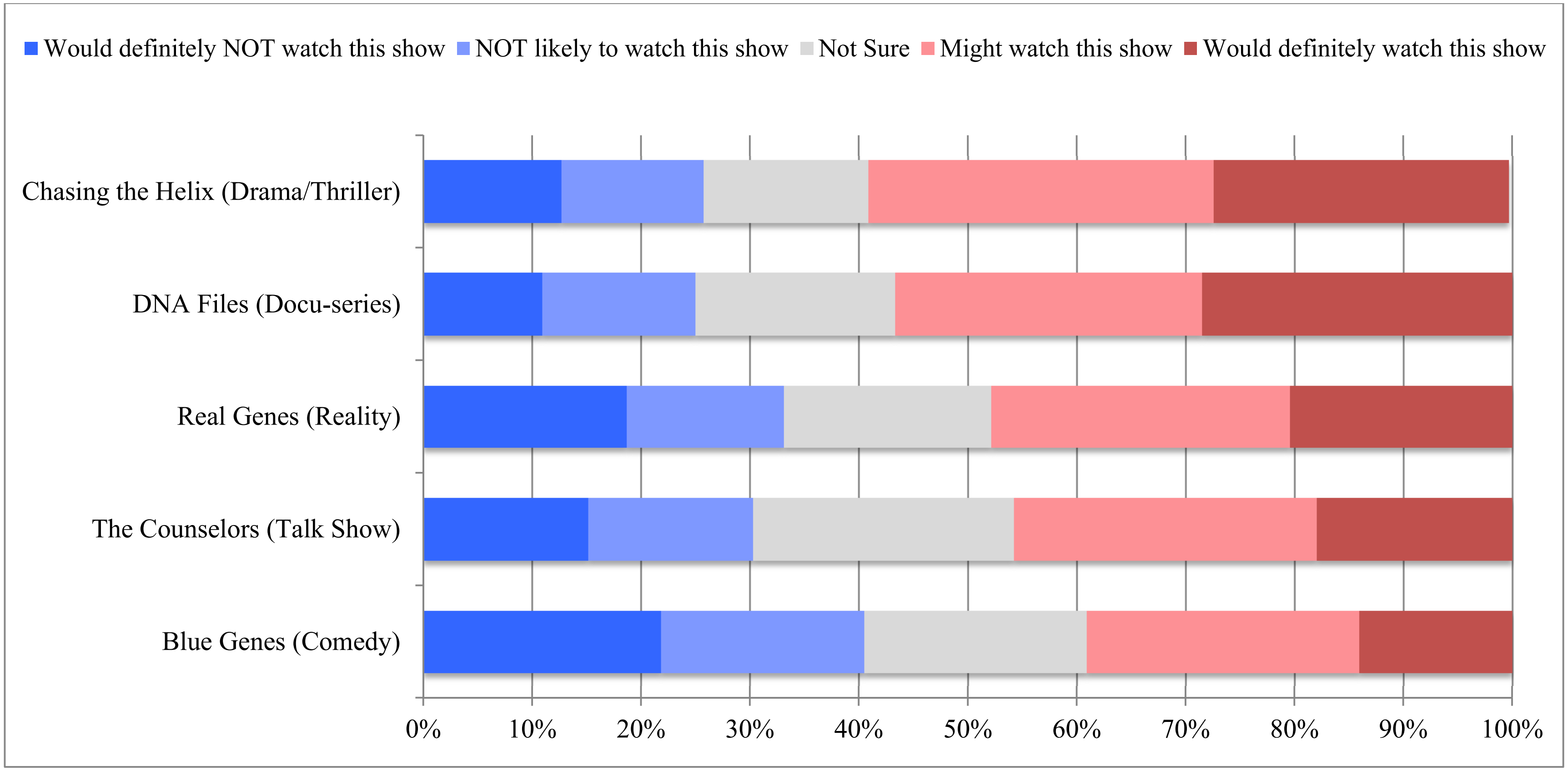


FIGURE 11.1 **If the following TV shows were to come out next season, how likely would you be to watch?**

CHAPTER 4: DISCUSSION

This was the first study to empirically explore awareness and perceptions about genetic counseling and to compare these among the disability community, a new parent community, and the general public. We hypothesized that the general awareness within each group would be low, but that individuals from the disability community or new parent community may have more knowledge than those from the general public.

By surveying 320 individuals, we were able to gauge their perceptions. It seems that the first thought participants had when they heard the term “genetic counseling” usually had to do with genetics itself (DNA, genes, makeup, body). Other common associations included risk assessment or predictions for the future as well as genetic disorders, heredity, and counseling. Surprisingly, only a small portion of respondents mentioned altering genes or eugenic principles. Within the population we studied, it seems that the phrase “genetic counseling” may not have as negative of a stigma as previously assumed, and the majority of individuals from each community associated the profession with the correct concepts. Participant responses to what a genetic counselor does were very similar to their first impressions of genetic counseling.

When examining all responses from first impressions and perceived genetic counselors’ roles that were associated with a specific genetic counseling setting, most mentioned the prenatal and preconception settings. For both questions, fewer than three percent of responses mentioned pediatrics, and fewer than two percent mentioned cancer. These responses are concerning because 29% of clinical genetic counselors currently work in a cancer setting, and 12% work in a pediatric setting. Fewer than two percent actually work in a designated preconception genetic counseling setting (infertility, IVF, PGD) (NSGC, 2014), but in reality many prenatal genetic counselors provide preconceptional counseling. The perceived scope of genetic counseling seemed to be narrower than the actual field. In examining our study results, there is a clear need for an increase in awareness and education about cancer genetic counseling. Individuals who have a family history that increases their risk to develop cancer will not seek cancer genetic risk assessment counseling if they are unaware of it and, therefore, may not learn about options for prevention or early diagnosis of cancer in themselves or their relatives. Since lack of understanding of the full scope of genetic counseling services is likely to be a barrier to proper referrals, it is also important to increase awareness among physicians and allied health professionals of various types of genetic counseling services and the referral indications for each.

When assessing where participants thought genetic counselors work, about half of responses mentioned a clinical setting. The clinic is the traditional genetic counseling setting, but as the profession continues to grow, the variety of roles will grow with it. In 2014, 80% of genetic counselors worked in a clinical setting, while 20% had a non-clinical role (NSGC, 2014).

Similar to a 2014 study that examined perceptions about genetic counseling in the rural Midwest (Riesgraf et al., 2014), about half of respondents reported having heard of genetic counseling before the present study. In the 2013 study that explored perceptions of genetic counseling in Canada (Maio et al., 2013), only one-third had heard of genetic counseling. Perhaps genetic counseling is more familiar to people in California or more publicized than it was several years ago.

In both of the prior studies, the majority of respondents who had heard about genetic counseling became aware of it though the media. In combining all of the media categories together, media was the most common way to have heard of genetic counseling (n=74, 43%), which was consistent with both the Canadian (Maio et al., 2013) and the rural Midwestern US (Riesgraf et al., 2014) studies.

We analyzed “media” subcategories categories including Internet, television, movies, news, or other and found that the news, meaning any print news as the question said “I have read about genetic counseling in the news”, was the top source of media responses, followed by the Internet and television. It is possible that respondents may have considered televised news to fall under the “news” category and future studies should somehow distinguish the survey wording. This illustrates the importance of providing simple and accurate information through each of these forms of media. Although this study focused on television education, there is a clear need to increase news coverage and include genetic counselors in news stories alongside physicians. Prior studies have examined news coverage of medical genetics (Bubela, 2004; Condit et al., 2001; Koren & Klein, 1991; Petersen, 2001; Väliverronen, 2006), but none to our knowledge have measured the visibility of genetic counseling in televised news or print media. Future directions may include this type of exploratory research.

We also found that aside from media, the most common way to have heard about genetic counseling was to have seen a genetic counselor or to have been referred. However, this was twice as common in the new parent community than in the disability community or general public. Our data showed that a new parent is more likely to have been referred to genetic counseling, even though one would expect that individuals in the disability community—especially those with a disability themselves—should have at least heard of genetic counseling. The lack of awareness of genetic counseling services among these individuals deprives them of services that could potentially be very helpful to them and their families (Rutherford, Zhang, Atzinger, Ruschman, & Myers, 2014; Vande Wydeven et al., 2012).

In assessing perceptions of what genetic counselors do, the new parent community was significantly more likely to mention prenatal counseling than the other population groups (p=0.010). Although half of them were referred to or saw a genetic counselor, we do not know whether it was for a prenatal appointment or for another indication. Judging by their perceptions, they are more likely to have heard about genetic counseling only within the context of prenatal care. When answering where a genetic counselor works, new parents were significantly more likely to mention a Maternal-Fetal Medicine practice or Obstetrician's office and significantly less likely to mention a hospital. If new parents do not understand the variety of roles of a genetic counselor, they may not avail themselves of genetic counseling services that could be beneficial for their children, parents, or siblings.

The general public was significantly more likely to mention altering DNA or having designer babies. Because this community may have fewer interactions with genetic counseling, it is important to dispel these misconceptions since the time may come when genetic counseling is necessary for an individual in this group and a basic understanding of what to expect from such a visit would improve the outcome of the appointment (Albada, van Dulmen, Bensing, & Ausems, 2012; Michie et al., 1997).

Analysis of knowledge scores revealed that respondents were more likely to recognize true purposes of genetic counseling than to understand that the misconception statements were actually false. In recognizing the 18 statements of purposes of genetic counseling as true or false, all populations were more likely to identify the *true* statements as true. If the number of correct responses had been closer to 50%, we would have concluded that the respondents were guessing; however, these numbers were well above 50%, indicating that the respondents were confident that these statements were true.

When identifying misconceptions, the study populations only answered correctly closer to half of the time for many of the statements, suggesting that these were more likely guesses and not actual beliefs. Any value that does not differ significantly from 50% could reflect “guessing”; however, the confidence intervals calculated showed a 95% probability that the true value of a “guess” lies within the interval of 39.5% to 50.5%. With respect to preventing genetic diseases or abnormalities, providing information and support to all pregnant women, and determining whether a child without symptoms is going to develop an adult-onset condition later in life, the total numbers of correct responses were each below the confidence interval possibly indicating that more than half of respondents truly have a misconception. Future directions may include identifying the direct source of these specific misconceptions in order to develop an effective intervention to correct them.

The new parent community was much more likely to identify a misconception as true even though they were also more likely to have been referred to or to have visited a genetic counselor. This illustrates an evident mismatch between patients’ assumptions and the actual goals of a genetic counseling session that should be addressed. In particular, the majority of the new parents thought that a purpose of genetic counseling was to prevent genetic diseases or abnormalities. If this were true, genetic counselors would be directive and more eugenic in their actions rather than offering a variety of options. Although one goal of prenatal screening and diagnosis may be prevention, another goal is educating and preparing parents for the possible birth of an affected child, so it is important that prenatal patients understand that they have choices and that the role of a genetic counselor is not to convince them one way or another but rather to guide them through making decisions that are best for them. This misconception may deter some people from utilizing genetic counseling services when they might actually benefit greatly from them.

Another common misconception is that genetic counseling is for ALL couples planning a pregnancy. The American College of Medical Genetics (ACMG) only recommends genetic counseling for specific indications, including advanced maternal age, a consanguineous union, an abnormal screening result, a possible teratogenic exposure, a fetal anomaly identified on ultrasound, a personal or family history of pregnancy complications, a positive carrier screen, a previous child with early death, recurrent miscarriages, or a personal or family history of a genetic condition or birth defect (Pletcher et al., 2007). The resources and funding should be allocated to those with “greatest need” to provide the “maximum benefit” with “equitable distribution” in order to promote and reward social usefulness (Rogowski, Grosse, Schmidtke, & Marckmann, 2014; Skirton, 2014). By these standards, the majority of couples do not need referral for genetic counseling, but it is important that both potential clients and their physicians are aware of the appropriate circumstances for referral.

The false statement that most participants believed was that genetic counselors determine whether a child without symptoms is going to develop an adult-onset condition (such as Huntington disease or Alzheimer disease) later in life. There has been considerable debate over predictive genetic testing of minors. “Opponents of testing highlight potential harms, while proponents look to testing as an opportunity to promote benefit, with each side drawing upon fundamental ethical principles to support their diametrically opposed positions” (Mand, Gillam, Delatycki, & Duncan, 2012). Proponents of presymptomatic testing of minors for adult-onset disorders believe that testing can decrease uncertainty, anxiety, and depression, have a positive effect on individual identity, self image, and self esteem, allow for psychological preparation, promote realistic expectations, realistically plan for the future, negate harm resulting from not testing, promote autonomy, and empower the minor to be an active participant in his or her own health. However, opponents worry that a positive result may have a negative impact on self-image and esteem, induce feelings of guilt or blame, stigmatize an individual, increase anxiety and depression, misattribute unrelated symptoms to the disorder, affect relationships, cause discrimination by insurance, employment, education, or peers, restrict choices, and disregard the patient's autonomy (Mand et al., 2012). Medical benefits of presymptomatic genetic testing of minors include "the possibility of evolving therapeutic interventions, targeted surveillance, refinement of prognosis, and clarification of diagnosis," while potential harms include "misdiagnosis to the extent that genotype does not correlate with phenotype, ambiguous results in which a specific phenotype cannot be predicted, and use of ineffective or harmful preventive or therapeutic interventions" (Ross, Saal, David, & Anderson, 2013). The ACMG issued a policy stating that although there are "limited circumstances in which predictive testing may be appropriate," the general consensus was that "The AAP [American Academy of Pediatrics] and the ACMG continue to support the traditional professional recommendation to defer genetic testing for late-onset conditions until adulthood" (Ross et al., 2013). This excludes disorders for which the results of testing would affect medical management of the child. Increasing the awareness of the potential benefits and detriments of testing minors would help parents to make more informed decisions during genetic counseling and may make them more likely to request a referral for genetic counseling to begin a discussion about this topic.

The majority of respondents correctly identified a genetic counselor as being qualified to provide genetic counseling, although this number was not 100%. Although the answer seems rather obvious, some respondents may have thought this was a trick question or believed that only a doctor is qualified to provide genetic counseling. Closer to half of respondents thought that a pediatrician, obstetrician, primary care physician, or oncologist is qualified to provide genetic counseling. This could indicate guessing, but could also be a true perception among the population. As mentioned earlier, physicians who are not knowledgeable about genetic counseling may order the wrong genetic tests, misinterpret genetic test results, and provide incorrect, or inadequate genetic counseling or none at all, even though it may be indicated (Brierley et al., 2010). Due to rapid advances in genetic technology and discoveries of new genetic mechanisms, a non-geneticist physician or other medical professional is unlikely to be qualified to evaluate and counsel about the majority of genetic disorders. For this reason, it is imperative that physicians either keep up to date with necessary genetic knowledge (which may prove to be difficult while simultaneously remaining current in their own specialties), or learn when referral is appropriate. Furthermore, when a patient is unaware that his or her physician is poorly qualified to provide adequate genetic counseling, he or she is not likely to seek information from an appropriate provider and could be left with inaccurate or inadequate information regarding his or her situation. For this reason and others, genetic counseling should be more accepted and understood. To accomplish this, we propose an education initiative that will reach wider audiences and will represent the true nature of genetic counseling as it is appropriately carried out in the real world, off of the television screen.

Hearing about genetic counseling through media was mostly reported by news and the Internet. This could be due to the lack of coverage on television. It is likely that the news and Internet discuss genetic counseling much more than television shows do. However, since approximately 90% of respondents claimed to watch television, and television has the potential to reach more viewers at once than any other source of media, a television show centered around genetics and the genetic counseling experience would be a massive educational movement for the profession. Our survey rated participants' likelihood to watch a particular television show, and the highest rated type of show was the drama/thriller. This is consistent with primetime television medical dramas such as *Grey's Anatomy* and *House MD*. A television drama may be most influential when teaching about a disorder because viewers learn more from a narrative with relatable characters than from the dry delivery of data. Incorporating genetic concepts into a storyline can "take the public beyond the understanding of scientific facts to the emotional appreciation of how it feels to have, or be at risk [for], a health condition" (Nisker, 2006) and may "trigger an emotion with laughter or tears that they remember" (Mink, 2015). In a narrative, "…we see and hear and feel the same things the characters do and from their same perspective" and they "offer us a way of experiencing...without experimenting with our own lives" (Burrell & Hauerwas, 1977; Montello, 1997; Nisker, 2006). Therefore, written storylines may expose the public not only to genetic counseling but also to the ethical and psychosocial issues that surround all aspects of it, including prenatal testing, disability, presymptomatic testing, and cancer genetics. Furthermore, portraying a wide variety of situations could help patients understand that they are not alone and arm them with the knowledge that a genetic counselor will be available to support and educate them when they are ready.

The documentary *Miss Representation* explores the under-representation of women in media and how young women need and want positive role models. The motto of the film is, "You can't be what you can't see," meaning that in order to reach a goal or fill a role, a person must envision himself achieving it. If we want to promote the profession of genetic counseling, it must be seen. Seeing the positive role model of a genetic counselor on television and becoming more familiar with the profession could increase referrals, decrease patient anxiety, and help patients prepare for the session, thereby increasing positive outcomes (Bernhardt, Biesecker, & Mastromarino, 2000). With better exposure, genetic counseling could also become more widely accepted as a potential career option, which would help to address the anticipated demand for genetic counselors fueled by the rapid advances in genetic and genomic medicine.

Limitations Of The Study:

Our study only surveyed a small number of participants within the new parent group and the general public. Of those in the disability community, not every participant had a disability. Therefore, we cannot draw definite conclusions regarding awareness and perceptions among all new parents, individuals with disabilities, and the general population. However, our data suggest that there is room to improve the understanding of genetic counseling services and that an entertaining educational intervention, if well crafted, could be successful.

We also recognize that there may be disagreement about our categorization of the open-ended responses in this study and the correct answers to our misconception and true purpose statements. Some misconceptions were correctly identified by only half of the participants, making it unclear whether half the participants believed the answers to be true and half believed them to be false, or whether most respondents were not sure and were guessing. These two possibilities have different implications. However, our data suggest that participants were able to recognize the true statements as facts with confidence.

We acknowledge that the wording of the misconceptions may have caused confusion. Some of our statements may be interpreted differently by the broader genetics community. This questionnaire was not validated and thus may not reflect the true assessment of knowledge or misconceptions. Participants may not have noticed the distinction between the statements asking about ALL pregnant women/couples or just those at risk. We understand that there may be disagreement over whether a true purpose of genetic counseling is to prevent disease or abnormalities. Some may argue that this statement is true; however, we believe that if this were a true purpose of the genetic counseling process, genetic counselors would not offer options that allow for a disease or abnormality to continue on to subsequent generations.

Conclusions:

Findings from this study indicate that around half of individuals sampled had heard of genetic counseling previously. Risk assessment and counseling were among the most frequently cited activities attributed to genetic counselors, while few felt that genetic counseling was related to eugenics. Respondents from the new parent community were more likely to have been referred to or to have seen a genetic counselor, while respondents with a disability were not as likely to have heard about genetic counseling and even less likely to have been referred. Respondents were more likely to correctly identify a true statement about genetic counseling as true, and less likely to correctly identify a misconception as false, overall demonstrating the need to focus on dispelling misconceptions rather than teaching about purposes that are more widely known. The most common misconceptions presented had to do with testing minors, providing prenatal services to all pregnant women, and preventing a disease or diagnosis. Some respondents believed that a pediatrician, obstetrician, primary care physician, or oncologist is qualified to provide genetic counseling, and while some of them are, the majority probably are not. These data reveal gaps in awareness of genetic counseling.

Our data also showed that the majority of participants in all groups watch TV and prefer to watch a medical thriller, followed by documentary series, and all groups rated comedy the lowest.

Since genetic counselors provide services to individuals preconceptionally, prenatally, and from infancy to old age, in theory anyone might need referral to a genetic counselor at some point in his or her life (Maio et al., 2013), so it is important that people are aware of the services available to them; otherwise, they will be unlikely to access them.

We propose that the development of an entertaining television narrative centered around genetic counselors would be valuable and could potentially bring more opportunities for better outcomes for a greater number of individuals as a result of increased awareness and access to genetic counseling services. Furthermore, the data collected in our study, as suggested by Maio et al., could be used to develop awareness-raising projects and to provide a baseline to which to compare future data gathered after the implementation of awareness-raising interventions.

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APPENDIX A

The Survey

Genetic Counseling

1. **In a few words, what is the first thing that comes to mind when you hear the term "genetic counseling"?***
   (Please write whatever thoughts you have below)

Genetic Counseling

2. **Before coming across the phrase while participating in this study, have you heard of "genetic counseling" before today?** *

   (You do not have to know what it is, just answer if you have heard of it before)
   Mark only one oval.

   ○ When I came across the phrase as part of participating in this study, it was the first time I have ever heard of genetic counseling *Skip to question 5.*

   ○ I have heard of genetic counseling before participating in this study

Genetic Counseling

3. **How did you become familiar with genetic counseling?** *

   (check all that apply)

   ☐ I have been referred to or seen a genetic counselor
   ☐ A friend or acquaintance has been referred to or seen a genetic counselor
   ☐ A family member has been referred to or seen a genetic counselor
   ☐ A friend or acquaintance is a genetic counselor
   ☐ A family member is a genetic counselor
   ☐ I have read about genetic counseling in the news
   ☐ I have seen a TV show in which a genetic counselor was mentioned or portrayed
   ☐ I have read about genetic counseling on the Internet
   ☐ I have seen a movie in which a genetic counselor was mentioned or portrayed
   ☐ I am or am studying to be a genetic counselor
   ☐ Other: ....

4. **If you have seen a TV show or movie in which a genetic counselor was mentioned or portrayed, please write the name of the television show(s) or movie(s) here.**

   ....

First Impressions

5. **What do you think genetic counselors do?** *

6. **Where do you think a genetic counselor would work?** *

7. **Please state whether you believe the following statements regarding the purpose of genetic counseling are true or false.** *

Mark only one oval per row.

	True	False
A purpose of genetic counseling is to provide referrals and resources for families with a genetic condition	○	○
A purpose of genetic counseling is to fix mutated genes	○	○
A purpose of genetic counseling is to calculate the risk a patient has of developing cancer based on family history and testing	○	○
A purpose of genetic counseling is to help people understand their options for genetic testing	○	○
A purpose of genetic counseling is to provide genetic testing to people with a family history of a genetic condition	○	○
A purpose of genetic counseling is to help people find their ethnic origins and understand their ancestry	○	○
A purpose of genetic counseling is to help couples have a child with desirable characteristics	○	○
A purpose of genetic counseling is to provide information and support to ALL pregnant women	○	○
A purpose of genetic counseling is to provide information and support to ALL couples planning a pregnancy	○	○
A purpose of genetic counseling is to provide information and support to pregnant women whose babies may be at risk for a genetic condition	○	○
A purpose of genetic counseling is to provide information and support to couples planning a pregnancy which may be at risk for a genetic condition	○	○
A purpose of genetic counseling is to provide an explanation of the preventative, screening and diagnostic options that are available to a patient with cancer	○	○
A purpose of genetic counseling is to prevent genetic diseases or abnormalities	○	○
A purpose of genetic counseling is to determine whether a child without symptoms is going to develop an adult-onset condition later in life such as Huntington or Alzheimer disease	○	○
A purpose of genetic counseling is to help police use DNA to solve crimes	○	○
A purpose of genetic counseling is to help families understand the condition in their families and what it means for them – even if the condition is caused by a combination of genes and environment.	○	○
A purpose of genetic counseling is to aid in determining if a person's autism, developmental delay, or intellectual disability was caused by genetic factors	○	○
A purpose of genetic counseling is to advise people about whether to have children	○	○

Genetic Counseling Providers

8. **Which of the following specialists are the most qualified to provide genetic counseling?** *

Mark only one oval per row.

	YES, this person is qualified to provide genetic counseling	NO, this person is NOT qualified to provide genetic counseling
a midwife	○	○
an internist	○	○
an obstetrician	○	○
a psychologist	○	○
a pediatrician	○	○
a genetic counselor	○	○
a primary care physician	○	○
an oncologist	○	○
a nurse	○	○
a social worker	○	○

Television vs. Online

9. **How do you watch TV shows?**

Mark only one oval.

○ Mostly online
○ Onine and TV equally
○ Mostly TV
○ I don't watch TV at all *Skip to question 11.*

10. **If the following TV shows were to come out next season, how likely would you be to watch?**

Mark only one oval per row.

	I would definitely NOT watch this show	I would NOT be likely to watch this show	Not sure	I might watch this show	I would definitely watch this show
The Counselors: A panel of geneticists and genetic counselors in a talk show setting with a studio audience that answer questions about genetics. (Similar to: The Doctors, Dr. Oz)	○	○	○	○	○
Chasing the Helix: A drama/thriller about a group of genetic counselors and the unique stories of their patients based on real life cases. (Similar to: House,Grey's Anatomy, Law and Order)	○	○	○	○	○
Blue Genes: A comedy that follows around a group of genetic counselors and their quirky patients. (Similar to: Scrubs)	○	○	○	○	○
DNA Files: A documentary series that discusses a different genetic disorder each episode and interviews experts, patients, and their families with each disorder. (Similar to: Mystery Diagnosis, Untold Stories of the ER, Extraordinary People)	○	○	○	○	○
Real Genes: A reality show that follows real genetic counselors in different clinical settings and the challenges they face with patients, insurance, medical staff, etc. (Similar to: NY Med, COPS, Keeping up with the Kardashians)	○	○	○	○	○

Demographics

11. **Which category below includes your age?** *
Mark only one oval.

○ 18-20
○ 21-29
○ 30-39
○ 40-49
○ 50-59
○ 60 or older

12. **With which gender do you identify?** *
Mark only one oval.

○ Male
○ Female
○ other

13. **What is the highest level of school you have completed or the highest degree you have received?** *
Mark only one oval.

○ None
○ Less than high school (0-8 years)
○ Some high school (9-11 years)
○ High school graduate (12 years)
○ Some College or University
○ College or University Graduate
○ Some Graduate School
○ Graduate or Professional Degree
○ Other: ....

14. **If you completed a graduate or professional degree, what type of degree did you recieve and/or what area did you specialize in?**

....

15. **What is your race/ethnicity?** *
(if mixed, please specify in other)
Mark only one oval.

○ Caucasian (non-hispanic)
○ Black or African-American
○ Asian
○ Hispanic / Latin
○ American Indian or Alaskan Native
○ Pacific Islander
○ Middle Eastern
○ East Indian
○ Prefer not to answer
○ Other: ....

16. **Which of the following best describes your current occupation?** *

Mark only one oval.

○ Administration
○ Art / Music / Writing
○ Banking / Finance
○ Construction
○ Education
○ Entertainment / Media
○ Hospitality
○ Law
○ Management
○ Medicine
○ Military
○ Politics / Government
○ Retired
○ Sales / Marketing
○ Science / Engineering
○ Student
○ Technology
○ Transportation
○ Unemployed
○ Other: ....

17. **What religion do you identify with?** *

Mark only one oval.

○ Buddhism
○ Catholicism
○ Hinduism
○ Inter/Non-denominational
○ Islam
○ Judaism
○ Latter Day Saints (Mormonism)
○ Native American
○ Other Christianity
○ Protestantism
○ No religion
○ Prefer not to answer
○ Other: ....

18. **In which state or U.S. territory do you live?** *

....

19. **What is your marital status?**

Mark only one oval.

○ single
○ married
○ not married, but living with partner

20. **Do you have children?** *

Mark only one oval.

- ○ Yes
- ○ No

21. **Are you a practicing physician?**

Mark only one oval.

- ○ Yes
- ○ No

22. **Do you have any sort of disability?**

Mark only one oval.

- ○ Yes
- ○ No

23. **How much total combined money did all members of your HOUSEHOLD earn last year?** *

Mark only one oval.

- ○ Less than $25,000
- ○ $25,000-$49,999
- ○ $50,000-$74,999
- ○ $75,000-$99,999
- ○ $100,000-$149,999
- ○ $150,000-$199,999
- ○ $200,000-$499,999
- ○ More than $500,000
- ○ I'd rather not say

Thank you!

Please return this survey to the study coordinator to receive a giveaway.

Thank you for taking the time to take this survey. Your answers will be very helpful in developing programs to spread awareness of genetic services.

If you would like to learn about genetic counseling, please visit DenaDNA.com or www.nsgc.org.

APPENDIX B

All Open-Ended Responses by Theme

"What is the first thing that comes to mind when you hear the term 'genetic counseling'?"

DNA/ Genes/ Makeup/ Body
Counseling based on your genetics. What your genes say determines the type of lifestyle you may have. Diet, activity, etc.
Body (internal) your make-up!
genes biological dna makeup
birth defects and family defects in the genes
Blood sample (from patient), lab test, list of blood components DNA (chromozones), proteins/fats, councelor tells results to patient, ?
DNA
Family make up of physical and mental abilities!
DNA
Checking out your DNA/RNA to see your geneology and see what you are prone to get. Like my mom had early Alzheimer's so I'm worried I'll get it too. Diabetes has a genetic factor as well as so many other illnesses. This way once you know you can adjust your lifestyle/diet/exercise etc and perhaps stave off some illnessess.
Professional advice on a person pre disposition to disease based on a person's genetic make up is.
Being aware of any deleterious mutations you might carry, so you know what diseases you (or your potential offspring) may be at risk for.
Learning more about your genes and your body's makeup
DNA, hormones, family diseases
What's up with your body from past family genes
Understanding one's genetic makeup (DNA) with regards to having children, possible future health issues, and taking proactive measures.
Human Genome Project
When you have a baby the doctors talk to you about what genes carry forward
Being talked to or informed about genetics
Information on ones Genetics
Looking at genes and counsel according to questions people have about themselves
Making people aware of the genes and traits they have in their dna for future reference ie having children
Information about unavoidable genetic conditions

Using genetics to predict and prevent disease
Certain physical things you have by virtue of your parents > characteristics or tendancies
Something that studies what are the genes that composes a human body
Genes!
The way your body is made up and functions
Determing which "bad" genes and carrier status
Your genetics and the history of whats in your genes to assess your personal future and/or children
Changing DNA, modify parents genetic to get the baby they designed
I think it has something to do with the individual helping you identify and understand your genetics
Genetic counseling is a medical service that examines DNA sequencing for possible congenital conditions. "GC" is on the cutting edge of medical exploration for the influence of certain genes for physical and mental conditions.
What you get from your genes
Something in the genes, choosing the genes for procreation
I know that it has to do with your genetics but how the counseling comes into all of this
Trying to avoid having a child with significant disabilities. I read in the Jewish Journal about the effort to prevent annoyed marraiges that might amplify or result in genetic diseases through an annonymous database which I thought was terrific. I do geneology research & read around DNA as a research tool for discovering ancestors
I would think that genetic counseling could take place after genetic testing. I have heard that genetic testing happens first to know before hand about possibilities of double dominant genes/cancer gene, etc. So genetic counseling would be discussing the options before and after having children.
Genes throughout your family
Testing someone's genes for abnormalities and to see if they will pass them along to offspring
I'm not sure. I have never heard of this. The only thing that I gather is that it is probably a type of counseling where they inform you of your genetic make up.
Studying DNA
Genetic. What and how your made up from mother and father
Parts of my body and how it works
How genetics apply to diseases
Someone who evaluates and explains results from DNA tests
Genetic- genes as related to propensity to illness & disability
A mix of genes and what would be resulting from it
Science, DNA, talking to Genetic
I am not sure what this is about. Maybe having to do with a persons genetic predisposition toward certain tendancies

Genetically see what is in ones body and consultation to proceed best to have the best quality of life or minimize chance of getting a condition
Looking at the DNA, genes of an individual to get insights on potential problems that could affect them. I think it can also be used for when you're planning on having children & are worried about possible risks.
Counseling on your genetic makeup (genes)
Sharing information about genetics with families and persons regarding impact of specific genetic diagnoses on life, health and medical factors.
Body Changes
doctors, genes, science
research of health regarding my genetics
A Dietition of your genes - someone who maps your genes and creates a regimine to keep you as healthy as possible tailored to your own genes
Counseling dealing with genetics
To learn about my genes.
finding out if you are prone to diseases that have a genetic basis
genetic history
Has to do with genes
finding out if you have genetic issues or traits
I think genetic counseling refers to knowing what yiu are genetically predisposed too. Example, pathological conditions, body types, hair color, eye color etc.
tryig to use their genetic makeup to improve their life
Understanding what you are inclined to get, based on your DNA. Preventing or preempting diseaseby seeing what you're inclined to have in the future.
Identifying genetic factors for disease and/or disabilities
dna
Genes, diseases, learning about transferring diseases to offspring
genetic-based advise
counseling on the body
DNA
Counseling someone about their genetic makeup
Genetic Makeup
Counceling people about theier anatomy and why their body worksdifferently from other peopl.
Helping talk about genetics
Talking about your genes
That's what I'm hoping to learn. Maybe telling me how genes affect my life.
What one needs to know about genetics and if genetics can help w/ disabilities

Counseling to talk about your genetic makeup and the possible risks that may be associated with your genes
talking about genes
counseling regarding genetic history and ensuing management
The gene combinations between parents and child
Understanding ones self based on our genetic make up
How genetics impact daily life
Learn about gene involvement in reproduction
I believe this genetic couseling involves looking at genes, and determining genetic disabilities by comparing DNA
people who need to know what is wrong with their genes
doing DNA test to learn about potential genetic defects
your body programmed to kill you
Understanding ones self based on our genetic make up
Help us to understand about genetic
Testing to understand genes, especially in genetic disabilities
Modified dna
genes
dna genes hereditary
info on how your genes will pass on to your kids
genetics
chromosomal problems
chromosones,abnormailties
counsel you on how your genes work
genetics
dna
blood
genes, relative, DNA
how your genes made you a person
genetic education
assessing the risks and benefits of potential genetic mutations
genetic consulting
Discovering the traits of different genes and strands of DNA

Risk/ predictions/ future / screening
Determining high risk for genetic disorders in children
Discovering whatever genetic factors may contribute to present or future illness.
Checking out your DNA/RNA to see your geneology and see what you are prone to get. Like my mom had early Alzheimer's so I'm worried I'll get it too. Diabetes has a genetic factor as well as so many other illnesses. This way once you know you can adjust your lifestyle/diet/exercise etc and perhaps stave off some illnessess.
Speaking with people about potential risks to their health based upon genetic testing future science maybe able to minimize these risks advising people who want a baby on potential birth defects
Professional advice on a person pre disposition to disease based on a person's genetic make up is.
Being aware of any deleterious mutations you might carry, so you know what diseases you (or your potential offspring) may be at risk for.
To help you understand you risks for a variety of genetic conditions and to help guide your decisions related to any genetic testing you are considering
Genetic testing that you then recieve relevant information on what health risks or strengths could be forseen in your future. How to be ahead of those risks.
I imagine it's counseling people on things they are prone to genetically.
The first thing that comes to mind is a discussion about genetic profiling or screening. The idea of what would be desirable in producing offspring of a certain genetic composition.
What diseases will I die from
screening for birth defects
Understanding one's genetic makeup (DNA) with regards to having children, possible future health issues, and taking proactive measures.
Counseling about questionable traits you get.
Trying to determine how to handle genetic disorders
Meeting with a doctor before having a baby to discuss risks or options to alter the babies genetics
Cancers screening, disease family hustory
Making people aware of the genes and traits they have in their dna for future reference ie having children
Risk assessment when preparing to have kids
information, prevention, high-risk
Something that deals with people's helth future
finding out risks of having a child with a particular genetic problem
Using genetics to predict and prevent disease
Determing which "bad" genes and carrier status
Your genetics and the history of whats in your genes to assess your personal future and/or children

I think of a team of healthcare members helping you decide on your plan for having children you may have known you carry a trait for some type of disorder. And also coundseling and assistance after the birth of a child and you discover they have an illness.
To do with birth in their traits & personality as well besides the physical aspect
Counselling on my is my daughter is Rett Syndrome and is importable to me and my oldest daughter. This condition and on tenure in family girls because they carrie the mutation.
Trying to avoid having a child with significant disabilities. I read in the Jewish Journal about the effort to prevent annoyed marraiges that might amplify or result in genetic diseases through an annonymous database which I thought was terrific. I do geneology research & read around DNA as a research tool for discovering ancestors
To see if babies going to have problems that can be prevented before birth. To consider terminations if necessary. Possible problems in future.
Being or becoming aware of any decision I might be predisposed to
Prescreening people for potential birth problems. Possibly determining a persons potential for success in certain treatment programs using drugs.
I think genetic counseling refers to examining the chances of a baby born with a genetic abnormality either before or after conception
Need more research, should not affect insurance entry, interested specifically in "Alzheimer's" predictability
Screening potential parents to see if they have hereditary conditions that they would pass on to their kids.
Checking on kids and how they will come out
Learning what ethnicity and any conditions that you may have
There has been genetic testing and a counselor will explain the implications
Health predictions based on family health expirience
To find out if I have a genetic problem that may be passed on to my future generation
Genetic- genes as related to propensity to illness & disability
A mix of genes and what would be resulting from it
I am not sure what this is about. Maybe having to do with a persons genetic predisposition toward certain tendancies
Looking at the DNA, genes of an individual to get insights on potential problems that could affect them. I think it can also be used for when you're planning on having children & are worried about possible risks.
Helping patients know their genetics for diagnose and prognosis
Sharing information about genetics with families and persons regarding impact of specific genetic diagnoses on life, health and medical factors.
Counsellor reviews condition/disease with person so the have an understanding of pros/cons of illness. Persons can use this information in helping them to make decisions about whether they wish to have children / or possible challenges they might face.
Testing and discussion about genetic conditions and predispositions

finding out if you are prone to diseases that have a genetic basis
risks
testing to see if you carry genetic markers that can determine futre/current diagnoses
I think genetic counseling refers to knowing what yiu are genetically predisposed too. Example, pathological conditions, body types, hair color, eye color etc.
Understanding what you are inclined to get, based on your DNA. Preventing or preempting diseaseby seeing what you're inclined to have in the future.
Look @ your genetics & see what it tell you about possible disease etc that you may have and how to cope or prepare yourself for it.
Screening your genetics to see what possible health issues can be determined
Determining your predispotition to certain medical conditeions
cancer that is inherited, family history, determine if one is suseptible to certain diseases, ancestry
Have get genetically tested to determine what potential genetic issues may come up in one's life. To use the info to manage one's medical issues.
Determining what precursors are in your genetic bank to help determine future diseases.
info on what test are available reliability and results and what results indicate
Counseling to talk about your genetic makeup and the possible risks that may be associated with your genes
possible cancer risks or health risks
What risk factors run in our family
for people who are considering having kids to somehow prevent risk of types of disabilities.
screening for undiagnosed disease proclivities and family history of genetic disease processes
What risk factors run in our family
Finding out possible illness dangers
generic screening of embryos
getting expert advice about your genetic history, possiblr recessive issues and whatnot
testing to see risk of inherited disease for self or children
screening
understanding risks
disease screening
Finding out if I have something that I pass to my offspring
family background screening
tell me about what my child may be like and how to develop strengths vs weaknesses
the future
prenatal screening
assessing the risks and benefits of potential genetic mutations

Rare disease/ Genetic Disorder/ Disability
Determining high risk for genetic disorders in children
discussing with patient (not a doctor) getting tested for diseases or defects that are inherited genetically (ie: Angelina Jolie breast cancer) Testing older pregnant women to see if their unborn embryo has genetic defects trisomy 21 etc (chromosome abnormalities)
Ashkenazi CP
Checking out your DNA/RNA to see your geneology and see what you are prone to get. Like my mom had early Alzheimer's so I'm worried I'll get it too. Diabetes has a genetic factor as well as so many other illnesses. This way once you know you can adjust your lifestyle/diet/exercise etc and perhaps stave off some illnessess.
My son has Loeys Dietz syndrome so, to me it means checking him for wellness to succeed in life. Checking bones, fingers, and body.
DNA, hormones, family diseases
helping person in genetic disorder
known "problems" passed down from generations.
How mental disorders come from one parent or the other
Trying to determine how to handle genetic disorders
Guidance from a medical practicioner regarding possible genetic disorders that could be aided or passed on
Information about unavoidable genetic conditions
Inherited disease
finding out risks of having a child with a particular genetic problem
when your baby has a disability
Possible birth defects, rare disease, breast cancer
Learning about inherited disorders traits, etc.
Disability medical condition affecting generation offer generation
Genetic counseling is a medical service that examines DNA sequencing for possible congenital conditions. "GC" is on the cutting edge of medical exploration for the influence of certain genes for physical and mental conditions.
I think of a team of healthcare members helping you decide on your plan for having children you may have known you carry a trait for some type of disorder. And also coundseling and assistance after the birth of a child and you discover they have an illness.
Counselling on my is my daughter is Rett Syndrome and is importable to me and my oldest daughter. This condition and on tenure in family girls because they carrie the mutation.
Talking to people who have genetic disorders

Trying to avoid having a child with significant disabilities. I read in the Jewish Journal about the effort to prevent annoyed marraiges that might amplify or result in genetic diseases through an annonymous database which I thought was terrific. I do geneology research & read around DNA as a research tool for discovering ancestors
Finding out what diseases or disorders a person made have inherited preventing this from occurring
Checking for the possibility of hereditary illnesses being passed on in a family. Choosing babies or sex or other qualities.
disabilities
I think genetic counseling refers to examining the chances of a baby born with a genetic abnormality either before or after conception
researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
Study and evaluation of genetic conditions and anomalies.
Testing someone's genes for abnormalities and to see if they will pass them along to offspring
counseling abnormality
How genetics apply to diseases
Screening potential parents to see if they have hereditary conditions that they would pass on to their kids.
Learning what ethnicity and any conditions that you may have
Genetic- genes as related to propensity to illness & disability
Helping patients know their genetics for diagnose and prognosis
Getting information about diseases
Counsellor reviews condition/disease with person so the have an understanding of pros/cons of illness. Persons can use this information in helping them to make decisions about whether they wish to have children / or possible challenges they might face.
Testing and discussion about genetic conditions and predispositions
When I hear the term genetic counseling I think about the need for unbiased, accurate information relating to genetic testing during pregnancy, specifically relating to Down syndrome.
counseling for people with genetic issues
Passing on my disease to my children
testing to see if you carry genetic markers that can determine futre/current diagnoses
Identifying genetic factors for disease and/or disabilities
Genes, diseases, learning about transferring diseases to offspring
My sons medical issues
Syndromes
Determining your predispotition to certain medical conditeions
What one needs to know about genetics and if genetics can help w/ disabilities
You find out what genetic diseases you have

To council thu the issues that come with genetic disorders
counseling of info and dealing with genetic disorders
Help with a genetic diagnosis
for people who are considering having kids to somehow prevent risk of types of disabilities.
screening for undiagnosed disease proclivities and family history of genetic disease processes
I believe this genetic couseling involves looking at genes, and determining genetic disabilities by comparing DNA
family member with a genetic disease
Inherited illness/disease
Ability to deal with genetic abnormalities or different illnesses
doing DNA test to learn about potential genetic defects
Genetic abnormalities
talking to couples that have a disabled child, if they choose to have another child what the probability of the second child inheriting the disease or disability as well
Testing to understand genes, especially in genetic disabilities
testing to see risk of inherited disease for self or children
Counseling about potential genetic defects for soon to be parents
down syndrom
chromosones,abnormailties
learning about how to deal with possible genetic issues either pre-birth ildren already born.or with ch
something to do with a disorder

Family / Inherited
birth defects and family defects in the genes
Maybe something that deals with you health and problem you may have that comes from your family
discussing with patient (not a doctor) getting tested for diseases or defects that are inherited genetically (ie: Angelina Jolie breast cancer) Testing older pregnant women to see if their unborn embryo has genetic defects trisomy 21 etc (chromosome abnormalities)
Family make up of physical and mental abilities!
DNA, hormones, family diseases
Family health patterns I think
Understanding options that are afforded to you when planning to have a child or if there is a history of genetic issues or abnormalities in your family.
What's up with your body from past family genes
Determining your family history

When you have a baby the doctors talk to you about what genes carry forward
known "problems" passed down from generations.
How mental disorders come from one parent or the other
Guidance from a medical practicioner regarding possible genetic disorders that could be aided or passed on
Cancers screening, disease family hustory
Inherited disease
Certain physical things you have by virtue of your parents > characteristics or tendancies
Learning about inherited disorders traits, etc.
Disability medical condition affecting generation offer generation
Your genetics and the history of whats in your genes to assess your personal future and/or children
Geneology and what my family is passing down
People want to know how healthy their family is
Hereditary
Counseling that has been past down to the there kids
family
Finding out what diseases or disorders a person made have inherited preventing this from occurring
I think about hereditary counseling
Checking for the possibility of hereditary illnesses being passed on in a family. Choosing babies or sex or other qualities.
Genes throughout your family
family background
Testing someone's genes for abnormalities and to see if they will pass them along to offspring
Genetic. What and how your made up from mother and father
Screening potential parents to see if they have hereditary conditions that they would pass on to their kids.
fathers
family traits
Health predictions based on family health expirience
Sharing information about genetics with families and persons regarding impact of specific genetic diagnoses on life, health and medical factors.
Gene from parents
genetic history
Passing on my disease to my children
provides awareness to family health issues
family history
Genes, diseases, learning about transferring diseases to offspring

Family
Bloodline
cancer that is inherited, family history, determine if one is suseptible to certain diseases, ancestry
family
I am concerned about the number of women in my family that may get cancer
What risk factors run in our family
The gene combinations between parents and child
screening for undiagnosed disease proclivities and family history of genetic disease processes
inheritant sickness
family member with a genetic disease
Inherited illness/disease
What risk factors run in our family
heriditate
Understanding what like family background and what similar and differences of who you are as an indivual.
dna genes hereditary
testing to see risk of inherited disease for self or children
info on how your genes will pass on to your kids
Finding out if I have something that I pass to my offspring
family background screening
genes, relative, DNA
family counseling

Counseling / Help/ Guidance
Counseling based on your genetics. What your genes say determines the type of lifestyle you may have. Diet, activity, etc.
To help you understand you risks for a variety of genetic conditions and to help guide your decisions related to any genetic testing you are considering
I imagine it's counseling people on things they are prone to genetically.
Discussing the pros and cons of trying to manipulate genetic outcomes
Counseling about being pregnant
Counseling about people who are wondering about their geneology
Counseling about questionable traits you get.
Looking at genes and counsel according to questions people have about themselves
helping person in genetic disorder
Trying to determine how to handle genetic disorders

Guidance from a medical practicioner regarding possible genetic disorders that could be aided or passed on
Being able to help yourself with little or no assistance
I think it has something to do with the individual helping you identify and understand your genetics
Helping people
I think of a team of healthcare members helping you decide on your plan for having children you may have known you carry a trait for some type of disorder. And also coundseling and assistance after the birth of a child and you discover they have an illness.
Counseling that has been past down to the there kids
I would think that genetic counseling could take place after genetic testing. I have heard that genetic testing happens first to know before hand about possibilities of double dominant genes/cancer gene, etc. So genetic counseling would be discussing the options before and after having children.
Help you with genetic counseling
I think about hereditary counseling
A new way to help people
researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
I'm not sure. I have never heard of this. The only thing that I gather is that it is probably a type of counseling where they inform you of your genetic make up.
counseling abnormality
Someone who evaluates and explains results from DNA tests
There has been genetic testing and a counselor will explain the implications
Genetically see what is in ones body and consultation to proceed best to have the best quality of life or minimize chance of getting a condition
Counseling on your genetic makeup (genes)
Helping patients know their genetics for diagnose and prognosis
Counsellor reviews condition/disease with person so the have an understanding of pros/cons of illness. Persons can use this information in helping them to make decisions about whether they wish to have children / or possible challenges they might face.
Testing and discussion about genetic conditions and predispositions
When I hear the term genetic counseling I think about the need for unbiased, accurate information relating to genetic testing during pregnancy, specifically relating to Down syndrome.
counseling about ancestry
Counseling dealing with genetics
helpful
counseling for people with genetic issues
genetic-based advise
counseling on the body
Counseling someone about their genetic makeup

Counceling people about theier anatomy and why their body worksdifferently from other peopl.
Helping talk about genetics
Genetic management based on breakdown to help improve quality of life.
Counseling to talk about your genetic makeup and the possible risks that may be associated with your genes
To council thu the issues that come with genetic disorders
counseling of info and dealing with genetic disorders
counseling regarding genetic history and ensuing management
Help with a genetic diagnosis
getting expert advice about your genetic history, possiblr recessive issues and whatnot
Help us to understand about genetic
Counseling about potential genetic defects for soon to be parents
counsel you on how your genes work
family counseling
genetic consulting

Testing
discussing with patient (not a doctor) getting tested for diseases or defects that are inherited genetically (ie: Angelina Jolie breast cancer) Testing older pregnant women to see if their unborn embryo has genetic defects trisomy 21 etc (chromosome abnormalities)
Blood sample (from patient), lab test, list of blood components DNA (chromozones), proteins/fats, councelor tells results to patient, ?
Honestly, not 100% sure. I imagine it involves testing a fetus for genetic abnormalities, possibly treating an abnormal embryo w/ molecular genetic techniques to improve the genetic abnormality
Speaking with people about potential risks to their health based upon genetic testing future science maybe able to minimize these risks advising people who want a baby on potential birth defects
To help you understand you risks for a variety of genetic conditions and to help guide your decisions related to any genetic testing you are considering
Genetic testing that you then recieve relevant information on what health risks or strengths could be forseen in your future. How to be ahead of those risks.
The first thing that comes to mind is a discussion about genetic profiling or screening. The idea of what would be desirable in producing offspring of a certain genetic composition.
Looking at genes and counsel according to questions people have about themselves
Determing which "bad" genes and carrier status
I think it has something to do with the individual helping you identify and understand your genetics
Genetic counseling is a medical service that examines DNA sequencing for possible congenital conditions. "GC" is on the cutting edge of medical exploration for the influence of certain genes for physical and mental conditions.

I would think that genetic counseling could take place after genetic testing. I have heard that genetic testing happens first to know before hand about possibilities of double dominant genes/cancer gene, etc. So genetic counseling would be discussing the options before and after having children.
Prescreening people for potential birth problems. Possibly determining a persons potential for success in certain treatment programs using drugs.
Testing someone's genes for abnormalities and to see if they will pass them along to offspring
Someone who evaluates and explains results from DNA tests
There has been genetic testing and a counselor will explain the implications
Genetically see what is in ones body and consultation to proceed best to have the best quality of life or minimize chance of getting a condition
Looking at the DNA, genes of an individual to get insights on potential problems that could affect them. I think it can also be used for when you're planning on having children & are worried about possible risks.
Testing and discussion about genetic conditions and predispositions
When I hear the term genetic counseling I think about the need for unbiased, accurate information relating to genetic testing during pregnancy, specifically relating to Down syndrome.
A Dietition of your genes - someone who maps your genes and creates a regimine to keep you as healthy as possible tailored to your own genes
testing to see if you carry genetic markers that can determine futre/current diagnoses
looking for problems
Look @ your genetics & see what it tell you about possible disease etc that you may have and how to cope or prepare yourself for it.
Screening your genetics to see what possible health issues can be determined
Have get genetically tested to determine what potential genetic issues may come up in one's life. To use the info to manage one's medical issues.
Determining what precursors are in your genetic bank to help determine future diseases.
You find out what genetic diseases you have
info on what test are available reliability and results and what results indicate
screening for undiagnosed disease proclivities and family history of genetic disease processes
I believe this genetic couseling involves looking at genes, and determining genetic disabilities by comparing DNA
doing DNA test to learn about potential genetic defects
generic screening of embryos
Gene testing, and discovering options what to do after
blood coultures
Testing to understand genes, especially in genetic disabilities
genetic mapping
testing to see risk of inherited disease for self or children
test for something wrong

sex

Lifestyle / Health / Preventions
Counseling based on your genetics. What your genes say determines the type of lifestyle you may have. Diet, activity, etc.
Maybe something that deals with you health and problem you may have that comes from your family
Checking out your DNA/RNA to see your geneology and see what you are prone to get. Like my mom had early Alzheimer's so I'm worried I'll get it too. Diabetes has a genetic factor as well as so many other illnesses. This way once you know you can adjust your lifestyle/diet/exercise etc and perhaps stave off some illnessess.
Speaking with people about potential risks to their health based upon genetic testing future science maybe able to minimize these risks advising people who want a baby on potential birth defects
My son has Loeys Dietz syndrome so, to me it means checking him for wellness to succeed in life. Checking bones, fingers, and body.
Genetic testing that you then recieve relevant information on what health risks or strengths could be forseen in your future. How to be ahead of those risks.
Family health patterns I think
Understanding one's genetic makeup (DNA) with regards to having children, possible future health issues, and taking proactive measures.
helping person in genetic disorder
information, prevention, high-risk
Something that deals with people's helth future
Using genetics to predict and prevent disease
I think of a team of healthcare members helping you decide on your plan for having children you may have known you carry a trait for some type of disorder. And also coundseling and assistance after the birth of a child and you discover they have an illness.
People want to know how healthy their family is
Trying to avoid having a child with significant disabilities. I read in the Jewish Journal about the effort to prevent annoyed marraiges that might amplify or result in genetic diseases through an annonymous database which I thought was terrific. I do geneology research & read around DNA as a research tool for discovering ancestors
To see if babies going to have problems that can be prevented before birth. To consider terminations if necessary. Possible problems in future.
Finding out what diseases or disorders a person made have inherited preventing this from occurring
Counseling does not go with genetic. hyped up, overpromising idea that will give people mostly useless information (although genetic markers are very important for health and drugs)
Health predictions based on family health expirience

Genetically see what is in ones body and consultation to proceed best to have the best quality of life or minimize chance of getting a condition
Sharing information about genetics with families and persons regarding impact of specific genetic diagnoses on life, health and medical factors.
research of health regarding my genetics
A Dietition of your genes - someone who maps your genes and creates a regimine to keep you as healthy as possible tailored to your own genes
finding out what health issues you have
provides awareness to family health issues
tryig to use their genetic makeup to improve their life
Understanding what you are inclined to get, based on your DNA. Preventing or preempting diseaseby seeing what you're inclined to have in the future.
Look @ your genetics & see what it tell you about possible disease etc that you may have and how to cope or prepare yourself for it.
Genetic management based on breakdown to help improve quality of life.
Screening your genetics to see what possible health issues can be determined
That's what I'm hoping to learn. Maybe telling me how genes affect my life.
Have get genetically tested to determine what potential genetic issues may come up in one's life. To use the info to manage one's medical issues.
possible cancer risks or health risks
counseling regarding genetic history and ensuing management
for people who are considering having kids to somehow prevent risk of types of disabilities.
Gene testing, and discovering options what to do after
health history
learning about how to deal with possible genetic issues either pre-birth ildren already born.or with ch

Prenatal / Birth Defects
birth defects and family defects in the genes
Determining high risk for genetic disorders in children
discussing with patient (not a doctor) getting tested for diseases or defects that are inherited genetically (ie: Angelina Jolie breast cancer) Testing older pregnant women to see if their unborn embryo has genetic defects trisomy 21 etc (chromosome abnormalities)
Honestly, not 100% sure. I imagine it involves testing a fetus for genetic abnormalities, possibly treating an abnormal embryo w/ molecular genetic techniques to improve the genetic abnormality
Speaking with people about potential risks to their health based upon genetic testing future science maybe able to minimize these risks advising people who want a baby on potential birth defects
Counseling about being pregnant
screening for birth defects

When you have a baby the doctors talk to you about what genes carry forward
birth defects
when your baby has a disability
Possible birth defects, rare disease, breast cancer
Knowledge of possibilities of birth defects when concieving a child especially with moms over 35 yo
I think of a team of healthcare members helping you decide on your plan for having children you may have known you carry a trait for some type of disorder. And also coundseling and assistance after the birth of a child and you discover they have an illness.
For pregnant women to see if fetus is healthy
To do with birth in their traits & personality as well besides the physical aspect
I would think that genetic counseling could take place after genetic testing. I have heard that genetic testing happens first to know before hand about possibilities of double dominant genes/cancer gene, etc. So genetic counseling would be discussing the options before and after having children.
To see if babies going to have problems that can be prevented before birth. To consider terminations if necessary. Possible problems in future.
Prescreening people for potential birth problems. Possibly determining a persons potential for success in certain treatment programs using drugs.
I think genetic counseling refers to examining the chances of a baby born with a genetic abnormality either before or after conception
fear of birth defects
Prenatal care
Checking on kids and how they will come out
When I hear the term genetic counseling I think about the need for unbiased, accurate information relating to genetic testing during pregnancy, specifically relating to Down syndrome.
about when you are born
done during pregnancy
Pregnancy over age 35 or at rick
someone having baby & need to know
Potential problems with a pregnancy
birth defects
talking to couples that have a disabled child, if they choose to have another child what the probability of the second child inheriting the disease or disability as well
child birthing couneling
Counseling about potential genetic defects for soon to be parents
Birth defects
learning about how to deal with possible genetic issues either pre-birth ildren already born.or with ch
tell me about what my child may be like and how to develop strengths vs weaknesses
prenatal screening

Fetus well being

Preconception
Speaking with people about potential risks to their health based upon genetic testing future science maybe able to minimize these risks advising people who want a baby on potential birth defects
Being aware of any deleterious mutations you might carry, so you know what diseases you (or your potential offspring) may be at risk for.
The first thing that comes to mind is a discussion about genetic profiling or screening. The idea of what would be desirable in producing offspring of a certain genetic composition.
Understanding options that are afforded to you when planning to have a child or if there is a history of genetic issues or abnormalities in your family.
Understanding one's genetic makeup (DNA) with regards to having children, possible future health issues, and taking proactive measures.
Choosing traits for a child
Trying to get pregnant and choosing the sex of the baby.
Meeting with a doctor before having a baby to discuss risks or options to alter the babies genetics
This is who you should have babies with
Making people aware of the genes and traits they have in their dna for future reference ie having children
Risk assessment when preparing to have kids
finding out risks of having a child with a particular genetic problem
Your genetics and the history of whats in your genes to assess your personal future and/or children
Knowledge of possibilities of birth defects when concieving a child especially with moms over 35 yo
Changing DNA, modify parents genetic to get the baby they designed
Something in the genes, choosing the genes for procreation
I think of a team of healthcare members helping you decide on your plan for having children you may have known you carry a trait for some type of disorder. And also coundseling and assistance after the birth of a child and you discover they have an illness.
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I would think that genetic counseling could take place after genetic testing. I have heard that genetic testing happens first to know before hand about possibilities of double dominant genes/cancer gene, etc. So genetic counseling would be discussing the options before and after having children.
Checking for the possibility of hereditary illnesses being passed on in a family. Choosing babies or sex or other qualities.
I think genetic counseling refers to examining the chances of a baby born with a genetic abnormality either before or after conception

researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
Testing someone's genes for abnormalities and to see if they will pass them along to offspring
Screening potential parents to see if they have hereditary conditions that they would pass on to their kids.
To find out if I have a genetic problem that may be passed on to my future generation
Looking at the DNA, genes of an individual to get insights on potential problems that could affect them. I think it can also be used for when you're planning on having children & are worried about possible risks.
Counsellor reviews condition/disease with person so the have an understanding of pros/cons of illness. Persons can use this information in helping them to make decisions about whether they wish to have children / or possible challenges they might face.
reproductive planning
for people who are considering having kids to somehow prevent risk of types of disabilities.
Learn about gene involvement in reproduction
generic screening of embryos
talking to couples that have a disabled child, if they choose to have another child what the probability of the second child inheriting the disease or disability as well
testing to see risk of inherited disease for self or children
it canbe hard to have a baby
learning about how to deal with possible genetic issues either pre-birth ildren already born.or with ch
Predetermining sex and physical attributes of children

Lab/ Research Project
Blood sample (from patient), lab test, list of blood components DNA (chromozones), proteins/fats, councelor tells results to patient, ?
Human Genome Project
Lab
Gene study
Something that studies what are the genes that composes a human body
Stem cell repair
Genetic counseling is a medical service that examines DNA sequencing for possible congenital conditions. "GC" is on the cutting edge of medical exploration for the influence of certain genes for physical and mental conditions.
Trying to avoid having a child with significant disabilities. I read in the Jewish Journal about the effort to prevent annoyed marraiges that might amplify or result in genetic diseases through an annonymous database which I thought was terrific. I do geneology research & read around DNA as a research tool for discovering ancestors
decoding human genome
researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
Study and evaluation of genetic conditions and anomalies.
Studying DNA
research of health regarding my genetics
stem cell research super soldier
stem cell science
Stem cells
genetic mapping

Genealogy
Checking out your DNA/RNA to see your geneology and see what you are prone to get. Like my mom had early Alzheimer's so I'm worried I'll get it too. Diabetes has a genetic factor as well as so many other illnesses. This way once you know you can adjust your lifestyle/diet/exercise etc and perhaps stave off some illnessess.
Determining your family history
Counseling about people who are wondering about their geneology
Geneology and what my family is passing down
Trying to avoid having a child with significant disabilities. I read in the Jewish Journal about the effort to prevent annoyed marraiges that might amplify or result in genetic diseases through an annonymous database which I thought was terrific. I do geneology research & read around DNA as a research tool for discovering ancestors
family background

Trying to figure out where we came from
Finding out the past bloodlines
Learning what ethnicity and any conditions that you may have
counseling about ancestry
Your genetic background
cancer that is inherited, family history, determine if one is suseptible to certain diseases, ancestry
family background screening
where r you come from

Desirable traits/ Eugenics
The first thing that comes to mind is a discussion about genetic profiling or screening. The idea of what would be desirable in producing offspring of a certain genetic composition.
Choosing traits for a child
Trying to get pregnant and choosing the sex of the baby.
This is who you should have babies with
Eugenics
A little scary because you can't change it, think Hitler
Changing DNA, modify parents genetic to get the baby they designed
Checking for the possibility of hereditary illnesses being passed on in a family. Choosing babies or sex or other qualities.
designer babies
stem cell research super soldier
designer babies
Predetermining sex and physical attributes of children

Alter Genetics
Honestly, not 100% sure. I imagine it involves testing a fetus for genetic abnormalities, possibly treating an abnormal embryo w/ molecular genetic techniques to improve the genetic abnormality
Discussing the pros and cons of trying to manipulate genetic outcomes
Meeting with a doctor before having a baby to discuss risks or options to alter the babies genetics
Changing DNA, modify parents genetic to get the baby they designed
Stem cell repair
Something in the genes, choosing the genes for procreation
Modified dna
selective traits

Cancer
discussing with patient (not a doctor) getting tested for diseases or defects that are inherited genetically (ie: Angelina Jolie breast cancer) Testing older pregnant women to see if their unborn embryo has genetic defects trisomy 21 etc (chromosome abnormalities)
Cancers screening, disease family hustory
Possible birth defects, rare disease, breast cancer
I would think that genetic counseling could take place after genetic testing. I have heard that genetic testing happens first to know before hand about possibilities of double dominant genes/cancer gene, etc. So genetic counseling would be discussing the options before and after having children.
cancer that is inherited, family history, determine if one is suseptible to certain diseases, ancestry
possible cancer risks or health risks
I am concerned about the number of women in my family that may get cancer

Adult Onset
Understanding one's genetic makeup (DNA) with regards to having children, possible future health issues, and taking proactive measures.
Information about unavoidable genetic conditions
Your genetics and the history of whats in your genes to assess your personal future and/or children
Need more research, should not affect insurance entry, interested specifically in "Alzheimer's" predictability
Genetically see what is in ones body and consultation to proceed best to have the best quality of life or minimize chance of getting a condition
testing to see if you carry genetic markers that can determine futre/current diagnoses
Look @ your genetics & see what it tell you about possible disease etc that you may have and how to cope or prepare yourself for it.

Pediatric
My son has Loeys Dietz syndrome so, to me it means checking him for wellness to succeed in life. Checking bones, fingers, and body.
I think of a team of healthcare members helping you decide on your plan for having children you may have known you carry a trait for some type of disorder. And also coundseling and assistance after the birth of a child and you discover they have an illness.
I would think that genetic counseling could take place after genetic testing. I have heard that genetic testing happens first to know before hand about possibilities of double dominant genes/cancer gene, etc. So genetic counseling would be discussing the options before and after having children.
My sons medical issues
learning about how to deal with possible genetic issues either pre-birth ildren already born.or with ch

Psychiatric/ Mental Illness
Mental Health problems
How mental disorders come from one parent or the other
Genetic counseling is a medical service that examines DNA sequencing for possible congenital conditions. "GC" is on the cutting edge of medical exploration for the influence of certain genes for physical and mental conditions.
CHANGE BEHAVIOR FOR BETTER

Ethnic prevalence
Ashkenazi CP
Trying to avoid having a child with significant disabilities. I read in the Jewish Journal about the effort to prevent annoyed marraiges that might amplify or result in genetic diseases through an annonymous database which I thought was terrific. I do geneology research & read around DNA as a research tool for discovering ancestors

Other
jurassic park
Not the original
Not the original brand
Learn something new
Help you with genetic counseling
Prescreening people for potential birth problems. Possibly determining a persons potential for success in certain treatment programs using drugs.
Genetic counseling is copy or made as same a brand name item
Commercial sales of the service to ill informed consumers
Counseling does not go with genetic. hyped up, overpromising idea that will give people mostly useless information (although genetic markers are very important for health and drugs)
bad news
Helping people Come to grips with who they are
misinformation
Why does my phone not respond when I want it to?
different
awareness
confusing
the unknown
fantastic + educational
sex

No idea
genetic what?
don't know about it
?
?
?
?
I have never heard of it before
Never heard of genetic counseling
What is genetic
Dont know
what is it?

"What is the first thing that comes to mind when you hear the term 'genetic counseling'?"

Risk Assessment
Help you find out what health problems you may suffer in the present or future
blood tests performed by Dr. go over risks of individual based on age, and/or family history of illnesses/diseases.
Look for indicators of future issues that may arise due to genetic factors
Speak with people on how their genetic make up can affect health or babies
Asses your risk for conditions based on your ethnicity, pedigree, and other factors
Counsel people on future things they may encounter due to their personal genetics
Advice about health concerns based on genes
They probably counsel people on their health history and how it may affect them to getting certain diseases based on their genetic makeup.
I think they help test and determine genetic maladies on predisposition to them
Risk stratify, and counsel people on whether testing is needed, why you might, also anticipate results and actions before testing
Probably assess clientele for potential risks and conditions that any offspring they have might be subject to
Inform parents-to-be about risks to their unborn children of having a genetic disease
Genetic sequencing, followed by discussions about genetic variability and their possibility of passing along specific genes.
identify specific gene/traits at risk for specific diseases and cancer.
Help people determine likelihood of transferring disease from and to family
genetic counselors interview families where there might be risk for genetic medical condition or in which a person with a genetic disease might have already been born. by taking careful history and blood work they might determine the chance that a child will be born with a particular condition. They might also interview people who have a cluster of symptoms and who want to know if they have a syndrome

Work with individuals to determine genetic sequences that would help predict and prevent disease
Work with people to determine risks for disease
Discuss risk of genetic disorders/stats, discuss severity of conditions, educate people, support people to make their own decisions
Counsel, educate, determine genetic risks
Inform family of possibilities of offspring are affected and trying to find out ways to prepare
Tell patients their risks
History, analysis, risk determination, genetic testing
Informs patients of their risks to diseases
Try to predict the odds of birth defects
Help deal with issues in future
Future possibilities or potential probabilities
They would let know your risk to future generation if you got married an have children
Advise people of probability of passing on certain conditions related to health
Share impact of the genetics risk with pregnancies and provide support and resources for families dealing with genetic concerns
assess risks and predispositions
I was referred to a genetic counselor while pregnant to help me assess my unborn daughter's health.
Help people review results of DNA testing so they know what diseases/conditions either themselves or their unborn babies may have.
Look into depth at your genes to see if you are predisposed to certain diseases or in other words what you may be more suseptable to in the future. It helps you be able to change your lifestyle so you can lower your chances of acquiring the disease.
Take information from genetic testing and talk with patients about their options and give information about diseases or potential diseases/future problems that may arise based on information collected from their genes.
Figure out your genes and then determine what risks you may have genetically.
Look at peoples family health history etc and see what the person may have. Look at the person's health and see what possible health risks/disease the person may have.
Counsel people in genetics, ie, people who may be at risk for having a child with special needs.

Share what family may pass through the next generation.
Counsel individuals regarding potential health concerns for their future based on their genetic makeup. Also consult on most efficient nutrition possibilities based on genetic makeup.
Inform you about risk factors associated with your family line
help those with genetic disease or family history understand the risks and processes of those diseases and being supportive of those diagnosed
can review certain RNA strands and determine if you have a genetic propensity to certain disorders
Inform you about risk factors associated with your family line
Counsel couples on the pobability of having a child w/ disabilities
Genetic counselors explain what could be the possible genetic disorders for your future children as well as possible diseases that your body would be weak against.
they determine what hereditary traits good or bad you have been passed down , likeliness of diseases, etc
help people understand genetic test results, risks, and to make decisions re: genetic risk
Genetic counselors map a family tree that lists any potential health issues/concerns and the create a 'map' of what may affect your child. In addition, they offer various types of testing to look for chromosonal deficiencies.
I think it's a good benefits on how to get information on possible outcomes. I think having as much information on anything is always good.
Weigh the risks involved due to age, race, genetic background
After having genetic study tests done a counselor would given risk factors r/t any positive test results.
They help couples determine what health issues their future children may have.
they talks about the difference in behaviors, what can and can not tranfer between genetics
They provide information about how your genetic background can have an affect on the next generation
educate people about the effects of genes being passed down & the possibility of them being expressed in future generations
They help assess the risks and benifits of possible mutations with one that is attempting to conseve

Lab Work/ Evaluate/ Analyze Genetics Of Patient

Study genes to help clients with a problem
testing, discussion
They take your family history and check your DNA, etc.
Analyze and interpret genetic data from patients could be mitochondrial or other
DNA sequencing/screening for mutations/etc and counseling to patients about the findings,
More focussed health counseling based on gene testing
Counsel people on maybe whether or not they should procreate based on genetic markers and family history.
Interpret and evaluate tests done on an individuals dna
Study components of a gene
Genetic sequencing, followed by discussions about genetic variability and their possibility of passing along specific genes.
Work with individuals to determine genetic sequences that would help predict and prevent disease
Take blood, test, research
Study genetic testing results & discuss results with the person
History, analysis, risk determination, genetic testing
A lot of lab work
Evaluate for genetic conditions, counsel patients regarding the affect of their genetic conditions on day-to-day life.
Test people's genes for abnormalities
Evaluate a person's Genetics.
Interpret genetic findings for patients such that appropriate life choices could be made (if there are choices) (impact on partnering)
Someone who evaluates and discuss DNA test results and options if any
Analyze genes and produce theories about it
draw blood, look at indicator genes advise them on preventive procedures etc.
I don't know. They look at your genetic structure/markers and tell you a possibility of whats affecting you and possible treatments
Do genetic testing to determine whether or not you have diseases
Maps your genes and measures what your body needs to function at its best performance
Look into depth at your genes to see if you are predisposed to certain diseases or in other words what you may be more suseptable to in the future. It helps you be able to change your lifestyle so you can lower your chances of acquiring the disease.

They likely run blood test and DNA test and then counsel you on the results of the DNA or blood test that they ran on you.
Read and understand strands of DNA and know what strengths and weakensses the body/mind has
They identify defective genes according to current knowledge and try to identify treatments.
Take information from genetic testing and talk with patients about their options and give information about diseases or potential diseases/future problems that may arise based on information collected from their genes.
Look at your genes and the genes of your partner to assist with families.
Figure out your genes and then determine what risks you may have genetically.
They examine a persons genetic make up and help understand if there are any genetic components to any medical issues.
examine peoples genetic codes and educate people
Genetic testing & research to determine relatability of genetics to reproduction?
DNA testing
Look at genes and determine DNA comparisons for diagnosing disabilities.
i think they do dna tests on people and then determine what expressed conditions might be caused from genetic origin
Analyze dna information and advise patients of possible treatments
can review certain RNA strands and determine if you have a genetic propensity to certain disorders
Review genetics testing and analyze data to better understand the genetic make up of a person
study genes
i think they study genes and tell people about it or help people that are having genetic probles
determine genes of unborn child
Pre-natal screening and post birth DNA checking for family illnesses, traits, concerns, etc.
study dna to determine weakness
study genetics and educate the public

Counseling/ Emotional Support
advise and counsel
They help to see what kind of activities are appropriate for my child & and any other questions I might have & also mental support.

More focussed health counseling based on gene testing
Counsel people on future things they may encounter due to their personal genetics
Counsel people on maybe whether or not they should procreate based on genetic markers and family history.
Meet with you to discuss options regarding genetic abnormalities or concerns you may have in this area.
Talking and supporting people with problems in that area, pregnancy helping
They probably counsel people on their health history and how it may affect them to getting certain diseases based on their genetic makeup.
Risk stratify, and counsel people on whether testing is needed, why you might, also anticipate results and actions before testing
Counsel!
Discuss risk of genetic disorders/stats, discuss severity of conditions, educate people, support people to make their own decisions
Counsel, educate, determine genetic risks
Consult patients on help, referring help
Counsel on preventive issues
Counsel you past down from parents
The work with people who may have rare diseases or conditions on how to cope with their things, medical doctors, etc who know how to cope with these things.
council
Help you deal with developmental disabilities you're born with.
Evaluate for genetic conditions, counsel patients regarding the affect of their genetic conditions on day-to-day life.
Give counseling about genes
They counsel people with genetic disabilities, not sure
Counsel people on their conditions
Help people accept their genetic limitation
Assist with patients either recently diagnosed and coping and outcomes of the diagnosis or to help them through the process of of finding their diagnosis.
Share impact of the genetics risk with pregnancies and provide support and resources for families dealing with genetic concerns
educate people about genetics, provide support and feedback
they counsel people who have a predisposition for a particular genetic based disease
psycholocial support for individuals with genetic issues

counsel families on health disorders and traits that are inherited due to the family gene pool
Counsel people on their genetic makeup
I think genetic counselors counsels people about the human anatomy and the differences. They might also help people cope with those differences.
Help family and people to deal with genetic disorders
Counsel people in genetics, ie, people who may be at risk for having a child with special needs.
Counsel individuals regarding potential health concerns for their future based on their genetic makeup. Also consult on most efficient nutrition possibilities based on genetic makeup.
Helps people come to grips with who they are because of their genetics
Give info and guidance
Determine how DNA and genetics are altered and council people on it.
help those with genetic disease or family history understand the risks and processes of those diseases and being supportive of those diagnosed
Counsel couples on the pobability of having a child w/ disabilities
Helping to understand how families have with differences and similarities to help if there are conflicts to know how to adapt and resolve conflits with people that have strugles with how their genetic background is like.
Counsel parents on the benefit of knowing what genes they pass on to their kids...like if there are certain illnesses and diseases that may be passed on.
counseling based on your genetics
councel and educate
counsel to improve development

Preconception
Speak with people on how their genetic make up can affect health or babies
Counsel people on maybe whether or not they should procreate based on genetic markers and family history.
Prepare couples to have better kids
Determine what genes are carried forward when you have babies.
Talking and supporting people with problems in that area, pregnancy helping
Help people make good babies
Probably assess clientele for potential risks and conditions that any offspring they have might be subject to

genetic counselors interview families where there might be risk for genetic medical condition or in which a person with a genetic disease might have already been born. by taking careful history and blood work they might determine the chance that a child will be born with a particular condition. They might also interview people who have a cluster of symptoms and who want to know if they have a syndrome
help inform people about their choices for having healthy babies, help determine choices regarding disease prevention
advise prospective parents
Helping people getting the right genders or genetic upnake of a child
I think that today with DNA & other medical testing they attempt to give information to couples who want children & also predict disease before it happens so people can try and take a preventative approach.
Determine what a person's child could inherit
Help families decide the chances for healthy children or help couples "design" babies they want
researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
Interpret genetic findings for patients such that appropriate life choices could be made (if there are choices) (impact on partnering)
They would let know your risk to future generation if you got married an have children
Determine the genetics of two individuals if they are compatible to produce a high quality offspring.
Look at your genes and the genes of your partner to assist with families.
Counsel people in genetics, ie, people who may be at risk for having a child with special needs.
Tell you weather or not you and your spouse should procreate
Assist w/ people who need to know what the genes may possibly carry to try to help w/ the future that babies may carry or develop regarding recessive genes
Talk to people who may have family histories of diseases before they have childern
Look at genes of two prospective parents before they have kids
Genetic testing & research to determine relatability of genetics to reproduction?

Talk to people with hereditary conditions about reproduction/concerns with passing on hereditary conditions, talk to expecting parents who have learned theor child may have inherited such a condition
Help parents select genetic traits of their babies
Counsel couples on the pobability of having a child w/ disabilities
perhaps work with couples or individuals with new ways to deal with having childern
Genetic counselors explain what could be the possible genetic disorders for your future children as well as possible diseases that your body would be weak against.
Counsel parents on the benefit of knowing what genes they pass on to their kids...like if there are certain illnesses and diseases that may be passed on.
They help couples determine what health issues their future children may have.
Assist people who want to have children to determine if they carry any genes that will adversely affect or cause a problem for their children.
They provide information about how your genetic background can have an affect on the next generation
They help assess the risks and benifits of possible mutations with one that is attempting to conseve

Explain Results/ Diagnosis/ Post Test Counseling
take results of tests they conducted and review results with you, answer questions on possible things passed in genes
Blood sample (from patient) Lab test List of blood components -DNA (chromozones), proteins/fats Councelor tells results to patient ?
DNA sequencing/screening for mutations/etc and counseling to patients about the findings,
Work through the process and results with patients
Helps people understand why/what/to who/something happen to them or other family members.
Interpret and evaluate tests done on an individuals dna
Genetic sequencing, followed by discussions about genetic variability and their possibility of passing along specific genes.

Discuss risk of genetic disorders/stats, discuss severity of conditions, educate people, support people to make their own decisions
Genetic counselors advise patients about the results of a DNA sequencing procedure which may indicate a future health condition.
Study genetic testing results & discuss results with the person
Someone who evaluates and discuss DNA test results and options if any
Counsel people on their conditions
They give information about what genetic testing will do and what a test means
Analyze genes and produce theories about it
Assist with patients either recently diagnosed and coping and outcomes of the diagnosis or to help them through the process of of finding their diagnosis.
Have studied the different conditions that result from differences/ abnormalities I the genetic codes. Then, able to use that information to explain to persons/families whose health/illnesses are a result of those genetic changes.
advise you on a course of action once you find out there is a genetic cause for an illness or disability
Help people review results of DNA testing so they know what diseases/conditions either themselves or their unborn babies may have.
They likely run blood test and DNA test and then counsel you on the results of the DNA or blood test that they ran on you.
discuss results of genetic tsting
Take information from genetic testing and talk with patients about their options and give information about diseases or potential diseases/future problems that may arise based on information collected from their genes.
Work with doctors to help patients understand the genetic issues if any and provide assistance or recommendation of services and treatment based on findings.
Advise you in results and what they mean
Tell you what genetic diseases you have.
What the test are, how they are administered and what the results indicate. Also long term planning.
tell people the findings of their genetic screening tests and inform them of options
give information based on analysis of test
Answer questions provide services or provide information regarding awareness for the disorder also help you through things regarding the disorder
Help patients with there genetic diagnosis

help those with genetic disease or family history understand the risks and processes of those diseases and being supportive of those diagnosed
They help you understand the results or potential results of what a genetic test may yield.
Help understand about your genetic disease
help people understand genetic test results, risks, and to make decisions re: genetic risk
After having genetic study tests done a counselor would given risk factors r/t any positive test results.
they assist familes with any diagnoses type of abnormalites. If it was genentic or not

Teach About Genetics
Teach you about your body and what makes you feel the way you do.
It deals with people's genetics, Take blood samples from people that volunteered & teach about information about geneticsch about information
Inform/teach/about genetics
Consult with people on how their body works and cells
Discuss risk of genetic disorders/stats, discuss severity of conditions, educate people, support people to make their own decisions
Counsel, educate, determine genetic risks
Help people understand their genetics
Give information about genes
Help provide teaching regarding genetic
Talk about genetics
educate people about genetics, provide support and feedback
To teach you about your genetic genes.
advise and make a person aware of there genetics for better awareness
teach
I think genetic counselors counsels people about the human anatomy and the differences. They might also help people cope with those differences.
examine peoples genetic codes and educate people
Explain ins & outs of genetics- individually
talk about genetic disies
Answer questions provide services or provide information regarding awareness for the disorder also help you through things regarding the disorder

Give info and guidance
Educate
help others understand genes
they talks about the difference in behaviors, what can and can not tranfer between genetics
i think they study genes and tell people about it or help people that are having genetic probles
councel and educate
study genetics and educate the public
educate people about the effects of genes being passed down & the possibility of them being expressed in future generations
give info about genetics
Educate people about fetus we'll being

Inheritance/ Hereditary
take results of tests they conducted and review results with you, answer questions on possible things passed in genes
Your genes from a parent
Helps people understand why/what/to who/something happen to them or other family members.
Determine what genes are carried forward when you have babies.
Helps you explore what disorder came from where and how to change/better it for you and your future generations.
Genetic sequencing, followed by discussions about genetic variability and their possibility of passing along specific genes.
Help people determine likelihood of transferring disease from and to family
Counsel you past down from parents
Check to see if there are any diseases, that are hereditary
Determine what a person's child could inherit
Give advice about hereditary disabilities.
Determine potential family physical inprints that you have inherited
They would let know your risk to future generation if you got married an have children
Advise people of probability of passing on certain conditions related to health
counsel families on health disorders and traits that are inherited due to the family gene pool

Discuss with parents/patients what inherited medical conditions exist in the family
Share what family may pass through the next generation.
No thoughts really. My daughter has breast cancer and I am wondering if it is familial.
Test for study family abnormalitlies
Study anything that has to do with genes within a family that can be found in families
Maybe something to do with dna or hereditary diseases
Talk to people with hereditary conditions about reproduction/concerns with passing on hereditary conditions, talk to expecting parents who have learned theor child may have inherited such a condition
they determine what hereditary traits good or bad you have been passed down , likeliness of diseases, etc
Counsel parents on the benefit of knowing what genes they pass on to their kids...like if there are certain illnesses and diseases that may be passed on.
they talks about the difference in behaviors, what can and can not tranfer between genetics
family
They provide information about how your genetic background can have an affect on the next generation
educate people about the effects of genes being passed down & the possibility of them being expressed in future generations
Describe how genes are split between parents.

Look At Family History
blood tests performed by Dr. go over risks of individual based on age, and/or family history of illnesses/diseases.
They take your family history and check your DNA, etc.
Asses your risk for conditions based on your ethnicity, pedigree, and other factors
Counsel people on maybe whether or not they should procreate based on genetic markers and family history.
Study the health patterns of family history
Finds ones Genetic History, health-wise and cultural backgrounds

genetic counselors interview families where there might be risk for genetic medical condition or in which a person with a genetic disease might have already been born. by taking careful history and blood work they might determine the chance that a child will be born with a particular condition. They might also interview people who have a cluster of symptoms and who want to know if they have a syndrome
Gives a pedigree and asks questions regarding the family and pregnancy
Study the health backgrounds of the patient via medical hx of patient and their families
They do research on different illnesses, and see if they can be prevented, or areas where illnesses are more prevalant & Family history
Look at family history and see what kind of problems you have
History, analysis, risk determination, genetic testing
Consider the ethics, risks, and benefits of sharing information based upon DNA analysis, including family history for expression
Discuss with parents/patients what inherited medical conditions exist in the family
Look at peoples family health history etc and see what the person may have. Look at the person's health and see what possible health risks/disease the person may have.
Theydrawblood theycheck yourfamily bloodlines
Talking about family history
Help connect family history
Talk to people who may have family histories of diseases before they have childern
Inform you about risk factors associated with your family line
help those with genetic disease or family history understand the risks and processes of those diseases and being supportive of those diagnosed
Inform you about risk factors associated with your family line
Genetic counselors map a family tree that lists any potential health issues/concerns and the create a 'map' of what may affect your child. In addition, they offer various types of testing to look for chromosonal deficiencies.
analysis on the structure of your family and the health history from age to as far back as you can go, to include job history of family members, environment, siblings, etc...

see what kind of gene personalities are in your family

Prenatal
tests expectant parents, diagnosis
Counsel parents who might have babies and genetic xy diseases
Determine what genes are carried forward when you have babies.
Talking and supporting people with problems in that area, pregnancy helping
Alter a baby's genetics
Inform parents-to-be about risks to their unborn children of having a genetic disease
genetic counselors interview families where there might be risk for genetic medical condition or in which a person with a genetic disease might have already been born. by taking careful history and blood work they might determine the chance that a child will be born with a particular condition. They might also interview people who have a cluster of symptoms and who want to know if they have a syndrome
Gives a pedigree and asks questions regarding the family and pregnancy
Inform family of possibilities of offspring are affected and trying to find out ways to prepare
They study genetic disorders in the birth- like Autism & Down syndrome etc
Try to predict the odds of birth defects
Share impact of the genetics risk with pregnancies and provide support and resources for families dealing with genetic concerns
I was referred to a genetic counselor while pregnant to help me assess my unborn daughter's health.
Help people review results of DNA testing so they know what diseases/conditions either themselves or their unborn babies may have.
They give information on possible birth defects.
Talk to people with hereditary conditions about reproduction/concerns with passing on hereditary conditions, talk to expecting parents who have learned theor child may have inherited such a condition
Genetic counselors map a family tree that lists any potential health issues/concerns and the create a 'map' of what may affect your child. In addition, they offer various types of testing to look for chromosonal deficiencies.
advise about genetic choices before baby is born

Counsel parents on the benefit of knowing what genes they pass on to their kids...like if there are certain illnesses and diseases that may be passed on.
determine genes of unborn child
study human genes, and help with gender baby precdiction.
Pre-natal screening and post birth DNA checking for family illnesses, traits, concerns, etc.
Educate people about fetus we'll being

Personal Genomics/ Health Counseling
Advice about health concerns based on genes
Advice people in the implications of their genetic makeup
assuming trying to improve ones health by understanding ones genetics
Consult best action to take to proceed to be the best you can be
Counsel individuals regarding potential health concerns for their future based on their genetic makeup. Also consult on most efficient nutrition possibilities based on genetic makeup.
Counsel people on their genetic makeup
Develop genetic "profiles" and advise clients on health management.
Figure out your genes and then determine what risks you may have genetically.
guide us through better health based on my genetic makeup
Help people understand their genetics
Help you identify your potential
Look into depth at your genes to see if you are predisposed to certain diseases or in other words what you may be more suseptable to in the future. It helps you be able to change your lifestyle so you can lower your chances of acquiring the disease.
Maps your genes and measures what your body needs to function at its best performance
More focussed health counseling based on gene testing
Read and understand strands of DNA and know what strengths and weakensses the body/mind has
Review genetics testing and analyze data to better understand the genetic make up of a person
study dna to determine weakness
study of genetic disease and maybe how you can improve our health by undertanding them

Take information from genetic testing and talk with patients about their options and give information about diseases or potential diseases/future problems that may arise based on information collected from their genes.
talks about their clients genes
They probably counsel people on their health history and how it may affect them to getting certain diseases based on their genetic makeup.
Unclear matching people with genetics options
Work with individuals to determine genetic sequences that would help predict and prevent disease

Explains Treatment Options/ Management Strategies
Advise options
advise you on a course of action once you find out there is a genetic cause for an illness or disability
Analyze dna information and advise patients of possible treatments
Answer questions provide services or provide information regarding awareness for the disorder also help you through things regarding the disorder
Evaluate for genetic conditions, counsel patients regarding the affect of their genetic conditions on day-to-day life.
help people understand genetic test results, risks, and to make decisions re: genetic risk
Helps you explore what disorder came from where and how to change/better it for you and your future generations.
I don't know. They look at your genetic structure/markers and tell you a possibility of whats affecting you and possible treatments
i would imagine they meet with parents and/or children to discuss how to deal with particular diseases/issues/characteristics that are a result of genetic conditions
Inform family of possibilities of offspring are affected and trying to find out ways to prepare
Look at clients and see if they're dealing with genetic illnesses properly
Meet with you to discuss options regarding genetic abnormalities or concerns you may have in this area.
Possibly discuss different options for parents who's children have genetic diseases.
Some kind of treatment for some kind diseases
Someone who evaluates and discuss DNA test results and options if any

Take information from genetic testing and talk with patients about their options and give information about diseases or potential diseases/future problems that may arise based on information collected from their genes.
tell people the findings of their genetic screening tests and inform them of options
They help to see what kind of activities are appropriate for my child & and any other questions I might have & also mental support.
They identify defective genes according to current knowledge and try to identify treatments.
Unclear matching people with genetics options
What the test are, how they are administered and what the results indicate. Also long term planning.
Work with doctors to help patients understand the genetic issues if any and provide assistance or recommendation of services and treatment based on findings.

Find Diagnosis
tests expectant parents, diagnosis
Helps people understand why/what/to who/something happen to them or other family members.
I think they help test and determine genetic maladies on predisposition to them
genetic counselors interview families where there might be risk for genetic medical condition or in which a person with a genetic disease might have already been born. by taking careful history and blood work they might determine the chance that a child will be born with a particular condition. They might also interview people who have a cluster of symptoms and who want to know if they have a syndrome
researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
I don't know. They look at your genetic structure/markers and tell you a possibility of whats affecting you and possible treatments
Assist with patients either recently diagnosed and coping and outcomes of the diagnosis or to help them through the process of of finding their diagnosis.
Do genetic testing to determine whether or not you have diseases
find out health issues

Relate genetics to ones well being and diagnosis.
Look at peoples family health history etc and see what the person may have. Look at the person's health and see what possible health risks/disease the person may have.
They examine a persons genetic make up and help understand if there are any genetic components to any medical issues.
Tell you what genetic diseases you have.
Help you find hralth issues
Help patients with there genetic diagnosis
i think they do dna tests on people and then determine what expressed conditions might be caused from genetic origin
help find your root cause of the problem
help to explain different problems you or your child might have

Surveillance/ Prevention
Helps you explore what disorder came from where and how to change/better it for you and your future generations.
Help you plan your future health
help inform people about their choices for having healthy babies, help determine choices regarding disease prevention
Work with individuals to determine genetic sequences that would help predict and prevent disease
Counsel on preventive issues
They do research on different illnesses, and see if they can be prevented, or areas where illnesses are more prevalant & Family history
I think that today with DNA & other medical testing they attempt to give information to couples who want children & also predict disease before it happens so people can try and take a preventative approach.
researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
Help deal with issues in future
draw blood, look at indicator genes advise them on preventive procedures etc.
advise you on a course of action once you find out there is a genetic cause for an illness or disability

Look into depth at your genes to see if you are predisposed to certain diseases or in other words what you may be more suseptable to in the future. It helps you be able to change your lifestyle so you can lower your chances of acquiring the disease.
help find problems before they happen
Take information from genetic testing and talk with patients about their options and give information about diseases or potential diseases/future problems that may arise based on information collected from their genes.
What the test are, how they are administered and what the results indicate. Also long term planning.
Answer questions provide services or provide information regarding awareness for the disorder also help you through things regarding the disorder
talk about certain possible was of reducing mutations? not too sure :)

Clinical Trials/ Research/ Rare Disease
Take blood, test, research
Talk and do research
research
research
They do research on different illnesses, and see if they can be prevented, or areas where illnesses are more prevalant & Family history
They study genetic disorders in the birth- like Autism & Down syndrome etc
The work with people who may have rare diseases or conditions on how to cope with their things, medical doctors, etc who know how to cope with these things.
Conduct research and discover peoples medical history.
researching and diagnosing rare and genetic diseases and providing info when people with rare diseases want to have children.
They identify defective genes according to current knowledge and try to identify treatments.
Study medical conditions that could be genetically caused
Genetic testing & research to determine relatability of genetics to reproduction?
Test for study family abnormalitlies
Research to benefit the human condition
Study genetic patterns for known issues.
study human genes, and help with gender baby precdiction.
study of genetic disease and maybe how you can improve our health by undertanding them

Alter DNA/ Designer Babies
alter dna to make super humans
Discuss ways to update genetics
Prepare couples to have better kids
Assist people with choices regarding genetic engineering
Counseling by touching genetics
Alter a baby's genetics
Help people make good babies
Helping people getting the right genders or genetic upnake of a child
Help families decide the chances for healthy children or help couples "design" babies they want
fix gene
Determine the genetics of two individuals if they are compatible to produce a high quality offspring.
Determine how DNA and genetics are altered and council people on it.
Help parents select genetic traits of their babies
talk about certain possible was of reducing mutations? not too sure :)
Talk to you about benefits and possibilities of genetic modifications

Advise People What To Do
advise and counsel
Counsel people on maybe whether or not they should procreate based on genetic markers and family history.
Advice about health concerns based on genes
Advice people in the implications of their genetic makeup
advise prospective parents
Give advice about hereditary disabilities.
Interpret genetic findings for patients such that appropriate life choices could be made (if there are choices) (impact on partnering)
Advise people of probability of passing on certain conditions related to health
advise you on a course of action once you find out there is a genetic cause for an illness or disability
advise and make a person aware of there genetics for better awareness
Tell you weather or not you and your spouse should procreate
Advise options
advise about genetic choices before baby is born

Pre-symptomatic
Help you find out what health problems you may suffer in the present or future
Counsel people on future things they may encounter due to their personal genetics
I think they help test and determine genetic maladies on predisposition to them
Genetic counselors advise patients about the results of a DNA sequencing procedure which may indicate a future health condition.
I think that today with DNA & other medical testing they attempt to give information to couples who want children & also predict disease before it happens so people can try and take a preventative approach.
assess risks and predispositions
they counsel people who have a predisposition for a particular genetic based disease
Help people review results of DNA testing so they know what diseases/conditions either themselves or their unborn babies may have.
i think this is somethiing that would be very valuable for people that may pre-disposed to a genetic disease
Look into depth at your genes to see if you are predisposed to certain diseases or in other words what you may be more suseptable to in the future. It helps you be able to change your lifestyle so you can lower your chances of acquiring the disease.
help find problems before they happen
Counsel individuals regarding potential health concerns for their future based on their genetic makeup. Also consult on most efficient nutrition possibilities based on genetic makeup.

Disabilities
They study genetic disorders in the birth- like Autism & Down syndrome etc
The work with people who may have rare diseases or conditions on how to cope with their things, medical doctors, etc who know how to cope with these things.
They keep with disable
Give advice about hereditary disabilities.
Help you deal with developmental disabilities you're born with.
They counsel people with genetic disabilities, not sure
Counsel people in genetics, ie, people who may be at risk for having a child with special needs.
WORK WITH PEOPLE WHO HAVE BEHAVIORAL PROBLEMS.

Look at genes and determine DNA comparisons for diagnosing disabilities.
Test for study family abnormalitlies
Counsel couples on the pobability of having a child w/ disabilities
they work with people and kids that have spepical problums

Screening
They do research on different illnesses, and see if they can be prevented, or areas where illnesses are more prevalant & Family history
Check to see if there are any diseases, that are hereditary
Take samples from patients in question, conduct genetic testing to screen for disease or genetic conditions a person may have. Testing for your ethnic background
Look at your genes and the genes of your partner to assist with families.
Assist w/ people who need to know what the genes may possibly carry to try to help w/ the future that babies may carry or develop regarding recessive genes
tell people the findings of their genetic screening tests and inform them of options
Determine if a child or parent caries a gene
Look at genes of two prospective parents before they have kids
screen for disesases
Assist people who want to have children to determine if they carry any genes that will adversely affect or cause a problem for their children.
Pre-natal screening and post birth DNA checking for family illnesses, traits, concerns, etc.
They help assess the risks and benifits of possible mutations with one that is attempting to conseve

Take Blood Sample/ Blood Test
blood tests performed by Dr. go over risks of individual based on age, and/or family history of illnesses/diseases.
Blood sample (from patient) Lab test List of blood components -DNA (chromozones), proteins/fats Councelor tells results to patient ?
It deals with people's genetics, Take blood samples from people that volunteered & teach about information about geneticsch about information

genetic counselors interview families where there might be risk for genetic medical condition or in which a person with a genetic disease might have already been born. by taking careful history and blood work they might determine the chance that a child will be born with a particular condition. They might also interview people who have a cluster of symptoms and who want to know if they have a syndrome
1st you take a blood sample, live normal lives, kind of nosy
Take blood, test, research
Take samples from patients in question, conduct genetic testing to screen for disease or genetic conditions a person may have. Testing for your ethnic background
draw blood, look at indicator genes advise them on preventive procedures etc.
They likely run blood test and DNA test and then counsel you on the results of the DNA or blood test that they ran on you.
Test blood for genetic disorders.
Theydrawblood theycheck yourfamily bloodlines

Pediatric
They help to see what kind of activities are appropriate for my child & and any other questions I might have & also mental support.
Work with children
Possibly discuss different options for parents who's children have genetic diseases.
genetic counselors interview families where there might be risk for genetic medical condition or in which a person with a genetic disease might have already been born. by taking careful history and blood work they might determine the chance that a child will be born with a particular condition. They might also interview people who have a cluster of symptoms and who want to know if they have a syndrome
they work with people and kids that have spepical problums

i would imagine they meet with parents and/or children to discuss how to deal with particular diseases/issues/characteristics that are a result of genetic conditions
Pre-natal screening and post birth DNA checking for family illnesses, traits, concerns, etc.
help to explain different problems you or your child might have

Pre-Test Counseling/ Testing Guidance
inform about options and test for genetic issues
Work through the process and results with patients
Risk stratify, and counsel people on whether testing is needed, why you might, also anticipate results and actions before testing
They give information about what genetic testing will do and what a test means
What the test are, how they are administered and what the results indicate. Also long term planning.
They help you understand the results or potential results of what a genetic test may yield.
Genetic counselors map a family tree that lists any potential health issues/concerns and the create a 'map' of what may affect your child. In addition, they offer various types of testing to look for chromosonal deficiencies.

Genealogy
give info on family history
Finds ones Genetic History, health-wise and cultural backgrounds
Take samples from patients in question, conduct genetic testing to screen for disease or genetic conditions a person may have. Testing for your ethnic background
Examine the human being records
To find out History
Trace peoples lineage

Connects To Support Groups/ Resources/ Referrals
Consult patients on help, referring help
Share impact of the genetics risk with pregnancies and provide support and resources for families dealing with genetic concerns
Work with doctors to help patients understand the genetic issues if any and provide assistance or recommendation of services and treatment based on findings.

Cancer
identify specific gene/traits at risk for specific diseases and cancer.
No thoughts really. My daughter has breast cancer and I am wondering if it is familial.

Other
Its good to have, a information
Something to do with Sperm banks
Help people
talk about health
1st you take a blood sample, live normal lives, kind of nosy
Help people who have genetic disorders
I think it will help my hang and will
Talk to family that might need genetic counseling
Help clients maneuver their medical systems
talk to people
Help answer questions
Scare people into feeling they are "doomed" by this genetic heritage
Help people accept their genetic limitation
Help people with diferents types of disease
Consider the ethics, risks, and benefits of sharing information based upon DNA analysis, including family history for expression
In my experience, genetic counselors consult with individuals facing issues on genetics for themselves and/or their family members.
Help with genetic issues
i think they help with genetics
Assist individuals with accessibility
i think this is somethiing that would be very valuable for people that may pre-disposed to a genetic disease
help you understand your medical history
advise and make a person aware of there genetics for better awareness
Create hoops to jump through
Its always a good idea to be informed about your body and its make-up, I think its positive
Helps people come to grips with who they are because of their genetics

They determine how a person will behave or act based on their genetic makeup. How our genetic changes affect our psyche
Determine how DNA and genetics are altered and council people on it.
they don't give the whole story
Find out about your genetics and explain why you are the way you are.
They determine how a person will behave or act based on their genetic makeup. How our genetic changes affect our psyche
Helping to understand how families have with differences and similarities to help if there are conflicts to know how to adapt and resolve conflits with people that have strugles with how their genetic background is like.
perhaps work with couples or individuals with new ways to deal with having childern
they talks about the difference in behaviors, what can and can not tranfer between genetics
i think they study genes and tell people about it or help people that are having genetic probles
talk about certain possible was of reducing mutations? not too sure :)
study human genes, and help with gender baby precdiction.
counsel to improve development
see what kind of gene personalities are in your family
get your genes checked where all your personality come from

All open-ended responses by theme:

"Where do you think a genetic counselor would work?"

Medical Office/ Clinic/ Private Practice
a clinic
A Medical Research facility
a private office
an office hospital
Anywhere- hospital, CBO, nonprofit, sperm bank, clinic
anywhere, healthcare setting
at a clinic or school/university
At a doctors office

At a drs office
At a hospital or clinic
at a hospital or clinic
At a hospital or other medical facility or in research
at a university or clinical setting
at home or office
blood-related facilitys
climics hospitals
clinic
clinic
clinic
Clinic
clinic
clinic
Clinic settings. Universities.
clinic, hospitals, health facility
clinics
Clinics, Hospitals
Doctor's office
doctor's office, hospital, private practice, non-profit org
Doctor's offices, their own practices, hospitals
doctors
doctors office
Doctors office
Doctors office
Doctors office
doctors office
Doctors office, disability centers
Doctors office?
doctors office/medical building where doctors are.
family office
Fertility clinics, oncology testing for cancer, diagnostic testing
Health clubs, hospital, private practice
health office
healthcare
heath clinics
her own clinic
hospiital, clinic, university
Hospital and/or clinic; OBGYN office
Hospital it dr office
Hospital or Clinic
hospital or docs office
hospital or doctors office
hospital or medical clinic
Hospital or medical office
hospital or medical office
hospital or private office

hospital or private office
hospital or private practice
hospital setting or a clinic
Hospital, Clinic, Private Practice
hospital, doctor office
Hospital, doctors office, fertility clinic, OB
Hospital, health care clinic, specialty medical center
Hospital, office
Hospital, outpatient clinics
hospital, private clinic
hospital, private practice
hospital, private practice
hospital, psychologist office, clinic
Hospital/clinic or universities (for research purposes)
hospitals and doctor offices
hospitals and/or clinics, universities
Hospitals- Medical facility, Regional Center
hospitals, clinics
Hospitals, clinics, research centers
hospitals, community organizations, private practice
hospitals, doctors office
hospitals, health clinics and physician's offices
Hospitals, private practice
hospitals, private, etc.
hospitals, research clinics, and universities
hospitals/clinics
I think a genetic counselor would be working with a primary care physician to help with a personalized health care plan.
I would suggest health clinics
In a clinic or office or with a OB/gyn
in a counsaling center
in a hospital or doctors office
In a medical center/hospital/counseling service centers-ob/gyn office
in a medical clinic
in a medical facility
In a medical office
In a medical setting
in a specialist's office
In an office
in an office
in an office
In an office
In conjunction w/ healthcare (doctor or hospital) perhaps in a mental health setting too
In conjunction with a geneticist
In doctors offices (specialist)
In hospitals or medical offices
in labs, in clincs

in medical settings
in office
in offiie
in research labs and medical centers
Independently or through clinics or hospitals, or nutritionists.
Intake at medical facility with focus on improving life
Kaiser
Lab, office, with the public
labs or doctor office
labs/ medical offices
maybe at a hospital or specialty office
medial building
medical center
medical centers
medical centers, insurance company
medical clinic
Medical facilities
Medical facilities, insurance company
Medical facilities/offices
medical facility
Medical facility, Huntsman Institute
medical facility/counseling
medical field or hospital
Medical field, obstetrics
medical group/hospital, university, private practice
Medical office
Medical office
Medical office
medical offices
medical profession
Nicu, outpatient, private practice
office
Office
office
office buildings
office, lab
Pedi Ward and Pedi Clinics
perhaps a health facility
Perhaps in conjunction with doctors such as neurologists, cardiovascular drs, etc
Physician's office
private health care office or hospital.
Private office
private practice
Private practice
Private Practice and schools
Private practice and/or provided through insurance or dr
Private practice or Family Planning

private, Doctors office, hospital
Schools, hospitals, with doctors
some connection to medical facilities, hospitals, clinics
Their own clinic or hospital or university
They should be at your regular dr visits
with biologist, private practice
With your pediatrician doctor
Within a medical environment
You would possibly find them at a hospital or possibly a special organization/clinic where the specializes in these things

Hospital
A "GC" would work in a hospital that offers the test
a hospital
A hospital
a hospital
a hospital or high risk fetal medicine
A hospital research center or teaching hospital
A hospital, lab, university, and occupational therapy.
Ambulatory setting, hospitals
an office hospital
Any hospital both mental & physical
Anywhere- hospital, CBO, nonprofit, sperm bank, clinic
At a hospital
at a hospital
At a hospital or clinic
at a hospital or clinic
At a hospital or other medical facility or in research
At a hospital with a cheif of genetics.
At a lab, hospital, research institute
childrens hospital
climics hospitals
clinic, hospitals, health facility
Clinics, Hospitals
doctor's office, hospital, private practice, non-profit org
Doctor's offices, their own practices, hospitals
family counselings, schools, hospitals
fertility clinics, hopitals, parent counseling centers
Health clubs, hospital, private practice
Health education in hospitals
Hopitals
hospiital, clinic, university
hospital
hospital
Hospital
Hospital

Hospital
hospital
hospital
hospital
hospital
hospital
Hospital
hospital
hospital
hospital
hospital
Hospital
Hospital
Hospital
hospital
hospital
hospital
hospital
hospital
hospital
Hospital affected and organizations that deal with disabilties
Hospital and or regional centers
Hospital and/or clinic; OBGYN office
Hospital it dr office
Hospital or Clinic
hospital or docs office
hospital or doctors office
Hospital or fertility clinic
hospital or medical clinic
Hospital or medical lab
Hospital or medical office
hospital or medical office
hospital or private office
hospital or private office
hospital or private practice
hospital or research facility
hospital or university
Hospital or university
hospital setting or a clinic
Hospital settings, Psychologist, sociologist,
Hospital, Clinic, Private Practice
hospital, doctor office
Hospital, doctors office, fertility clinic, OB
hospital, duh.
Hospital, health care clinic, specialty medical center
Hospital, Medical University
Hospital, office

Hospital, outpatient clinics
hospital, private clinic
hospital, private practice
hospital, private practice
hospital, psychologist office, clinic
Hospital, university
Hospital? Research center
Hospital/clinic or universities (for research purposes)
Hospital/research center
hospitals
hospitals
hospitals
hospitals
Hospitals
hospitals
hospitals and doctor offices
Hospitals and obgyn facilities
hospitals and/or clinics, universities
hospitals mainly....
Hospitals- Medical facility, Regional Center
hospitals, clinics
Hospitals, clinics, research centers
hospitals, community organizations, private practice
hospitals, doctors office
hospitals, fertility clinics,
hospitals, health clinics and physician's offices
hospitals, MFM offices, cancer centers
Hospitals, or counseling offices. Phloebotomy.
Hospitals, private practice
hospitals, private, etc.
Hospitals, public health centers, government health organizaitons
hospitals, research clinics, and universities
hospitals, schools,
hospitals, wellness centers
hospitals/clinics
hospitol
In a hospital
in a hospital
In a hospital
In a hospital
in a hospital or doctors office
In a hospital or treatment center
In a lab, hospital, place for partners, that can't have kids or are planning to have children
In a medical center/hospital/counseling service centers-ob/gyn office
In conjunction w/ healthcare (doctor or hospital) perhaps in a mental health setting too
In hospitals or medical offices
Independently or through clinics or hospitals, or nutritionists.

Independently/hospitals
Kaiser
lab or hospital or university
lab/hospital
Lab/hospital, homeopathic office, wellness center
Laboratories, hospitals
Labs, hospitals, colleges, Universities
maybe at a hospital or specialty office
medical field or hospital
medical group/hospital, university, private practice
Pedi Ward and Pedi Clinics
place like UCLA
Planned parenthood of a hospital
Possibly a hospital or psychiatric setting
private health care office or hospital.
private, Doctors office, hospital
probably in a lab or hospital
schools & media environment hospitals
Schools, hospitals, with doctors
some connection to medical facilities, hospitals, clinics
Their own clinic or hospital or university
universities or hopitals
You would possibly find them at a hospital or possibly a special organization/clinic where the specializes in these things

School/ Universities
A hospital research center or teaching hospital
Academia
at a clinic or school/university
at a university or clinical setting
Clinic settings. Universities.
family counselings, schools, hospitals
hospiital, clinic, university
hospital or university
Hospital or university
Hospital, Medical University
Hospital, university
Hospital/clinic or universities (for research purposes)
hospitals and/or clinics, universities
hospitals, research clinics, and universities
hospitals, schools,
lab or hospital or university
Labs, hospitals, colleges, Universities
medical group/hospital, university, private practice
near research univeristies
place like UCLA

Private Practice and schools
schools
schools & media environment hospitals
Schools, hospitals, with doctors
Their own clinic or hospital or university
universities or hopitals
university researcher
universty labs

Lab
A hospital, lab, university, and occupational therapy.
at a lab or something
At a lab, hospital, research institute
At a laboratory
Hospital or medical lab
in a lab
In a lab
In a lab, hospital, place for partners, that can't have kids or are planning to have children
in a lab, know chemistry & how molecules connect, function, and perform to a office too
in labs, in clincs
in research labs and medical centers
lab
Lab
Lab
lab or hospital or university
Lab, office, with the public
lab/hospital
Lab/hospital, homeopathic office, wellness center
Laboratories, hospitals
labs or doctor office
Labs, hospitals, colleges, Universities
labs/ medical offices
office, lab
probably in a lab or hospital
research lab
universty labs

MFM Center/ OB Gyno
a hospital or high risk fetal medicine
Hospital and/or clinic; OBGYN office
Hospital, doctors office, fertility clinic, OB
Hospitals and obgyn facilities
hospitals, MFM offices, cancer centers
In a clinic or office or with a OB/gyn
In a medical center/hospital/counseling service centers-ob/gyn office
Medical field, obstetrics
ob
ob office

Obg
obgy
Perinatologist office, IVF clinic
prenatal
with OBGYN

Research
A hospital research center or teaching hospital
A Medical Research facility
Artificial insemination clinics, drug research facilities, drug treatment
At a hospital or other medical facility or in research
At a lab, hospital, research institute
hospital or research facility
Hospital? Research center
Hospital/clinic or universities (for research purposes)
Hospital/research center
Hospitals, clinics, research centers
hospitals, research clinics, and universities
in research labs and medical centers
near research univeristies
research lab
university researcher

Family Planning/ Fertility Clinic
Artificial insemination clinics, drug research facilities, drug treatment
Family planning
fertility clinics, hopitals, parent counseling centers
Fertility clinics, oncology testing for cancer, diagnostic testing
Hospital or fertility clinic
Hospital, doctors office, fertility clinic, OB
hospitals, fertility clinics,
In a lab, hospital, place for partners, that can't have kids or are planning to have children
Maybe at a family planning center or for the medical industry.
Perinatologist office, IVF clinic
Planned parenthood of a hospital
Private practice or Family Planning

Counseling Center/ mental health
Counseling center
Counselor office psychiatry mentalhealth
Counselor office psychiatry mentalhealth
family counselings, schools, hospitals
fertility clinics, hopitals, parent counseling centers
hospital, psychologist office, clinic
Hospitals, or counseling offices. Phloebotomy.
In conjunction w/ healthcare (doctor or hospital) perhaps in a mental health setting too
medical facility/counseling
private, Doctors office, hospital

Regional Center/ Disability Center/ Organization
Doctors office, disability centers
Hospital affected and organizations that deal with disabilties
Hospital and or regional centers
Hospitals- Medical facility, Regional Center
with Calif. early start program for families
With parents and families dealing with disabilities

Health Club/ Wellness Center
Health clubs, hospital, private practice
hospitals, wellness centers
Lab/hospital, homeopathic office, wellness center
Wellness center

Cancer Center
Fertility clinics, oncology testing for cancer, diagnostic testing
hospitals, MFM offices, cancer centers

Other
All over
Anny where
Anytime there are makers
anywhere
Anywhere there are parents that are in need of counseling
anywhere?
at a genetics center
at home
at home or office
disorders
doctor's office, hospital, private practice, non-profit org
everywhere
Fertility clinics, oncology testing for cancer, diagnostic testing
For anyone who is open minded
Genetics
Help change my life's mistake
hospitals, MFM offices, cancer centers
In a rich area
In a science building
in my body
Lab, office, with the public
Lab/hospital, homeopathic office, wellness center
Maybe at a family planning center or for the medical industry.
medical centers, insurance company
Medical facilities, insurance company
nursing, phycology
Person interested in understanding his/her habits, medical condition, personal trait which cannot be explained. Medical condition which pop up.
schools & media environment hospitals

TV info
with kids or with syciatrists
with your disease tell you your chances with your disease
yes
yes
yes

If you have seen a TV show or movie in which a genetic counselor was mentioned or portrayed, please write the name of the television show(s) or movie(s) here:
Bones
brad pitt wife story
can't remember
can't remember
Can't remember.
Can't think of anything right now!
Don't remember
dr oz show
Dr. Oz
ER, Law & Order
Gattaca is the movie and "Bones" and the CSI series on TV
House or Grey's Anatomy
I do not remember the name of the show
I don't remember exactly, but it was a news type show.
I saw a show online that illusrated making mock babies via a computer. Each couple had to give a mouth swab. Their DNA was collected and placed in a computer program. Then thecomputer was able to generate the probability of having children with the muatation.
law and order svu
Lorenzo's Oil
MOM- AA Meetings
movie has been made- is looking for national distributor Twitch- Huntington Disease
n/a
n/a
news program can't remember
No
no
no
On a crime show, someone who was adopted, wanted information about family health history.
Oprah
Parents wanting a baby which is either a boy or girl
PBS/Educational shows
Still alice
Still Alice
Still Alice
The Big Bang Theory

think so - PBS
Unless you live in a cave you should know a little something. Like stem cell research it's in its early stages but I know it exists
yes, but I can't remember

If you completed a graduate or professional degree, what type of degree did you recieve and/or what area did you specialize in?
AA + resource specialist for families dealing w/ disabilities
AA Communication Studies BS Rehabilitation Services
AA- TV/Film & Paralegal
Accounting
ADN Nursing
architect
Architecture
art
Art and theater w/ teaching credential
AS Human Biology
Associate degree in nursing
Associates in Chemical Dependency Canceling
B a science
BA
BA - Psych, BA - Sociology, BS - Crim Justice
bachelorsof nursing
Biochemistry
Biostatistics ms
Brit & American Studies
BS
BS Accounting
Bs animal science reproductive phsiology
bs compuer integrated manufacturing
BS in Business
BS in Physics & Engineering
busines
busines
Business

Business
Business
business
business
Business Administration
Business Management
business.
Child development
child development
communication studies
Computer Application
Computer science
Cosmetoligist
Cosmetology
counseling with genes
criminal justice
DDS
dental
dental assisting
Doctor of Physical Therapy
Doctorate of Physical Therapy
Doctorate of Physical Therapy
Early childhood education
Early Childhood Education/Special Education
Economics
Economics
Economics/cinema/TV
EdD - Ed Psych
Education
education
education
Education/Adult Ed
ems
endocrinology
eng

Engineering
English
English BA
English, Music
Estetics
fashion merchandising
film studies
Film studies and Forensic Science
Finance & Media Arts
geography/urban planning
getting PhD
Graduate degree in Education
health ed
Health Wellness
HVAC/Music
Internal medicine
International Security
IT
JD Law, MA Philosophy
Judaic Studies
Kinesiology
Kinesiology- Exercise Science
Law
Law
legal studies but 20 year in the nursing field
Liberal Arts
M.A. Educational Administration
MA Broadcasting
MA Education Race and Ethnic Studies
MA History
MA in Education
MA in Math
ma teaching
MA- Elementary Education
MA. REHAB COUNSELOR

managemeny
Master of Occupational Therapy
Master's in Political Science
Masters
Masters - counseling
Masters Educational Leadership
Masters in Education with concentration on teaching skills & methodologies
Masters in Occupational therapy
Masters in School Admin/School Psych
MAT Early Childhood Administration
MD/Dermotology
Media Broadcasting
Molecular Biology
mpa and counseling
MPH
MS Chemistry
MS MEd
MS Quantitative and systems Biology
MS Special Education & Administration
MS- Psychology (Industrial)
MSEE
MSME
MSN
MSW
MSW, LCSW, worked for many years with Deaf people and people with all 3 types of Usher Syndrome
n/a
N/A
Neurophysiology
neuropsychology
Nurse
nursing
Nursing
Nursing
Nursing
nursing FNP

ob gyn NP
Occupational Therapist
Occupational Therapist
OT
pastry
pharacy
phd business
PhD Chemistry
PhD Clinical Psych
Physician Assistant, MS
Physics
Psychology
Psychology
PT
Res & Coding
RN
RN nursing
Secondary Education w/ a macro stamp in art
single subject secondary teaching cred
social worker
Special education
Special Efucation
Speech Lang Pathology
Systems engineering at USC
telecom / film studies
Telecommunications
Theater arts

APPENDIX C

Mean Knowledge Score Tables

What is the highest level of school you have completed or the highest degree you have received?	Mean	N	Std. Deviation	Std. Error of Mean
No Answer	10.2	5	1.92	0.860
Less than high school (0-8 years)	9.5	4	1.73	0.866
High school graduate (12 years)	11.4	32	2.27	0.401
Some College or University	12.2	82	2.24	0.247
College or University Graduate	12.7	98	2.02	0.204
Some Graduate School	12.8	28	2.44	0.460
Graduate or Professional Degree	13.1	71	2.19	0.259
Total	12.4	320	2.25	0.126

$p<0.0005$

With which gender do you identify?	Mean	N	Std. Deviation	Std. Error of Mean
Female	12.6	201	2.36	0.166
Male	12.2	116	2.04	0.189
Other	13.0	3	2.65	1.528
Total	12.4	320	2.25	0.126

$p=0.085$*

**p-value was calculated excluding the "other" category for gender*

Which of the following best describes your current occupation?	Mean	N	Std. Deviation	Std. Error of Mean
Medicine / Healthcare	13.3	32	2.47	0.436
Education	13.0	39	2.37	0.379
Retired	12.8	30	2.32	0.424
Science/ Engineering/ Technology	12.7	21	1.74	0.380
Sales / Marketing	12.6	22	1.94	0.414
Administration/ Management/ Hospitality	12.4	35	2.45	0.414
Other	12.3	22	2.34	0.498
Politics / Government/ Law	12.3	13	2.02	0.559
Homemaker/ Caregiver/ Unemployed	12.3	38	1.90	0.308
Student	12.1	25	2.38	0.476

$p=0.110$

Counseling/Social Work	12.0	8	2.78	0.982
Entertainment / Media	11.6	9	2.70	0.899
Art / Music / Writing	11.4	9	1.51	0.503
Business/ Banking/ Finance	11.4	11	2.06	0.622
No Response	10.3	6	1.03	0.422
Total	12.4	320	2.25	0.126

What religion do you identify with?	Mean	N	Std. Deviation	Std. Error of Mean	
Buddhism	11.00	9	2.00	0.667	p=0.082
Catholicism	12.59	75	2.33	0.269	
Inter/Non-denominational	12.43	14	2.28	0.609	
Judaism	13.20	15	2.24	0.579	
Latter Day Saints (Mormonism)	13.86	7	1.95	0.738	
No Religion/ Spiritual, Not Religious	12.54	71	2.10	0.249	
No Response	10.00	4	1.63	0.816	
Other	11.78	9	1.92	0.641	
Other Christianity	12.13	72	2.17	0.256	
Prefer not to answer	12.85	27	2.36	0.455	
Protestantism	12.65	17	2.67	0.647	
Total	12.45	320	2.25	0.126	

In which state or U.S. territory do you live?	Mean	N	Std. Deviation	Std. Error of Mean	
California	12.40	310	2.25	0.128	p=0.038
Other US State	13.90	10	2.02	0.640	
Total	12.45	320	2.25	0.126	

What is your marital status?	Mean	N	Std. Deviation	Std. Error of Mean	
Married	12.46	130	2.24	0.196	p=0.923
Single	12.44	190	2.27	0.164	
Total	12.45	320	2.25	0.126	

Do you have children?	Mean	N	Std. Deviation	Std. Error of Mean

No	12.55	158	2.30	0.183	p=0.416
Yes	12.35	162	2.21	0.174	
Total	12.45	320	2.25	0.126	

Are you a practicing physician?	Mean	N	Std. Deviation	Std. Error of Mean	
No	12.48	310	2.25	0.128	p=0.135
Yes	11.40	10	2.07	0.653	
Total	12.45	320	2.25	0.126	

Do you have any sort of disability?	Mean	N	Std. Deviation	Std. Error of Mean	
No	12.66	211	2.17	0.149	p=0.017
Yes	12.03	109	2.36	0.226	
Total	12.45	320	2.25	0.126	

How much total combined money did all members of your HOUSEHOLD earn last year?	Mean	N	Std. Deviation	Std. Error of Mean	
I'd rather not say	12.3	81	2.38	0.264	p=0.818
Less than $25,000	12.4	46	2.45	0.362	
$25,000-$49,999	12.4	45	2.19	0.327	
$50,000-$74,999	12.2	35	2.70	0.456	
$75,000-$99,999	12.4	39	2.04	0.326	
$100,000-$149,999	12.5	38	2.00	0.324	
$150,000-$199,999	13.1	20	1.65	0.369	
More than $200,000	13.1	16	1.98	0.496	
Total	12.4	320	2.25	0.126	

Which category below includes your age?	Mean	N	Std. Deviation	Std. Error of Mean	
18-29	12.0	68	1.96	0.237	p=0.146
30-39	12.4	68	2.28	0.276	
40-49	12.3	64	2.27	0.283	
50-59	12.8	75	2.34	0.270	
60 or older	12.9	45	2.39	0.356	
Total	12.4	320	2.25	0.126	

Before coming across the phrase while participating in this study, have you heard of "genetic counseling" before today?	Mean	N	Std. Deviation	Std. Error of Mean
NO	11.9	148	2.12	0.174
YES	12.9	172	2.28	0.174
Total	12.4	320	2.25	0.126

$p<0.0005$

I have been referred to or seen a genetic counselor	Mean	N	Std. Deviation	Std. Error of Mean
Had not heard of genetic counseling prior to this study	11.9	147	2.108	0.174
Yes	13.1	52	2.144	0.297
No	12.8	121	2.336	0.212
Total	12.4	320	2.252	0.126

$p<0.0005$

Population	Mean	N	Std. Deviation	Std. Error of Mean
Disability Community	12.6	209	2.390	0.165
New Parent Community	11.5	42	1.671	0.258
General Public	12.6	69	1.996	0.240
Total	12.4	320	2.252	0.126

$p=0.013$