Genetic Information Nondiscrimination Act (GINA) and Its Affect on Genetic Counseling Practice: A Survey of Genetic Counselors

Master’s Thesis

Presented to

The Faculty of the Graduate School of Arts and Sciences
Brandeis University
Genetic Counseling Program
Barbara Lerner, MS, CGC, Project Advisor
And
Committee Members:
Leigha Senter, MS, CGC, Patricia (Winnie) Roche, M. Ed., JD

In Partial Fulfillment
Of the Requirements for

Master’s Degree

By
Abhilasha Khattri Pamarti

May 2011
Acknowledgements

I would like to take this opportunity to express my gratitude to my committee chair Barbara Lerner for all her time, help and encouragement throughout this research project. I also want to thank my committee members- Patricia (Winnie) Roche and Leigha Senter- for their invaluable feedback and suggestions; the Brandeis Genetic Counseling Program faculty and staff for their guidance and support; Scott Motyka for his assistance and expertise in statistical analysis; class of 2011 for making this process enjoyable with their support and wit; genetic counselors who took the time to complete the survey; Carin Huizenga (MS, CGC) for providing her survey questions some of which I modified and used in my survey; my wonderful family for their unconditional love and my dearest husband Sri for his unwavering support, help, understanding and love without which it was not possible for me to successfully finish this project.
Abstract

Genetic Information Nondiscrimination Act (GINA) and Its Affect on Genetic Counseling Practice: A Survey of Genetic Counselors

A Thesis presented to the Genetic Counseling Program

Graduate School of Arts and Sciences

Brandeis University

Waltham, MA

By Abhilasha Khattri Pamarti

The Genetic Information Nondiscrimination Act (GINA) designed to prevent genetic discrimination by employers and healthcare insurers, became a federal law in May 2008. Genetic counselors are in a unique position to comment on GINA’s impact on the delivery of genetic services. The aim of this study was to assess changes in genetic counseling practices since the implementation of GINA. We assessed genetic counselors’ knowledge about the scope of GINA and their attitude regarding genetic discrimination and GINA. We also assessed counselors’ perceptions of their client’s experiences with genetic discrimination since GINA. An anonymous online survey consisting of open and
closed ended questions was completed by 257 genetic counselors recruited from the National Society of Genetic Counselors (NSGC) general and Cancer SIG listservs. Results showed that genetic counselors are knowledgeable about the major protections offered by GINA. However, there is still confusion about its protections for individuals pursuing direct-to-consumer testing and limitation regarding pre-existing genetic conditions. Genetic counselors reported that they now discuss genetic discrimination with more clients than they did prior to GINA. Still, they discuss the law with fewer than 50% of their clients. A majority (64.6%) of the counselors reported specifically discussing GINA only when the client asked about it. Cancer genetic counselors discuss GINA with more clients (68%) than genetic counselors working in pediatric, prenatal or other specialties (68%, 28%, 11% and 39% respectively). Genetic counselors are confident that GINA will provide its intended protections and reported reassuring their clients to that regard. In fact, our respondents reported that they would be more likely to personally pursue genetic testing for conditions such as BRCA1/2 without concern of discrimination. In conclusion, our results show that genetic counselors have an overall awareness about and confidence in the protections offered by GINA.
# Table of Contents

Acknowledgements iii

Abstract iv

List of Tables ix

List of Figures x

Introduction 1

Perceptions of the Existence of Genetic Discrimination 2

The Genetic Information and Nondiscrimination Act (GINA) 8

Perceptions regarding the effect of GINA since its implementation 10

Purpose of my study 13

Methods 16

Study Design 16

Study Procedures 16

Data Collection 17

Data Analysis 17

Compensation 18
Results

Demographics

Genetic counselor knowledge about limitations and protections of GINA

Genetic counselor attitude regarding genetic discrimination and GINA

Genetic counselor reporting of their clients’ perceptions about GINA and experiences with genetic discrimination after implementation of GINA

Views of genetic counselors about the impact of GINA

Discussion

Genetic counselor knowledge regarding protections and limitations of GINA

Genetic counselor attitude regarding genetic discrimination and GINA

Genetic counselor reporting of their clients’ perceptions about GINA and experiences with genetic discrimination after implementation of GINA

Limitations

Conclusion

Future research

Appendices

Appendix I: Recruitment notice

Appendix II: Informed Consent

Appendix III: Survey
List of Tables

Table I. Demographic information of the genetic counselors 21

Table 2: Genetic counselor’s responses for client reporting of genetic discrimination 26

Table 3: Circumstance when genetic counselors discuss GINA with their clients 28
List of Figures

Figure 1: Distribution of genetic counselor’s score on GINA-related knowledge questions 23

Figure 2: Genetic counselor’s discussion about GINA with clients according to their work specialty 30

Figure 3: Confidence and reassurance response ratings 32

Figure 4: Mean of responses for disclosure to others 34

Figure 5: Mean of responses for counselor’s estimation of client concern for discrimination 36

Figure 6: Percentage for number of client requests regarding anonymous genetic testing 37
**Introduction**

The Human Genome Project was completed in April 2003 opening the door for the infinite exploration of human genetics. Within the last decade genomic information has grown exponentially (K. L. Hudson, Holohan, & Collins, 2008). According to Center for Disease Control and Prevention website genetic tests have been developed for more than 1700 diseases, of which around 1400 are available for use in clinical settings (Prevention, 2011). These genetic tests can be used to identify the risk of developing certain diseases. Some of them are also available directly to consumers and a growing number are associated with common complex diseases such as depression and cardiovascular diseases (K. Hudson, Javitt, Burke, & Byers, 2007). Genetic testing enables people to take educated, preventive measures leading to a healthy and well-informed society. The rapidly growing research in Human Genetics will eventually lead to personalized medicine in the future. As the genetic testing becomes more relevant, people should be made aware of the complex socio-legal issues associated with the results of testing.

In this era of fast changing genomic medicine if the genetic details of an individual are not protected from unauthorized access, then the potential misuse of that information in the form of genetic discrimination is very much a possibility. Genetic discrimination most often refers to discrimination directed against an individual or family
based solely on an apparent or perceived genetic variation from the “normal” human genotype (Billings et al., 1992). This discrimination can potentially be health insurance discrimination, employment discrimination, life insurance discrimination, long-term care insurance and social discrimination. To protect individuals from some of these discriminations state and federal laws have been enacted. The most recent federal legislation, the Genetic Information Nondiscrimination Act (GINA) was signed into law in May, 2008 to prevent genetic discrimination by employers and health insurers (Institute, 2009). It was a very important enactment by congress intended to enable more open approach by the individuals towards genetic testing. It was also anticipated that a nondiscrimination law would lead to transparency and thus better care of patients and would encourage participation in research to combat genetic diseases.

**Perceptions of the Existence of Genetic Discrimination**

Before the enactment of GINA, both health care providers and patients often expressed concerns regarding potential discrimination based on the result of the genetic testing. Various consumer and medical professional groups supporting the enactment of GINA asserted that the fear of discrimination often caused patients to forego genetic testing which resulted in hindered access to highest quality health care. This fear may also cause decreased enrollment in clinical trials leading to slowed research to find medication and therapies (Fairness, 2008). A few studies were done prior to the enactment of GINA to assess the existence of genetic discrimination. A research survey administered to health professionals and insurance providers found almost no well-documented cases of health-insurers either asking for or using presymptomatic genetic
test results in making their decisions to provide insurance (Hall & Rich, 2000a). These results were the same in states with and without their own genetic antidiscrimination laws. However, the participants in this study were health care providers and representatives of the insurance industry, and not patients. Hence the data was potentially skew in favor of non-existent genetic discrimination. The result of this study suggested that an individual with a serious genetic condition who is presymptomatic should experience little or no difficulty in obtaining health insurance. This supported the claim of health insurers that genetic discrimination does not exist and is irrationally feared and theoretical (Nowlan, 2002).

**Perception of genetic counselors:** Only a handful of studies have been done to assess genetic counselors’ perception and practices regarding genetic discrimination. Prior to passing of GINA, one survey of the National Society of Genetic Counselors (NSGC) cancer special interest group (SIG) reported that 68% of their study participants (total 163 participants) predicted that they would not bill insurance companies for their own genetic testing because of the fear of discrimination. Around 26% of them would use an alias when undergoing genetic testing to avoid potential discrimination (Matloff et al., 2000). This indicated considerable fear in the cancer genetic counselor community of genetic discrimination. In a subsequent study, also conducted prior to the passing of GINA, 25 cancer genetic counselors were interviewed regarding their definitions, perceptions, and experiences with genetic discrimination (Pfeffer, Veach, & LeRoy, 2003). Around 96% of the sample reported always or almost always discussing genetic discrimination in their cancer counseling sessions. Although, 82% regarded the risk to be lower to what is generally perceived, 40% reported possible instances of genetic discrimination. A few of
these instances were reported to be denial of life and health insurance, social discrimination and employment discrimination. Another survey of NSGC cancer SIG members suggested that there has been a decreased fear of genetic discrimination among cancer providers over an eight year time span (Huizenga et al., 2010). Although, these studies indicate a change in the beliefs and practices of genetic counselors overtime, they were done on small sample sizes and limited to just cancer genetic counseling practice.

Often, fear of genetic discrimination motivates patients to request anonymous testing by their health-care providers. In a pre-GINA survey of the NSGC familial cancer risk counseling SIG (n=115), 42.7% genetic counselors cited the threat of life insurance discrimination as the reason for pursuing anonymous testing by patients as compared to other counselors who cited health insurance (30%) or employment discrimination (29.1%) as justifications (Ader, Susswein, Callanan, & Evans, 2009). This study’s results might be different if conducted now, following the enactment of GINA. In general, there was a strong consensus among genetic counselors that anonymous testing must be used in only specific circumstances and should not be offered routinely (Ader, et al., 2009). The study did not mention the specific circumstances. In conclusion, Genetic Counselors have been aware and wary of potential discrimination, but their fear seems to be decreasing over time.

Perception of clinicians: Several studies have been done to assess clinician’s attitude towards genetic discrimination and their subsequent referral practices. In one study in which health professionals at a cancer genetics conference in California were surveyed, 52.4% of (n=271) respondents believed that mutation carriers experience difficulty in
obtaining health insurance and 13% reported not encouraging their patients to pursue genetic testing in spite of cancer family history due to concerns about potential genetic discrimination (Nedelcu et al., 2004). This indicated their concern regarding genetic discrimination, and its effect on access to care. The same research group carried out another survey a few years later on a larger group of non-genetics health providers (n=1181) and found that 75% of participants believed that patient fear of genetic discrimination would lead to their patients declining genetic testing (Lowstuter et al., 2008). More than 60% of them were not aware of anti-discriminating laws and 11% of them did not refer patients for genetic testing due to concerns regarding genetic discrimination. The analysis of results showed that the higher the fear of genetic discrimination, the less likely that it was that a clinician was likely to refer patients for testing. This study was localized to a specific geographical area, thus cannot be generalized nationally. In another national survey, 81% of physicians (n=1251) thought that patients with positive genetic test results are at risk for health insurance discrimination and more than 53% agreed that confidentiality of these results is hard to ensure (Freedman et al., 2003). All these studies suggest that health care providers held a general apprehension about genetic discrimination which may have resulted in decreased testing and access to appropriate medical care.

**Perception of patients:** Despite the potential psychological consequences of genetic testing, carriers and non-carriers of genetic diseases mostly have a positive attitude towards genetic testing (Lynch et al., 2006). In a cohort study done on first degree relatives of patients with Hereditary Nonpolyposis Colorectal Cancer (HNPCC), 97% of participants (n=111) expressed the intent to pursue genetic testing and 51% eventually
chose to undergo the testing (Hadley et al., 2003). Interestingly, 39% of the relatives identified a potential effect on their health insurance as the most important reason to forego testing. Recently, a case study was reported about a patient electing to pursue direct to consumer genetic testing due to the fear of genetic discrimination (Roberts, Riegert-Johnson, & Thomas, 2011). This suggests a persistent health insurance discrimination fear in patients even after the GINA-enactment influencing medical care decisions.

Patients with a genetic disease as compared to those with a non-genetic disease are twice as likely to report denials of health insurance or offers of insurance at prohibitive rates (Kass et al., 2007). But concerns about the possibility of genetic discrimination are not limited to those directly affected by diseases with a genetic component. In a very large nation-wide study, 40% of primary care patient population (n=86,859) felt that genetic testing might prompt difficulties in getting or maintaining health insurance (M. Hall et al., 2005). Patients presented with testing decisions for adult onset diseases and cancer are also majorly influenced by this fear (M. A. Hall & Rich, 2000b). Despite all of this, some publications suggest that discrimination complaints are exaggerated and anecdotal and without any objective proof for the validity of these incidents, this calls into question how concerned any patient should be about this issue (Klitzman, 2010; Nowlan, 2002). It has been reported that patients’ fears of genetic discrimination do not play any role in their decision regarding genetic testing in prenatal or pediatric settings (M. A. Hall & Rich, 2000b). The non-existence of discrimination fear may be related to the critical circumstances surrounding these settings.
In the past, research groups have proposed that laws that protect employment rights for people with disabilities should be extended to include protections against discrimination on the basis of carrier status or predisposition to develop genetic conditions in asymptomatic individuals, and that this would alleviate any concerns about genetic discrimination (Wertz, 2002). Other researchers suggested the need for comprehensive, coordinated empirical research about the nature and extent of genetic discrimination across countries with highly developed genetic services. The purpose would be to explore the existence of genetic discrimination prior to instituting any legislative changes (Otlowski, Taylor, & Barlow-Stewart, 2003).

Other laws related to genetic discrimination: Forty-six states passed some type of genetic privacy legislation prior to passing of GINA, (Klitzman, 2010) but there was no comprehensive and uniform legislative framework for genetic discrimination to guide the development of these laws. In 2000, an executive order banned federal employers from obtaining or releasing genetic information about an employee or his family members. Also, it prohibited a range of employment discrimination against any federal employee. Although it was a good initiative, still its application was limited as it was effective for just federal employees and was limited to employment purposes (Eltis, 2007). Americans with Disabilities Act (ADA) does not specifically address genetic discrimination but provides somewhat limited protection at the workplace for people with expressed genetic conditions. The Health Insurance Portability and Accountability Act of 1996 (HIPPA) provides some protection against genetic discrimination to group policy holders but not to people with individual policies.
The Genetic Information and Nondiscrimination Act (GINA)

The Genetic Information Nondiscrimination Act (GINA) was signed into law in May, 2008 by President George W. Bush 13 years after first being introduced in the House of Representatives (GINA§101, 2008). The provisions of Title I of GINA governs health insurance and group health plans and went into effect in January 2010 whereas the provisions of Title II governing employment non-discrimination went into effect in November, 2009. Title I of GINA prohibits group and individual health insurers from utilizing a consumer’s or his/her family members’ genetic information to determine eligibility or premiums. Furthermore, health insurers cannot request or require an individual or his/her family members to undergo genetic testing. However, the statute permits health insurer to use genetic testing information in making coverage determinations for specific claims. Consequently, if an insured individual wanted to permit an insurer from having such permissible access to genetic information he or she would have to pay out of pocket and not submit a claim for coverage. According to Medicare and health insurance policies genetic information cannot be considered a preexisting condition that serves as the basis for denying a policy or placing conditions on the termination of the policy. As defined in GINA, genetic information includes information about an individual’s genetic results, the genetic test results of the individual’s family members, and the manifestation of a genetic disease or disorder in the individual’s family members. The statue defines genetic test as an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes. GINA does not prohibit health care providers from recommending genetic tests to their patients (GINA§101(d), 2008).
As for protection against employment discrimination under GINA, employers cannot use a person’s genetic information to make employment decisions regarding hiring, promotions, privileges, compensation, and termination. Employers are prohibited from requesting, requiring or purchasing the genetic information of an individual or his family (except when it is public or inadvertently provided as part of the medical history) (K. L. Hudson, et al., 2008). Employers can access employee’s genetic information as a part of a wellness program or genetic monitoring program after obtaining the employee’s written consent. GINA provides a baseline for protection against genetic discrimination for all its citizens but does not preempt more protective state laws. Remedies for violation of GINA include corrective action and monetary penalties (Fairness, 2008).

**Limitations of GINA:** GINA does not provide comprehensive protection from genetic discrimination. It does not govern other forms of insurances such as life and disability insurance. Premiums for life insurance can be very high, however, most of the individuals who can afford the premiums can get the coverage when they apply (Nowlan, 2002). However, genetic mutation carriers are at a risk of potentially being denied an independent life insurance policy. Insurance companies claim that if the medical and genetic information is not disclosed to them then it might lead to adverse selection and economical dysfunction. The long term aspect of life insurance as compared to health insurance is an important economic factor causing the life insurers companies to insist on access to all the medical and genetic information of the insured. On the other hand, supporters of including life insurance protections in GINA argue about the rarity of most of the genetic diseases as compared to more common multifactorial non-genetic diseases thus not affecting the life insurers economically (Slaughter, 2008).
GINA also does not protect against discrimination by disability or long-term care insurers. Nor does it protect veterans or military personnel from health insurance discrimination (Hudson, 2008). GINA exempts employers with less than 15 employees from the employment non-discrimination sections of the law. Also, it does not mandate that any insurer include coverage for any particular genetic test or treatment for a genetic disease as part of any policy. Although, GINA protects predictive genetic information of an individual by restricting the access of health insurer to the genetic information, GINA does not apply to a manifested disease or condition in an individual. In so far as employment circumstances are concerned, an individual with a manifested genetic illness may nevertheless be protected against discrimination by the Americans with Disability Act (Klitzman, 2010). Also, it does not prohibit health insurers’ and employers’ access to all health related information thus not fully protecting the public. For example someone suspected of familial hypercholesterolemia (covered by GINA) may have to undergo low density lipoprotein level testing which does not fit the definition of “genetic test” under GINA and therefore the results are not protected by GINA (McGuire & Majumder, 2009).

While GINA provides protection against employment and health insurance discrimination, it does not give any consideration to the social implications. There is a stigma attached to being a gene mutation carrier in our society (Klitzman, 2010).

Perceptions regarding the effect of GINA since its implementation

Perception of genetic counselors: Genetic counselors are considered to be a crucial population in gauging the possible effects of GINA (Klitzman, 2010). Still, no study has
been reported until now on genetic counselors’ perception and attitude towards GINA and whether any changes in their practices have occurred since enacting GINA.

**Perception of clinicians:** With GINA in effect, it can be assumed that clinicians would be more comfortable in offering genetic testing to patients due to decreased concerns about genetic discrimination. However, one study of non-geneticist physicians (n=56 participants) done soon after the passage of GINA found that 21.5% physicians failed to refer patients whom they felt were appropriate candidates for cancer genetic testing (Fusina, 2009). Over half of them (57.1%) were aware of the existence of GINA suggesting that concerns of physicians regarding genetic discrimination still remained despite GINA. Over one third (37.5%) of the remaining physicians with no prior knowledge of the law felt that law could make them more likely to recommend genetic testing. In another larger study of family physicians (n=401) approximately 17 months after GINA was signed into law, over half of respondents still had no awareness of GINA (Bretl, 2010). Most of the respondents were highly concerned for health insurance (44.0%), life insurance (49.6%), and long term care insurance (41.9%) discrimination. These results suggest continued concern by clinicians regarding genetic discrimination despite the implementation of GINA.

**Perception of patients:** Since the implementation of GINA, few studies have reported the perception of patients confronting discrimination because of genetic testing or having a genetic disease. One of these studies was published post-enactment of GINA, however, the interviews of the patients were done pre-GINA. Patients (n=64) were often found to be wary and unclear about legislative protections against genetic discrimination despite
assurance from genetic counselors (Klitzman, 2010). The authors of this study concluded that patients feel that laws might be beneficial but still have limited impact, are difficult to enforce and not at all effective against implicit, subtle discrimination. The subjects were wary of the precariousness of the laws therefore influencing their decisions regarding testing, treatment and disclosure to insurers. Also, these subjects expressed concerns about life, long-term care and disability insurance discrimination. Although this study highlighted some of the above mentioned important issues to be considered post-enactment of GINA like potential life and long-term care insurance discrimination, it still should be taken with caution due to small sample size and absence of a control population and statistical analysis.

Critics of the concept of genetic discrimination argue that it does not exist, just a fear and not a sufficient justification for enacting a legislation. The supporters of its existence claim that though there are not a lot of documented cases, still it can potentially happen and it’s best to be preemptive. Many of research studies in the past suggested a prevailing apprehension of genetic discrimination among genetic counselors, clinicians and patients. GINA supporters are hopeful that it will facilitate increased participation by the public in research and eliminate fear of genetic discrimination. Critics of GINA are apprehensive about its application in just employment and health insurance and not in other potential type of discrimination like lie insurance and disability insurance discrimination (McGuire & Majumder, 2009).

GINA is a very important step to ensure genetic privacy and nondiscrimination. However, it is still unclear how the general population, patients, and health providers
discuss genetic testing and potential discrimination during a genetic counseling session since the implementation of GINA. To effectively implement GINA patients and health care providers must be educated about its protections and limitations. Genetic counselors, as central figures to the delivery of genetics services have firsthand experience with patients, other health care providers and the health insurers. They are involved in educating these groups for genetic purposes. Thus assessing changes in the genetic counseling practices following GINA implementation would be an important approach to understanding the law’s effectiveness. Until now there has been no published study of genetic counselors’ knowledge of and attitudes towards GINA and to assess their experiences with genetic discrimination since its implementation.

**Purpose of my study**

The **purpose** of my study is to explore whether GINA is being perceived as an effective law by genetic counselors and their patients, and if the genetic counseling practice has changed as a result of GINA. Identifying changes in genetic counseling practice is important due to several reasons. First, it will help to estimate the trust GINA has acquired among genetic counselors and their clients. Second, it will provide an assessment of whether genetic discrimination is still a legitimate concern among genetic counseling clients. Third, it will provide insights into whether GINA is discussed during genetic counseling sessions or impacts how counselors practice and patients make decisions about testing and disclosing genetic information. The result of this study will be useful in improving education and communication about GINA for both genetic counselors and patients.
This study specifically aims to: 1) Describe counselor’s experiences discussing concerns of genetic discrimination with patients in different specialty settings 2). Ascertain whether genetic counselors and their patients trust the ability of GINA to actually provide the protections it was designed to give. 3). Assess the current knowledge about GINA among genetic counselors by specialty. Following are the hypotheses for this project.

For assessment of genetic counselor’s knowledge about GINA:

1. Genetic counselors are knowledgeable about the scope and limitations of GINA.

For assessment of genetic counselor’s attitude towards GINA:

2. Genetic Counselors are having the conversation about genetic discrimination with more clients since the GINA implementation.

3. Most Genetic counselors have never counseled a client who is/have been a victim of genetic discrimination.

4. Genetic counselors within cancer setting are more likely to report that they are aware of genetic discrimination incidents than genetic counselors in pediatric, prenatal or other settings.

5. Genetic counselors are discussing GINA with most of their clients.

6. Genetic counselors working in cancer clinic discuss GINA more often than the genetic counselors working in pediatric, prenatal or other clinics.

7. Genetic counselors are confident of the protections provided by GINA.
8. Genetic counselors are comfortable disclosing their own genetic information to their primary care physician, friends, family and colleagues at work.

For assessment of genetic counselor’s experience while counseling clients regarding genetic discrimination after implementation of GINA:

9. The majority or more than 50% of clients who come for genetic counseling have no prior awareness of GINA.

10. According to the experience of counselors, clients in genetic counseling sessions express less fear or anxiety about genetic discrimination since the GINA implementation after the implications of GINA are discussed with them.

11. Genetic counselors’ clients are more willing to undergo genetic testing after the implications of GINA are discussed with them.
Methods

Study Design

This study received human subject approval from the Brandeis University Institutional Review Board. This is a quantitative cross sectional study of genetic counselors currently practicing in United States.

Study Procedures

Recruitment Procedures and Criteria: This study recruited from the National Society of Genetic Counselors (NSGC) listserv, which has more than 2500 enrollees. An email posted to the listserv on January 18, 2011 contained recruitment notice (Appendix I) and link to an anonymous online survey (Appendix III). The survey was also posted on the NSGC listserv of Special Interest Groups for Familial Cancer Risk Counseling which has around 700 enrollees. It is likely that there was an overlap of subscribers between the two listservs. Eligibility to participate included being a United States based practicing genetic counselors.

Instrument Design: The survey tool was formulated to ascertain the knowledge, attitude and client experience of genetic counselors regarding GINA. The survey consisted of 32 questions that were both open and closed ended. The four sections of the survey included questions to assess 1) selected counselor demographics and practice characteristics (e.g.
gender, age, state residency, years in practice, area of specialty), 2) counselor knowledge about the scope and limitations of GINA, 3) counselor attitudes towards GINA, 4) counselor experience counseling clients regarding genetic discrimination pre and post passing of GINA. For the scale questions, the lowest value always signifies low likelihood of performing an action or disagreement with the statement. Higher values indicates more likely to perform an action or agree with the statement. For example 1 in a scale of 5 means least likely and 5 means most likely. The scale always started from 1. The open ended questions had space for participants to elaborate on their experience regarding genetic discrimination and affect of GINA. I incorporated a few modified questions from two previous surveys of genetics professionals to compare the results (Huizenga, et al., 2010; Matloff, et al., 2000). The modified questions are noted in the survey (Appendix III).

Data Collection

Data was collected trough an anonymous online survey using Qualtrics (www.qualtrics.com), an Internet based survey platform (Appendix III). The survey was open for approximately three weeks beginning in January 2011. Reminders were posted twice at one week intervals.

Data Analysis

Upon the closing of the survey, responses were downloaded into Predictive Analytic Software (PSAW) Statistics version 18.0 for data analysis. Descriptive statistics were used to characterize the respondents’ demographics and practices and obtain an
aggregated assessment of their attitudes and experiences with GINA. The statistical comparisons based on practice characteristics such as specialty, regarding counselors’ knowledge, attitude and practice after GINA implementation, were performed using bivariate statistical tests such as chi square association analysis, one-way ANOVA tests, tukey HSD (honestly significant difference) tests and independent sample t-tests. While performing independent sample t-tests on the scale questions, we considered mid-point of the scale as the test value as it represents neither likely nor unlikely to perform an action or agreement with the statement. This way a t-value greater than the test value signifies more likelihood of performing an action and a t-value smaller than the test value signifies less likelihood of performing an action.

Compensation

Participants who completed the survey were given the option of entering a raffle for one of two $25 gift certificates to Amazon.com. To keep the survey anonymous, I gave an independent raffle survey link to them on the last page of the study survey thus making sure that respondents’ email addresses were not linked to their survey responses.
Results

A total of 304 surveys were started with varying degree of completion. The respondents who completed the survey till or more than the Section I (with GINA-related knowledge questions) were included in the analysis. Thus a total of 257 survey responses were used.

Demographics

Table I shows the distribution of respondents’ gender, region, degree, distribution of clinical vs. non-clinical practice and specialty of practice. Out of 248 participants who responded to the question, 241 were females (97.2%) and 7 were males (2.8%). This represents almost the same distributions as 2010 Professional Status Survey (PSS) of 95% female and 5% male (Baxter, 2010). The respondent age ranged from 24 years to 61 years with a mean age of 33.43 years. Approximately 70% of the respondents were 35 years old or younger while 58% of the PSS respondents were 34 years old or younger. Participants were given the choice of the same six geographical regions as PSS. All regions were represented with the largest group (33.4%) of respondents representing region 4.
**Practice Characteristics:** Out of 257 respondents, the majority (N=205, 79.8%) hold a MS/MA/ScM in genetic counseling (vs. 77% in PSS), followed by MS/MA/ScM genetics (Human Medical) (N=41, 16% vs. 21% in PSS). The number of years respondents reported practicing genetic counseling ranged from less than 1 year to 32 years, with a mean of 7.8 years. More than half (52.5%) of the sample have been practicing for 5 or fewer years and an additional 21.3% have practiced for between 6 and 10 years. Out of 257 respondents, 241 (93.8% vs. 82.6% in PSS) reported practicing with at least some client interaction and they were categorized as “clinical genetic counselors” for the remainder of the results, while the remaining 16 (6.2% vs. 17.4% in PSS) counselors reported no client interaction at all and were categorized as “non-clinical genetic counselors”.

Respondents were asked to report the percentage of working time spent in 15 specialties areas of genetic counseling. They were assigned to a specific specialty if they spent equal to or more than 50% of their time in that specialty as was done in PSS (Baxter, 2010). If a counselor reported spending less than 50% time in all the categories or spent 50% time in 2 categories then they were assigned to the group “others”. Also, any specialty with less than 15 people in it was merged with the “others” group. Therefore, the specialty area of practice were narrowed down to 4 groups; Cancer (N=82, 31%), Prenatal (N=60, 23.4%), Pediatrics (N=27, 10.5%) and Others (N=88, 34.2%).
Table I. Demographic information of the genetic counselors

<table>
<thead>
<tr>
<th></th>
<th>Frequency (n)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender (N=248)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>241</td>
<td>97.2</td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>2.8</td>
</tr>
<tr>
<td><em><em>Region</em> (N=247)</em>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>29</td>
<td>11.7</td>
</tr>
<tr>
<td>2</td>
<td>57</td>
<td>23.1</td>
</tr>
<tr>
<td>3</td>
<td>29</td>
<td>11.7</td>
</tr>
<tr>
<td>4</td>
<td>82</td>
<td>33.2</td>
</tr>
<tr>
<td>5</td>
<td>20</td>
<td>8.1</td>
</tr>
<tr>
<td>6</td>
<td>30</td>
<td>12.1</td>
</tr>
<tr>
<td><strong>Degree (N=257)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MS/MA/ScM genetic counseling</td>
<td>205</td>
<td>79.8</td>
</tr>
<tr>
<td>MS/MA/ScM genetics (Human Medical)</td>
<td>41</td>
<td>16.0</td>
</tr>
<tr>
<td>MS/MA other/non-genetics</td>
<td>8</td>
<td>3.1</td>
</tr>
<tr>
<td>PhD</td>
<td>4</td>
<td>1.6</td>
</tr>
<tr>
<td>MPH</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>MBA</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>MSW/MSSW</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Med</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Other advanced degree</td>
<td>2</td>
<td>0.8</td>
</tr>
</tbody>
</table>
Clinical vs. Non-Clinical Practice (N=257)

<table>
<thead>
<tr>
<th></th>
<th>Clinical</th>
<th>Non-Clinical</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>241</td>
<td>16</td>
</tr>
<tr>
<td>Specialty of Practice (N=257)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>82</td>
<td>31.9</td>
</tr>
<tr>
<td>Prenatal</td>
<td>60</td>
<td>23.3</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>27</td>
<td>10.5</td>
</tr>
<tr>
<td>Others</td>
<td>88</td>
<td>34.2</td>
</tr>
</tbody>
</table>

*Region 1= (CT, MA, ME, NH, RI, VT, CN), Region 2= (DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI), Region 3= (AL, FL, GA, KY, LA, MS, NC, SC, TN), Region 4 = (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI), Region 5 = (AZ, CO, MT, NM, TX, UT, WY), Region 6 = (AK, CA, HI, ID, NV, OR, WA)

Genetic counselor knowledge about limitations and protections of GINA

To assess the respondent knowledge about the limitations and protections of GINA respondents were given 15 statements with true/false/uncertain response options. One point was awarded for each correct answer so score could range from 0 to 15. The mean for knowledge of the sample is 11.07 (SD 2.56), which is significantly greater than the test value 7.5 (t(256)=22.01, p<0.05) (Figure 1). Thus the sample of genetic counselors had significant knowledge of scope and limitations of GINA. More than 56% of genetic counselors answered correctly when asked about the general provisions of GINA. An impressive 99.3% of respondents knew that GINA protects against the use of genetic information to discriminate in health insurance. However, only 33.8% of respondents could answer correctly about the scope of GINA for direct-to-consumer
genetic testing result and only 44.2% of respondents knew that GINA does not prohibit health insurers from using information about an existing genetic condition.

**Figure 1: Distribution of genetic counselor’s score on GINA-related knowledge questions**

Results from one-way ANOVA test to analyze if the genetic counselor’s knowledge about GINA differed according to their work specialty were statistically significant at the p<.05 level for the four specialty groups [F(3, 253)= 11.71, p< 0.01]. Post hoc comparison using the Tukey HSD test indicated that the mean score for the cancer genetic counselors (M 11.89, SD 1.62) was significantly different than prenatal genetic counselors (M 9.6, SD 3.17) and pediatric genetic counselors (M 10.37, SD 2.43). However the mean score of cancer genetic counselors did not significantly differ than the mean of genetic counselors in the “others” specialty (M 11.35, SD 2.42).
Genetic counselor attitude regarding genetic discrimination and GINA

**Hypothesis 1:** Genetic counselors are having the conversation about genetic discrimination with more clients since the GINA implementation.

The respondents were asked about the proportion (none, few, most, all) of clients with whom they discuss genetic discrimination before and since the GINA implementation. A paired samples t test revealed a statistically significant difference pre and post-GINA implementation for the proportion of conversation the respondents had with their clients [Post-GINA M 3.92, SD 1.42, pre-GINA M 3.81, SD 1.46, t(194) = 2.27, p = 0.02]. A one-way ANOVA test was conducted to assess whether there is an association between genetic counselor work specialty and the frequency of discussion about genetic discrimination with the clients. There was a significant association between specialty and the discussion frequency about genetic discrimination [F(3, 230)= 46.17, p< 0.01]. Post hoc comparison using the Tukey HSD test indicated that the mean frequency for the cancer genetic counselors (M 4.85, SD 1.00) was significantly different than prenatal genetic counselors (M 2.58, SD 0.98), pediatric genetic counselors (M 3.48, SD 1.22) and the genetic counselors in the “others” specialty (M 3.99, SD 1.30). Thus, genetic counselors in cancer setting discuss genetic discrimination with more clients as compared to genetic counselors in pediatric, prenatal or “others” settings.

**Hypothesis 2:** Most Genetic counselors have never counseled a client who is/have been a victim of genetic discrimination.
The counselors were asked if any of their clients reported experiencing discrimination in health insurance or employment. Out of total 223 respondents only 16 (7.2%) reported counseling client who had been a victim of health insurance discrimination. Out of these 16 respondents, 10 genetic counselors reported counseling these clients only before GINA was enacted, one only since GINA was enacted and five both before and since GINA was enacted (Table 2). A chi-square fitness test revealed that the total number of responses were not uniformly distributed among the yes and no categories and majority of genetic counselors have never counseled a client who has experienced health insurance discrimination, $\chi^2(1, N = 223) = 163.59 \ p < .001$. Out of total 227 respondents only 10 (4.4%) reported counseling client who had been a victim of employment discrimination. Out of these 10 respondents, four genetic counselors reported counseling these clients only before GINA was enacted, one only since GINA was enacted and five both before and since GINA was enacted (Table 2). A chi-square fitness test revealed that these responses are not uniformly distributed between the yes and no categories; the majority of genetic counselors having never counseled a client who experienced employment discrimination $\chi^2(1, N = 227) = 188.76 \ p < .001$. 


Table 2: Genetic counselor’s responses for client reporting of genetic discrimination

<table>
<thead>
<tr>
<th>Client reporting of health insurance discrimination (N=223)</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, before GINA enactment</td>
<td>10</td>
<td>4.5</td>
</tr>
<tr>
<td>Yes, since GINA enactment</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Yes, both before and after GINA enactment</td>
<td>5</td>
<td>2.2</td>
</tr>
<tr>
<td>No neither before or after GINA enactment</td>
<td>207</td>
<td>92.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Client reporting of employment discrimination (N=227)</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, before GINA enactment</td>
<td>4</td>
<td>1.8</td>
</tr>
<tr>
<td>Yes, since GINA enactment</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Yes, both before and after GINA enactment</td>
<td>5</td>
<td>2.2</td>
</tr>
<tr>
<td>No neither before or after GINA enactment</td>
<td>217</td>
<td>95.6</td>
</tr>
</tbody>
</table>

Out of 26 counselors who reported counseling clients who had experienced either health or employment discrimination 23 gave details about the genetic conditions for which their clients were discriminated. Two counselors reported a diagnosis of Huntington Disease, 10 counselors reported the diagnosis of hereditary breast and ovarian cancer (BRCA testing), 3 counselors reported it for other cancers (prostate cancer, Lynch syndrome, Li-Fraumeni Syndrome), 2 counselors reported discrimination for Marfan Syndrome. The other 5 genetic counselors gave the diagnosis of Down Syndrome, Familial hypercholesterolemia, Neurofibromatosis type I, Stargardt disease and Myotonic dystrophy. One genetic counselor reported that military personnel feared the potential for
discrimination and another reported that the client only knew of someone who was
denied insurance coverage but did not personally experience it.

Selected quotes from genetic counselors regarding their experience with discrimination:

“Both were Huntington's. First pt [sic], she told her friend/boss about a positive presymptomatic
test. They started treating her differently. She was no longer the "darling" of the company. Eventually,
they found fault with her. She was later laid off. Sh [sic] was NOT symptomatic.”- regarding Huntington's
disease.

“An individual with NF1 was fired because he was working in the service sector and multiple
clients worried he had a communicable disease.”- regarding Neurofibromatosis type I.

“Patient was fired after management found out about her vision issues, but different reason was
evoked for the firing (performance, even though she was a top notch performer).”- regarding Stargardt
disease (ABCA4).

“Don't know all of the details of the case just that supposedly she was told that her position was no
longer available after she had told her employer that she was BRCA+ and was out on medical leave/paid
time off for prophylactic surgeries.”- regarding BRCA testing.

“There were problems with children with history of a birth defect getting health insurance at a
reasonable rate/ being denied. Also there was some discrimination with the military and two patients with
myotonic dystrophy.”- regarding birth defects, Marfan Syndrome and Myotonic dystrophy.

**Hypothesis 3:** Genetic counselors within cancer setting are more likely to report that they
are aware of genetic discrimination incidents than genetic counselors in pediatric,
prenatal or other settings.

Out of the 16 genetic counselors who reported counseling a client who was a
victim of health insurance discrimination, 5 work in cancer specialty, 4 work in prenatal
specialty, 3 work in pediatrics and 4 work in other specialties. Among the 10 genetic
counselors who reported counseling a client who was a victim of employment
discrimination, 3 reported working in cancer specialty, 1 in prenatal specialty, 2 in
pediatric specialty and 4 in other specialties. These counselors are unequally distributed
in different specialties; 5 out of 82 for cancer (5/82=0.06), 4 out of 60 for prenatal
(4/60=0.06), 3 out of 27 for pediatrics (3/27=0.11), and 4 out of 88 for “others” specialty
(4/88=0.04). However, when asked about the details of these discriminatory cases the majority (56.52%) of the reported cases were in the cancer setting.

**Hypothesis 4:** Genetic counselors are discussing GINA with most of their clients.

Genetic counselors were asked for the approximate percentage of their clients with whom they discuss GINA. The mean value for discussion of GINA with clients is 42.7% (SD 35.38), in other words genetic counselors discuss GINA with less than 50% of their clients t(180)= -2.78, p<0.01. This does not support the proposed hypothesis that genetic counselors are referring to GINA to most of their clients. In a related question, the counselors were given six circumstances to determine when they are likely to talk to their clients about GINA. The response of genetic counselors is summarized in Table 3.

**Table 3: Circumstance when genetic counselors discuss GINA with their clients**

<table>
<thead>
<tr>
<th>Circumstance when genetic counselors discuss GINA with their clients (N=257)</th>
<th>Frequency (n)</th>
<th>Percentage (%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>With every client as a part of the genetic counseling process</td>
<td>54</td>
<td>21.0</td>
</tr>
<tr>
<td>While offering a genetic testing to a relative of an affected person</td>
<td>101</td>
<td>39.3</td>
</tr>
<tr>
<td>When the genetic diagnosis would not change the medical care</td>
<td>32</td>
<td>12.5</td>
</tr>
<tr>
<td>When the client asks about it</td>
<td>166</td>
<td>64.6</td>
</tr>
<tr>
<td>Never</td>
<td>8</td>
<td>3.1</td>
</tr>
<tr>
<td>Under specific circumstances not listed above</td>
<td>65</td>
<td>25.3</td>
</tr>
</tbody>
</table>

*Please note that it was a check all that apply question so the total of percentage is not 100%.
Of the 65 respondents who reported discussing GINA with their clients in other circumstances not provided in the survey, 32 provided additional information. Of those, the most common circumstance (n=16) was while offering genetic testing to an unaffected or presymptomatic individual. The second common circumstance (n=11) was genetic testing for cancer predisposition syndrome. Four counselors discuss it when a client expresses a concern about discrimination or specifically asks about the law. Health insurance concerns (self-employment, private insurance, change of insurance) were inductive for some genetic counselors (n=3) to talk about GINA. Rest of the counselors (n=3) reported discussing GINA with a client as part of the informed consent process for enrollment in a research study.

**Hypothesis 5:** Genetic counselors working in cancer specialty discuss GINA more often than the genetic counselors working in pediatric, prenatal or other specialties.

A one-way ANOVA test was conducted to compare the relationship between genetic counselor specialty and the percentage of clients GINA was discussed with. There was a significant difference between different specialties in the percent of clients with whom they discussed GINA [F(3, 177)= 34.93, p< 0.01]. Post hoc comparison using the Tukey HSD test indicated that the mean score for the cancer genetic counselors (M 68.29, SD 29.76) was significantly different than prenatal genetic counselors (M 11.38, SD 14.86), pediatric genetic counselors (M 28.91, SD 27.09) and genetic counselors in the others specialty (M 39.16, SD 33.13) (Figure 2). These results support the hypothesis.
Figure 2: Genetic counselor’s discussion about GINA with clients according to their work specialty

<table>
<thead>
<tr>
<th>Counselor Work Specialty</th>
<th>Discussion with clients about GINA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>75%</td>
</tr>
<tr>
<td>Others</td>
<td>45%</td>
</tr>
<tr>
<td>Pediatric</td>
<td>30%</td>
</tr>
<tr>
<td>Prenatal</td>
<td>10%</td>
</tr>
</tbody>
</table>

Hypothesis 6: Genetic counselors are confident of the protections provided by GINA.

To test this hypothesis, genetic counselors were asked a total of nine questions. The first two questions asked how confident are they about the ability of GINA to protect against health insurance discrimination and employment discrimination. A majority of the respondents (53%) were somewhat confident and 40.1% were very confident as compared to a total of 6.9% of respondents who answered somewhat unconfident and not at all confident for protection against health insurance discrimination. For the protections offered by GINA against employment discrimination, 52.8% of respondents were somewhat confident and 37.8% were very confident against the small total of 9.3% of respondents who felt somewhat unconfident and not at all confident. Genetic counselors reported an average confidence rating of 3.32 (SD 0.637, t(246)= 20.23, p<0.05) for
health insurance protections and 3.27 (SD 0.66, t(245)=18.35, p<.005) for employment protections provided by GINA on a 4-point scale (Figure 3) which is significantly greater than the midpoint 2.5.

I conducted a one-way ANOVA test to analyze if the genetic counselor confidence with protections offered by GINA varied according to their work specialty. There was a significant association between specialty and the confidence about GINA’s protections at the p<0.05 level for the four specialties. [F(3, 243)= 5.68, p< 0.01]. Post hoc comparison using the Tukey HSD test indicated that the mean confidence score for the cancer genetic counselors (M 3.54, SD 0.55) was significantly different than prenatal genetic counselors (M 3.21, SD 0.74), pediatric genetic counselors (M 3.08, SD 0.5) and genetic counselors in the “others” specialty (M 3.25, SD 0.62). These results support the hypothesis.

The respondents were asked how reassuring do they try to be with their clients regarding the effectiveness of GINA to protect against health insurance and employment discrimination. Regarding health insurance protections 57.9% of counselors were very reassuring and 39.4% were somewhat reassuring (total 97.3%) while only 2.7% reported to be minimally reassuring. For employment insurance protections 52.8% of respondents reported to be very reassuring, 44% were somewhat reassuring (total 96.7%) and only 3.3% were minimally reassuring and not at all reassuring. The average degree of reassurance offered to clients was significantly greater than the midpoint value of 2.5 on a scale of 4. The mean reassurance rating was 3.55 (SD 0.55, t(220)= 28.41, p<0.01) for health insurance protections and 3.49 (SD 0.58, t(217): 25.31, p<0.01) for employment protections (Figure 3). There was a positive correlation between confidence in health insurance discrimination protection, and reassurance offered to the clients (r= 0.63,
p<0.01). Also, a positive correlation was found between confidence in employment
discrimination protection and reassurance offered to the clients (r= 0.67, p<0.01).

**Figure 3: Confidence and reassurance response ratings**

To assess respondents’ confidence in GINA when considering their own
healthcare respondents were asked if their probability of carrying a BRCA mutation is
50%, to what extent would their decision to get tested or not be influenced by concerns
about health insurance and employment discrimination. The mean response was found to
be 1.97 for health insurance (SD 1.16, t(250)= 21.01, p<0.05) and 1.58 for employment
(SD 0.95, t(249)= 32.09, p<0.05) discrimination. This is significantly less than the
midpoint (3.5) on the scale. Approximately 89% of the respondents answered “not”
concerned, “minorly” concerned and “somewhat” concerned for health insurance
discrimination whereas 95.2% answered “not” concerned, “minorly” concerned, and
“somewhat” concerned for employment discrimination while getting tested for BRCA
mutation. This indicates that counselor decision to get tested appears not to be influenced by concerns about either forms of discrimination for a genetic test like BRCA.

The respondents were asked that if they were to undergo predictive genetic testing for BRCA, how likely are they to seek coverage from insurance, use alias, or pay out of pocket. The mean of responses for whether they would seek insurance coverage was 6.16 (SD 1.32), which is significantly greater than the midpoint 4 on the scale (t(250)= 25.92, p<0.01). The genetic counselor mean response regarding using an alias was 1.55 (SD 1.04) which is significantly less than the midpoint 4 on a scale of 7 (t(250)= 37.26, p<0.01). The respondent mean regarding paying out of pocket for BRCA testing was 2.28 (SD 1.61) which is significantly less than the midpoint 4 [t(250)= 16.98, p<0.01]. Approximately 87% of genetic counselors are very likely, likely and somewhat likely predicted to seek insurance coverage for BRCA testing and 92% are very unlikely, unlikely and somewhat unlikely to use an alias.

**Hypothesis 7:** Genetic counselors are comfortable disclosing their own genetic information to their primary care physician, friends, family and colleagues at work.

To test this hypothesis genetic counselors were asked that in case of being tested positive for a BRCA mutation, how likely would they be to disclose their carrier status to various categories of individuals. The mean response for disclosing to their primary care physician was 6.52 (SD 0.94, t(250)= 42.73, p<0.01), 6.96 for their spouse (SD 0.27, t(250)= 172.08, p<0.01), 6.90 for close family member(s) (SD 0.36, t(249)= 128.69, p<0.01), 6.13 for close friend(s) (SD 1.20, t(250)= 28.04, p<0.01), 4.46 for work place colleagues (SD 1.84, t(250)= 3.99, p<0.01) on a scale of 7 (Figure 4). All these mean
values are greater than the mid-point 4. Specifically, 94.8% of genetic counselors reported that they are very likely, likely or somewhat likely to disclose their positive BRCA status to their primary care physician. This percentage was 100% for their close family member (s), 89.2% for their close friend (s), 51.8% for their colleagues at work place. On the contrary, respondents’ willingness to disclose to their employer was lower than the mid-point of the scale \([M \ 3.01, \ SD \ 1.83, \ t(249)= 8.55, \ p<0.01]\) (Figure 4).

**Figure 4: Mean of responses for disclosure to others**

![Bar chart showing the mean responses for disclosure to others.](chart)

**Genetic counselor reporting of their clients’ perceptions about GINA and experiences with genetic discrimination after implementation of GINA**

The questions in this section were presented to only those genetic counselors who have at least some client interaction, categorized as “clinical genetic counselors” \((n=241)\). Genetic counselors with no client interaction \((n=16)\) did not get to answer this section of the survey.
**Hypothesis 1:** The majority of clients who come for genetic counseling have no prior awareness of GINA.

To test this hypothesis, genetic counselors were asked for the approximate percentage of their current client population that they think is aware of the existence of GINA before the counseling session. According to the genetic counselors, the mean percentage of clients aware of GINA before the genetic counseling session begins is 15.7% (SD 15.22, t(212)= 5.67, p<0.01). The sample mean is less than my predicted value of 50 which indicates that according to the counselors majority of their client population has no prior awareness of GINA before the genetic counseling session.

**Hypothesis 2:** According to the experience of counselors, clients in genetic counseling sessions express less fear or anxiety about genetic discrimination since the GINA implementation after the implications of GINA are discussed with them.

To test this hypothesis, counselors were asked to assess their clients’ level of concern since the beginning of 2010, regarding health insurance, employment, life insurance, disability insurance, long-term insurance, and social discrimination. Means for all the different type of discrimination were in the range of 1.45 to 2.93 on a scale of 7 indicating that the clients did not appear to be concerned about any of these discrimination. The mean for client concern for various type of discrimination was; 2.93 for health insurance (SD 1.79, t(216)= 4.67, p<0.01), 1.48 for employment (SD 1.23, t(190)= 22.73, p<0.01), 2.22 for life insurance (SD 1.67, t(200)= 10.82, p<0.01), 1.45 for disability insurance 1.45 (SD1.22, t(185)= 22.93, p<0.01), 1.57 for long-term insurance
(SD1.43, t(179)= 18.09, p<0.01), 1.64 for social (SD: 1.50, t(187)= 16.88, p<0.01). All of these values of mean were below the mid-point of 4 on a scale of 7 (Figure 5).

Figure 5: Mean of responses for counselor’s estimation of client concern for discrimination

To further test this hypothesis, genetic counselors were asked about the approximate number of clients they have counseled since the beginning of 2010 who requested anonymous genetic testing after discussion of GINA. Out of total 257 respondents, only 33 (12.8%) reported anonymous testing requests from the clients. The majority of these 33 respondents (51.4%) had only 1 client who made this request (Figure 6).
The respondents were also asked about the percentage of their client population since the beginning of 2010 who were concerned about health insurance and employment discrimination after a discussion of GINA. The mean for percentage of clients reported to be concerned about health insurance discrimination was 12.9% (SD 15.76, t(200)= 33.30, p<0.01) and for employment discrimination the mean was 8.8% (SD 13.82, t(175)= 39.59, p<0.01). These mean values are significantly less than 50% supporting the hypothesis that majority of genetic counselor’s clients are not concerned about health insurance and employment discrimination following a discussion with the genetic counselor about GINA.
Hypothesis 3: Genetic counselors’ clients are more willing to undergo genetic testing after the implications of GINA are discussed with them.

I tested this hypothesis by asking the respondents to assess the likelihood of a client to opt out of genetic testing after the discussion of GINA due to the fear of health insurance and employment discrimination. Approximately 94% of the counselors reported that their clients are very unlikely, unlikely or somewhat unlikely to opt out of the testing for fear of health insurance discrimination and 98% chose these choices for employment discrimination. The mean likelihood of clients opting out of genetic testing as reported by genetic counselors on a six-point scale was 1.97; due to fear of health insurance discrimination (SD 0.85, t(202)=25.65, p<0.01) and 1.66; due to fear of employment discrimination (SD 0.74, t(199)=35.22, p<0.01). These values of mean are significantly less than the midpoint 3.5 thus supporting the hypothesis that clients are not likely to opt out of genetic testing due to fear of health insurance or employment discrimination after the GINA discussion.

I conducted a one-way ANOVA test to analyze if genetic counselors’ client likelihood to opt out of genetic testing varied according to their work specialty. There was a significant association between specialty and the confidence about GINA’s protections at the p<0.05 level for the four specialties. [F(3, 199)= 3.38, p= 0.02]. Post hoc comparison using the Tukey HSD test indicated that the likelihood of opting out of genetic testing for the clients of cancer genetic counselors (M 1.76, SD 0.71) was significantly different than clients of prenatal genetic counselors (M 2.15, SD 1.00), pediatric genetic counselors (M 2.26, SD 0.93) the genetic counselors in the others specialty (M 2.05, SD 0.84).
To further test the above hypothesis, I asked the respondents to give the extent of their agreement for the statement, “Fewer people decline genetic testing when I discuss GINA in my sessions as compared to when I do not discuss GINA.” The respondent agreement mean was 4.18 (SD1.46) on a scale of 7 which was more than the midpoint 4 but this was not statistically significant. The respondents were also asked to give the extent of their agreement for the statement, “I have seen an increase in the number of individuals willing to participate in genetic research after I have informed them about GINA.” The respondent agreement mean was 3.99 (SD 1.37) on a scale of 7 which was less than the midpoint 4. This too was not statistically significant. Thus, these results do not support my hypothesis.

Views of genetic counselors about the impact of GINA

Genetic counselors were asked to discuss thoughts or concerns about the impact of GINA has had on their practices and a total of 62 counselors responded. Eighteen genetic counselors felt GINA provides reassurance for their clients. These counselors pointed out that GINA is “an important first step”, “a huge milestone even though not perfect”, “especially beneficial when talking with African-American and Jewish patients”. However, they also indicated a general mistrust of insurance companies and government by the clients. Thirteen counselors reported that their clients are still wary about being discriminated due to their genetic status. The reasons for this included “it will not always be in place”, “limitations of GINA”, “it merely establishes a process….in no way prevents and [sic] insurance payer or employer from taking an action”, “patients… do not trust the system”, “patients still rely heavily on ‘hear-say’ in which their friends have friends of friends who were reportedly [discriminated] against (by
health insurers, mostly), “it would be hard to prove genetic discrimination…GINA is too
new a law”, “media and actually some doctors are not helping as they actually warn them
NOT to do genetic testing because they will be discriminated against”.

Yet another group of 11 counselors said that most of their clients do not think or
are unconcerned about genetic discrimination. They have other larger concerns (e.g.
medical, immigration, children) than genetic discrimination. Three counselors said that
the general public is still unaware of GINA. A few (n=6) genetic counselors discussed
their concerns about limitations of GINA for coverage of life insurance, disability
insurance, long-term care insurance and military personnel. A few counselors thought
that GINA had a “minimal impact” or were unsure about its impact.
**Discussion**

This study assesses the changes in the practice of genetic counseling since the implementation of GINA, a federal law designed to protect the public from health insurance and employment discrimination due their genetic status (GINA §101, 2008). The majority of studies done before and since the passage of GINA included small sample sizes with a focus solely on cancer genetic testing. Thus they are not conclusive. This is the first study to assess genetic counselors’ attitudes towards genetic discrimination and GINA since the implementation of law.

A total of 304 surveys were started and 257 of these were completed to an extent suitable for analysis. This represents approximately 10% of more than 2500 genetic counselors reported in PSS (Smith, 2009).

**Genetic counselor knowledge regarding protections and limitations of GINA**

A recent survey of genetic counselors reported that 55% of their sample wanted to learn more about GINA’s protections against health insurance discrimination and 71% of counselors wanted more clarity over what GINA does not cover (Zonno, 2009). My sample of genetic counselors had significant knowledge of the scope and limitations of GINA. In two recently conducted surveys, over half of surveyed non-geneticist physicians were unaware of the existence of GINA (Bretl, 2010; Fusina, 2009). Not
surprisingly, the general awareness of genetic counselors about GINA is greater than non-geneticist physicians’ awareness as GINA is a legislature applicable to the genetics profession.

This is the first study to report the GINA-related knowledge assessment of genetic counselors and thus will be useful as the baseline of genetic counselors’ knowledge about GINA. According to this study’s results genetic counselors are aware of the main protections offered by GINA, there is still a need for educating them about the details of GINA relevant to their practice. Only a small percentage of the respondents could correctly answer the knowledge questions about the details such as scope of GINA for direct-to-consumer genetic testing result and its limitation regarding pre-existing genetic conditions.

When comparing knowledge by specialty of work, cancer genetic counselors scored higher than pediatric or prenatal genetic counselors. However, the cancer genetic counselors do not appear to know more when compared to genetic counselors working in other specialties. Unlike prenatal and pediatrics, cancer counseling is mostly done for adults and people may tend to be more worried about the immediate potential discrimination than they would be for their children or potential offspring discrimination possibility in the future. The predisposition genetic testing for hereditary cancer syndrome is likely to raise client anxiety levels by providing predictive (not diagnostic) information that leaves them in a critical position for making decisions based on risk estimates alone (Matloff, et al., 2000). Therefore, it is possible that cancer genetic
counselors encounter more queries from anxious clients and need to be more aware of the anti-discriminatory laws.

**Genetic counselor attitude regarding genetic discrimination and GINA**

Ideally, GINA should help in reducing fear of discrimination thereby encouraging individuals to pursue genetic testing when useful to the individual. If this law is viewed in general as effective against genetic discrimination then GINA has been successful in achieving its goal. In the few studies conducted since the enactment of GINA, clinicians were found to still be apprehensive in referring clients for cancer genetics testing and clients did not feel fully protected against genetic discrimination (Fusina, 2009; Klitzman, 2010). This is the first study to assess the attitude of genetic counselors regarding genetic discrimination since GINA enactment.

According to the current study’s results, genetic counselors are now discussing genetic discrimination with more clients as compared to before the advent of GINA. This may be because now they have an anti-discriminatory federal law to cite. My data confirms the findings from a previous survey, conducted after GINA was signed into law, of genetic counselors which found that 75% of the respondents felt comfortable or very comfortable talking about discrimination with their clients (Zonno, 2009). In addition, when I compared the proportion of clients across specialties, cancer genetic counselors were found to be discussing genetic discrimination with more clients than the genetic counselors practicing in other specialties. This is consistent with the finding of a recent study that around 96% of cancer genetic counselors reported always or almost always discussing genetic discrimination in their counseling sessions (Pfeffer, et al., 2003).
Genetic counselor reported cases of genetic discrimination: Most of the study sample has never counseled a client who has been a victim of genetic discrimination. Many of the few counselors who have counseled such reported counseling these clients before GINA was enacted but not since. This is indicative of the likelihood that perceived or actual genetic discrimination is decreasing since the advent of GINA. My results confirm the previous reports that genetic discrimination is mostly feared as opposed to actually happening (Hall & Rich, 2000a; Nowlan, 2002). Most of the genetic counselors [n=16 (health insurance discrimination), n=10 (employment discrimination)] who reported counseling the discriminated patients were sure that the discrimination claim was valid for most (91.3%) of their clients. Thus, these data contradict the reports of almost no documented case of genetic discrimination (Hall & Rich, 2000a). A majority (56.52%) of the reported genetic discrimination cases were in the cancer setting. However, this study sample size is too small to conclusively predict that genetic counselors within the cancer setting are more likely to report genetic discrimination incidents than genetic counselors in other settings.

Genetic counselors’ practice regarding GINA: My results indicate that while counselors are having more discussions with their clients about genetic discrimination, they still are not discussing GINA specifically with most of their clients. The counselors who do discuss GINA with their clients chose to do it under certain circumstances. The majority (64.6%) of counselors reported discussing it when the client asks about it. It was a question in which they could choose multiple options. Thus, raising the question that whether remaining 36% do not discuss it when the client asks about it or they preferred another choice as a better assessment of their practice. The next more frequently cited
circumstance in which the counselors discussed GINA included while offering genetic testing to a relative of an affected person and to an unaffected or presymptomatic individual. My results show that genetic counselors working in cancer genetics discuss GINA with more clients than the genetic counselors working in pediatric, prenatal or other specialties. This is an encouraging result indicating that whenever the concern of genetic discrimination is raised in a session, the counselors (at least cancer genetic counselors) are likely to discuss GINA.

The study sample reported having confidence in the protections provided by GINA. Cancer genetic counselors were found to be more confident when compared to other counselors. This is concordant with a study reporting 64% of cancer genetic counselors expressed confidence in existing federal laws prohibiting genetic discrimination (Huizenga, et al., 2010). In the current study, genetic counselors were likely to be reassuring with their clients regarding the effectiveness of GINA to protect against health insurance and employment discrimination. I found that genetic counselors’ confidence in GINA is positively correlated with the reassurance they offered to their clients, which is concordant to the previous surveys (Huizenga, et al., 2010).

**Genetic counselors’ attitude regarding their own healthcare decisions:** The majority of the counselors reported being unconcerned about either forms of discrimination when speculating about whether they would pursue testing for a BRCA mutation. Presumably, this is a result of their confidence in GINA. In the past, similar results were obtained in two studies when 84.5% and 94.7% of cancer genetics professionals predicted that they
would pursue genetic testing for BRCA in the same scenario (Huizenga, et al., 2010; Matloff, et al., 2000).

In a study done in 2000, only 23.9% of cancer genetics professionals predicted that they would submit a bill for genetic testing to their insurance company for reimbursement and 74.2% of the respondents said they would not use an alias (Matloff, et al., 2000). Ten years later in a similar study done pre-GINA, a majority of cancer genetics professionals (88%) predicted billing the insurance company and 98% said that they would not use an alias (Huizenga, et al., 2010). Similarly, we found that the majority of genetic counselors are likely to seek coverage from insurance (87.3%) for the genetic testing and are not likely to use alias (92.8%). This suggests that genetic counselors continue to not be concerned about genetic discrimination for either their patients or themselves.

Majority of the study respondents are likely to disclose their positive BRCA mutation carrier status to their primary care physician, spouse, close family member(s), close friend(s), and colleague at work place but not to their employer. In Matloff’s study, 81.5% respondents predicted they would disclose their genetic information to their physician, 97.5% to their family members, 58.6% with friends and 30.4% with colleagues (Matloff, et al., 2000). In the subsequent Huizenga study, 97.3% of cancer genetics professionals would share their genetic information with their physician, 100% with their family members, 64% with friends and 33.3% with colleagues (Huizenga, et al., 2010). My study found that a similar number of counselors would be willing to disclose their BRCA genetic result to their physician and family members and an even greater number
to their friends and colleagues. This indicates an increasing degree of confidence in genetic professionals regarding reduced risk of genetic discrimination since GINA implementation. However, there still remains a low likelihood that counselors would disclose the result to their employer. Regardless of whether there are non-discrimination laws such as GINA to protect an individual, the counselors in this study were still unwilling to share their personal test results with employers. This, however, may have little to do with concerns about discrimination that it does with the social barriers that exist between an employee and her employer.

**Genetic counselor reporting of their clients’ perceptions about GINA and experiences with genetic discrimination after implementation of GINA**

According to my findings, the vast majority (85%) of clients who come for genetic counseling have no prior awareness of GINA. These results are concordant with the 70% unaware cancer genetic counseling patients reported in a recent study (Senter-Jamieson, 2010). The increase in the percentage of GINA-unaware clients in the current study may be attributed to the fact that the patient population in the Senter-Jamieson’s study had already been to cancer genetics clinic while we asked about patient knowledge prior to the counseling session.

In previous studies approximately 40% of patients were reported to be concerned about genetic discrimination by health insurers (Hadley, et al., 2003; M. Hall, et al., 2005). Concordant to these reports, clinical genetic counselors in the current study reported that their clients have a low level of concern regarding health insurance, employment, life insurance, disability insurance, long-term insurance, and social
discrimination. Since the beginning of 2010, majority of genetic counselors (87.2%) have never been requested by their client for anonymous genetic testing after a discussion of GINA. Out of 33 subjects in the current study who reported receiving requests from clients for anonymous testing, 13 work in cancer specialty. This is approximately 15% of the cancer respondents. This is contrary to a previous study, in which 70% of cancer genetic counselors reported receiving requests for anonymous testing (Ader, et al., 2009). These data are suggestive of decreasing client concern regarding genetic discrimination over time.

In a pre-GINA study, 64% of cancer genetics professionals agreed that their clients are not likely to decline genetic testing due to fear of health discrimination (Huizenga, et al., 2010). Concordant with this, the current study subjects reported that their clients are not likely to opt out of genetic testing due to fear of either type of discrimination. Cancer genetic counselors were found to least likely report that their clients may opt out of genetic testing than genetic counselors in other specialties. However, genetic counselors reported no difference in a client’s decision to pursue genetic testing regardless of whether GINA was discussed or not. Also, they reported not having seen an increase in the number of individuals willing to participate in genetic research after they have informed them about GINA. Thus, although genetic counselors think that their clients are not likely to opt out of genetic testing due to the fear of discrimination, they feel that discussing GINA with a client would not make them any more likely to opt for genetic testing or enrollment in genetic research. It is hard to assess GINA’s specific impact on people’s decision to get tested with so many other factors.
simultaneously playing a role in their decision-making. As one of the respondent aptly states,

“It is difficult to separate the impact of GINA and the impact of the growing field of genetics; the growing reports of genetics in the news; the increased number of famous people speaking out about hereditary cancer; the increase positive involvement in [by] insurance companies developing policies for coverage of genetic testing; increase discoveries and acceptance in general for genomic medicine. You can't assume an increase in genetic referral and genetic testing is due solely to GINA. Additionally, you have new healthcare reform as a huge discussion in Congress with a big emphasis on no pre-existing conditions and insurance for all.”

Limitations

The participation in this study was voluntary. However, counselors who are interested in GINA, mention GINA in their counseling sessions or have had some firsthand genetic discrimination experience are more likely to complete the survey due to personal interest, thus leading to selection bias that may impact results. Due to small sample size, I was not able to get a broad variety of genetic counselors. This lead to inability to test the hypotheses that compare genetic counselors based on different area of specialty other than prenatal, cancer and pediatrics. This is a retrospective study about genetic counselors’ attitudes after GINA implementation. Therefore, recall bias is a possible concern when counselors responded to survey questions. The counselors’ reports about the impact of GINA on their clients are likely to be influenced by their own belief and not necessarily what clients are actually experiencing. Also, clients with the greatest fear of discrimination might not even come to the genetic counseling sessions and thus the genetic counselors’ experience would not incorporate those patients’ view. One respondent mirrors the same concern,
“My guess is the most important filter is whether patients get to the genetic counseling appointment in the first place. I would imagine lots of folks who do not make appointments or do not arrive for appointments are concerned about discrimination.”

However, in spite of these limitations genetic counselors are highly skilled and sensitive professionals trained to observe and assess the concerns of clients. Therefore, their views are a very important indicator of the GINA’s impact.
Conclusion

This study aims to assess changes in genetic counseling practice after the implementation of GINA. This is the first study to report the assessment of the knowledge of genetic counselors regarding protections and limitations of GINA. Also, this is the first report of genetic counselors’ attitude regarding genetic discrimination and GINA since its enactment. Genetic counselors were found to be aware of the main protections offered by GINA, but there is still a need of educating them about the relevant details of GINA. Genetic counselors reported discussing genetic discrimination with more clients as compared to before the implementation of GINA. However, counselors do not quote GINA to most of their clients. Majority of the counselors discuss it when the client asks about it. Genetic counselors working in cancer specialty discuss GINA with more clients than the genetic counselors working in pediatric, prenatal or other specialties. Genetic counselors are confident and reassuring to their clients regarding protections provided by GINA and do not appear to be concerned about genetic discrimination while deciding to get themselves tested for a genetic test like BRCA. Clinical genetic counselors reported that the majority (85%) of their clients have no prior awareness of GINA and have low concern regarding various types of potential discriminations for their genetic status. Thus, their clients are not likely to opt out of genetic testing due to fear of discrimination. It was not clear if this client behavior is due
to implementation of GINA. Conclusively, the genetic counselors and their clients do not appear concerned about genetic discrimination in the post-GINA era.

**Future Research**

Genetic Counselors’ awareness and response to discrimination risks for presymptomatic versus symptomatic clients should also be investigated. There is a need to assess the awareness and understanding of GINA by a variety of health care professionals and the general public. A large research study designed to explore concerns, ambiguities and issues concerning GINA and its implementation would be very beneficial. Also, any change in the general population’s perception regarding genetic discrimination in the light of GINA implementation should be investigated. Although recently a few small scale studies (Klitzman, 2010; Senter-Jamieson, 2010) were conducted on individuals confronting genetic disease to assess their view and experience of discrimination, we need a larger study to identify the concerns of the clients population. Until now there are very few documented cases of genetic discrimination in the literature, thus it will be interesting to see if these cases would increase with more clients perhaps feeling safer to get tested and disclose after GINA implementation.

The forms, degree and frequency of genetic discrimination should be explored more in the future. More research should be done to understand the subtle discrimination types and incidents in order to address them. Studies should be done to explore the psychosocial discrimination as to when do clients reveal or conceal their genetic information to family and friends and what are the factors influencing their decision. The discrimination faced by clients from different cultures should be explored in detail.
Appendices

Appendix I: Recruitment Notice

Email Subject Line: Invitation for study assessing genetic counseling practice after GINA implementation

Dear genetic counselors,

My name is Abhi K. Pamarti and I am a second year student in the Brandeis genetic counseling program. I am writing to ask for your participation in a brief survey assessing the effect of Genetic Information Nondiscrimination Act (GINA) on genetic counseling practices in the United States. This survey is the basis of my Master’s thesis and Brandeis IRB has approved it. The results of my thesis will be useful in improving education and communication about GINA for genetic counselors, other genetic health care providers and users of genetic services.

You are eligible to participate if you are a genetic counselor in the United States. Your participation in this study is completely voluntary, and survey responses are anonymous. It requires only about 15 minutes of your time. There are no foreseeable risks associated with this project. However, if you feel uncomfortable answering any questions, you can either skip the question or withdraw from the survey at any point.
As a gesture of appreciation for your time and input, you have the option of entering a raffle. The two raffle winners will each receive $25 gift certificate for Amazon.com. Your contact information will not be connected to your survey responses.

Please access the following website to participate in the survey:

*Link to the survey*

If you encounter any problems related to the survey or have questions about the study, you may contact me at akhattri@brandeis.edu or the thesis chair and Brandeis faculty, Barbara Lerner at lerner@brandeis.edu

Thank you for your Consideration!

Abhi K. Pamarti

Brandeis University,

akhattri@brandeis.edu
Appendix II: Informed Consent (This text appeared on the first page of the Internet based survey)

Please take a moment to read the following consent agreement:

I understand that this is a research study assessing effect of Genetic Information Nondiscrimination Act (GINA) on genetic counseling practices. I am aware that my responses to the survey questions will be used to assess genetic counselors’ attitudes, experiences and knowledge about GINA. Analysis of my responses will be useful in improving education and communication about GINA for genetic counselors, other genetic health care providers and users of genetic services.

I understand that participation is voluntary and all responses are anonymous. I may refuse to participate or choose to stop participating at any time without consequence. If I have any questions regarding this research, I may contact the student investigator, Abhi K. Pamarti at akhattri@brandeis.edu or Brandeis University faculty, Barbara Lerner at lerner@brandeis.edu

I understand that at the end of the survey I may choose to enter a raffle for $25 gift certificate for Amazon.com. My contact information will not be connected to my survey responses.

I indicate my willingness to participate in this study under these conditions by clicking on the link below to enter the survey.

Note: If you have questions about your rights as a research subject please contact the Brandeis Institutional Review Board at irb@brandeis.edu or 781-736-8133.
Appendix III: Survey

1. **Informed consent**
2. Are you a genetic counselor in USA?
   Y:1, N:2
3. Thank you for your interest in this study.
4. **Are you primarily** a clinical (you counsel patients as part of your job) or non-clinical (you do not counsel patients as part of your job) genetic counselor?
   1: At least some clinical genetic counseling
   2: At least some clinical research that involves client interaction
   3: No clinical interaction with clients at all
   4: I do both clinical and non-clinical genetic counseling
5. **What is your main role as a clinical genetic counselor? (Please choose all that apply)**
   1. Clinical
   2. Research/Study Coordinator
   3. Administrative
   4. Clinical Coordination
   5. Management
   6. Teaching/Education/Supervising Students
   7. Customer Liaison
   8. Lab Support
   9. Grant Management
   10. Other
6. **What is your main role as a non-clinical genetic counselor? (Please choose all that apply)**
   1. Laboratory
   2. Genetic Testing
   3. Cancer Genetics
   4. Education: Public or Professional
   5. Specialty Disease
   6. Public Health
7. This survey is divided into 4 sections:

8. **Please state if following statements are true or false:**

   - [ ] **True**
   - [ ] **False**
   - [ ] **Unsure**

   **Q8_1** The provisions of GINA went into effect in 2009.
   **Q8_2** GINA includes information about family history of an individual in its definition of genetic information.
   **Q8_3** GINA does not include information about a disease that is already manifested in an individual (e.g., signs, symptoms, diagnosis of disease) in the definition of genetic information.
   **Q8_4** GINA prohibits the use of genetic information to discriminate in health insurance.
   **Q8_5** Under GINA an employer can request that an employee provide the employer with his genetic information.
   **Q8_6** GINA applies to disability insurers.
   **Q8_7** GINA applies to life insurers.
   **Q8_8** GINA applies to people who get health care through US military.
   **Q8_9** GINA does not govern the actions of health care providers.
   **Q8_10** GINA mandates health insurance coverage for treatment (if genetic testing indicates the need of that treatment).
   **Q8_11** According to GINA, a health insurer can request an applicant to take a genetic test to determine the eligibility for coverage.
GINA protects a patient’s test results obtained through his direct-to-consumer testing.

GINA prohibits health insurers from using information about an existing genetic condition.

GINA covers information obtained from tests to evaluate such things as a CBC or cholesterol analysis.

GINA does not apply to employers with less than 15 employees.

9. **Section 2:** This section has questions regarding your practice and beliefs with respect to genetic discrimination and GINA.

10. *With how many clients did/do you discuss genetic discrimination..*

11. **Before GINA was enacted**

   **NOW,**

   After GINA has been enacted

   **Have any of your clients reported that they have experienced discrimination in ..**
1. Yes, before GINA was enacted
2. Yes, since GINA was enacted in November 2009
3. Yes, both before and after GINA enactment
4. No, neither before or after GINA enactment
5. Uncertain

Q11_1 health insurance
Q11_2 employment

12. If yes for either or both type of discrimination in the previous question, then what were the hereditary syndrome(s) or gene(s) in question?
13. Please provide some information regarding the situation in which the discrimination occurred for your client(s).
14. With approximately what percentage of your clients do you discuss GINA? (move the slide bar to the percentage that best answers the question)- Bar is 0 to 100
15. Under what circumstances do you discuss GINA with a client? (Check all that apply)
   1. I discuss it with every client as a part of the genetic counseling process
   2. I discuss it when I offer a genetic testing to a relative of an affected person.
   3. I discuss it when the genetic diagnosis would not change the medical care.
   4. I discuss it when the client asks about it.
   5. I never discuss it with my clients
   6. I discuss it under specific circumstances not listed above.

16. Please specify the circumstance(s).
17. *How confident are YOU about the ability of GINA to protect against

   Q17_1 health insurance discrimination
   Q17_2 employment discrimination

   1 Not at all confident
   2 Somewhat unconfident
   3 Somewhat confident
   4 Very confident
   5 No Opinion

59
18. *In general, how reassuring do you try to be with your clients regarding the effectiveness of GINA for purposes of*

- [ ] 1 Not at all reassuring
- [ ] 2 Minimally reassuring
- [ ] 3 Somewhat reassuring
- [ ] 4 Very reassuring
- [ ] 5 I do not talk about GINA with my clients

Q18_1 health insurance
Q18_2 employment

19. *If your probability of carrying a BRCA mutation is 50%, your decision to get tested or not would be influenced by concerns about*

- [ ] 1 No
- [ ] 2 Minorly
- [ ] 3 Somewhat
- [ ] 4 Largely
- [ ] 5 Very largely
- [ ] 6 Entirely
- [ ] 77 Uncertain

Q19_1 health insurance discrimination
Q19_2 employment discrimination

20. *If you were to undergo predictive genetic testing for BRCA, how likely would you be to:*

- [ ] 1 Very Unlikely
- [ ] 2 Unlikely
- [ ] 3 Somewhat Unlikely
- [ ] 4 Uncertain
- [ ] 44 Somewhat Likely
- [ ] 5 Likely
- [ ] 6 Very Likely

Q20_1 Seek insurance coverage for the cost of testing?
Q20_2 Use an alias (fake name)?
Q20_3 Pay out of pocket?
21. *If you tested positive for being a BRCA mutation carrier, how likely you would be to disclose your carrier status to,

<table>
<thead>
<tr>
<th>Very Unlikely</th>
<th>Unlikely</th>
<th>Somewhat Unlikely</th>
<th>Undecided</th>
<th>Somewhat Likely</th>
<th>Likely</th>
<th>Very Likely</th>
</tr>
</thead>
</table>

Q21_1 Your primary care physician?
Q21_2 Your spouse?
Q21_3 Other close family member(s)?
Q21_4 Your close friend(s)?
Q21_5 A colleague at your workplace?
Q21_6 Your employer?

22. Section 3: This section has questions about your clients’ experiences with genetic discrimination before and after implementation of GINA. Please give your best assessment for each question.

23. What is the approximate percentage of your client population that you think is aware of the existence of GINA before the genetic counseling session begins? (move the slide bar to the percentage that best answers the question) Bar is 0 to 100

24. In your opinion, how concerned were the clients you have seen since the beginning of 2010 with each of the following? (move the slide bar to the number that best answers the question) Bar is 0 (low) to 7 (high)

Health insurance discrimination
Employment discrimination
Life insurance discrimination
Disability insurance discrimination
Long-term insurance discrimination
Social discrimination

25. *Since the beginning of 2010, what is the approximate number of clients who have requested anonymous genetic testing after discussing GINA with them?

26. Since the beginning of 2010, after discussing GINA with you, approximately what percentage of your client population was still concerned about. Bar is 0 to 100
health insurance discrimination
employment discrimination

27. *After discussing GINA with a client, how likely is he/she to opt out of
genetic testing due to fear of “...”

<table>
<thead>
<tr>
<th></th>
<th>Very Unlikely</th>
<th>Unlikely</th>
<th>Somewhat Unlikely</th>
<th>Somewhat Likely</th>
<th>Likely</th>
<th>Very Likely</th>
<th>Uncertain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q27_1 health insurance discrimination
Q27_2 employment discrimination

28. Please rate the amount you agree with each of the following statements below.

29. Fewer people decline genetic testing when I discuss GINA in my sessions as
    compared to when I do not discuss GINA.
    1 Strongly Disagree
    2 Disagree
    3 Somewhat Disagree
    4 Neither Agree nor Disagree
    5 Somewhat Agree
    6 Agree
    7 Strongly Agree
    88 I do not discuss GINA with my patients

30. I have seen an increase in the number of individuals willing to participate in
genetic research after I have informed them about GINA.
    1 Strongly Disagree
    2 Disagree
    3 Somewhat Disagree
    4 Neither Agree nor Disagree
    5 Somewhat Agree
31. **Do you have any thoughts or concerns about the impact GINA has on the delivery of genetic testing and services?**

32. **Section 4:** This section has demographic and your field-of-practice related questions.

33. **What is your age (in years)?**

34. **What is your sex?**

1. Male
2. Female
33. I do not want to disclose

35. **What degrees do you currently hold? (Please chose all that apply)**

1. MS/MA/ScM genetic Counseling
2. MS/MA/ScM genetics (Human Medical)
3. MS/MA Other/non-genetics
4. PhD
5. MPH
6. BSN/RN
7. MBA
8. Currently in advanced degree program
9. MSN
10. MSW/MSSW
11. JD
12. Med
13. Other advanced degree

36. **Which Region are you currently practicing in?**
37. **How many years have you been a genetic counselor?**

38. **In January 2010, approximately what percentage of your time did you spend in each of the following specialty area? (Note: Should total 100%)**

39. Your responses have been recorded. Thank you for your time and interest.

Would you like to enter a raffle for a $25 gift certificate for Amazon.com? (Your contact information will not be connected to your survey responses)

- yes
- No
40. Please click the link below to write your email address for entering in the raffle.

http://atrial.qualtrics.com/SE/?SID=SV_eer8haWTyzeNPkU

*Questions modified or adapted from the survey of Huizenga et al.
References


10.1056/NEJMp0803964


