An Assessment of Genetic Counselors' Numeracy and its Relationship with Risk Assessment and Communication Practices

Thesis

Presented in Partial Fulfillment of the Requirements for the Degree Master of Science in the Graduate School of The Ohio State University

By

Samantha Seh-jung Choi

Graduate Program in Genetic Counseling

The Ohio State University

2020

Thesis Committee

Kate Shane-Carson, MS, LGC, Advisor

Leigha Senter, MS, LGC

Dawn C. Allain, MS, LGC

Copyrighted by

Samantha Seh-jung Choi

2020

#### Abstract

**Purpose:** We sought to address three aims within our study: (1) Assess objective and subjective numeracy of practicing genetic counselors (GCs) and genetic counseling trainees (GCTs), (2) Explore the relation of numeracy with GCs' and GCTs' preference for the format of communicating statistical risk information to both patients and providers, and (3) Examine the relation of numeracy on GCs' and GCTs' interpretation of risk information for patients. **Method:** GCs who were members of the National Society of Genetic Counselors (NSGC) and GCTs who were enrolled in an Accreditation Council for Genetic Counseling (ACGC)-accredited genetic counseling graduate program completed a survey about their preference for the format of risk communication to patients and healthcare providers, a task to assign qualitative labels to various numeric formats, an objective numeracy scale, and a subjective numeracy scale. **Results:** On average, GC and GCT objective numeracy was high with means of 4.2 (SD = 1.3) and 3.7 (SD = 1.3), respectively, and an overall mean of 3.9 (SD = 1.3, range = 1-6). GC and GCT subjective numeracy was also high with means of 5.0 (SD = 0.60) and 4.7 (SD =(0.65), respectively, and a total mean of 4.8 (SD = 0.60). Overall, GCs and GCTs use different numeric formats when communicating with patients when compared to other healthcare providers. There was no evidence that either subjective or objective numeracy had any effect on preference for the format of risk communication. There were significant

differences in GCs' and GCTs' interpretation of risk between format. There is some suggestion that individuals with lower subjective and objective numeracy levels were less likely to be consistent in their interpretations across numeric formats. **Conclusion:** Overall, GCs and GCTs have high objective and subjective numeracy; however, differences in these abilities may still have significant impact on patient care.

# Dedication

This manuscript is dedicated to my family, whose endless love and encouragement has been unfailing, in this project and everything I do. It is also dedicated to Chris. You always believe in me, even when I don't believe in myself. Thank you for everything.

## Acknowledgments

First and foremost, I would like to thank my advisor, Kate Shane, for her continued guidance and support throughout this project. I would also like to express my gratitude to Dawn Allain and Leigha Senter for serving on my committee and providing thoughtful contributions to my thesis. Thank you to Ellen Peters for her genuine enthusiasm and expertise in designing this study. Finally, a special thank you to the Ohio State Genetic Counseling Graduate Program for providing funding for this project. This would not have been possible without the continued dedication of everyone involved.

# Vita

May 2014	Covenant Day School
May 2018	B.S. Psychology,
	Kent State University
May 2020	M.S. Genetic Counseling,
	The Ohio State University, in progress

# Publications

Choi, S., Taber, J., Thompson, C., & Sidney, P. (in press). Math anxiety, but not induced stress, is associated with objective numeracy. *Journal of experimental psychology: applied*.

# Fields of Study

Major Field: Genetic Counseling

# Table of Contents

Abstractii
Dedication iv
Acknowledgmentsv
Vitavi
List of Tablesix
Chapter 1. Introduction
The Importance of Rational Numbers1
Health Numeracy
Patient Numeracy
Physician Numeracy
Genetic Counselor Numeracy
The Current Study
Chapter 2. Methods 10
Subjective Numeracy
Preference for Format of Risk Communication11
Assignment of Evaluative Labels
Hypothetical Patient Scenario
Objective Numeracy
Demographics
Analyses15
Chapter 3. Results
Demographics
Subjective and Objective Numeracy18
Preference for Format of Risk Communication 19
Differences in Risk Interpretation across Format

Differences in Risk Interpretation across Format in Relation to Numeracy	
Chapter 4. Discussion	22
Limitations	27
Future Directions	28
Bibliography	30
Appendix A. Tables	35
Appendix B. Participant Recruitment Materials	40
Appendix C. Survey	42

# List of Tables

Table 1. Demographics (n=217)	. 35
Table 2. Distributions of Subjective and Objective Numeracy Scores	. 35
Table 4. Demographics across Numeracy Categories	. 37
Table 5. Genetic Counselor and Genetic Counseling Trainee Communication Formats	
with Patients versus Providers	. 37
Table 6. Differences in Risk Interpretation across Formats for the Value 0.002	. 38
Table 7. Differences in Risk Interpretation across Format for the Value 0.25	. 39

## Chapter 1. Introduction

The ability to understand, apply, and assign meaning to numeric information is vital to an individual's success in navigating a variety of domains in daily life. From education to business to healthcare, numeric tasks are widespread throughout today's society. Any number of daily activities such as taking a prescription, leaving a tip at a restaurant, and budgeting finances requires the use of simple mathematics. Moreover, pursuit of higher education, particularly in STEM-related fields (science, technology, engineering, and mathematics) requires the understanding of more complex mathematics. The Importance of Rational Numbers

While many daily activities involve only simple calculations using natural or counting numbers, others require the use of rational numbers such as percentages, ratios, fractions, and decimals. Research has shown that the use of rational numbers is required for a number of jobs across many types of employment. For example, in a survey of over 2300 adults in the United States, 68% indicated that they use fractions while at work. This consisted of 82% of upper white collar workers, 68% of lower white collar workers, 70% of upper blue collar workers, 58% of lower blue collar workers, and 40% of service workers (Handel, 2016).

Despite the widespread use of rational numbers, research has continually shown that both students and adults have difficulty working with these types of numbers (DeWolf, Grounds, Bassok, & Holyoak, 2014; Siegler & Lortie-Forgues, 2017; Reyna & Brainerd, 2007). Furthermore, adults typically have less positive attitudes towards rational numbers when compared to whole numbers (Sidney, Thompson, Fitzsimmons, & Taber, 2019). Therefore, adults within our society are consistently forced to understand, apply, and assign meaning to numeric information that they have difficulty working with and do not like.

#### Health Numeracy

The ability to comprehend, use, and attach meaning to numbers is termed numeracy (Nelson, Reyna, Fagerlin, Lipkus, & Peters, 2008). Numeracy has been associated with decision making in a variety of research studies across multiple contexts (Cokely et al., 2018; Ghazel, Cokely, & Garcia-Retamero, 2014; Peters, 2012). For example, individuals who have lower numeracy are more likely to make decisions that are influenced by factors unrelated to numerical information such as affect, framing effects, and other biases (Peters et al., 2006; Reyna, Nelson, Han, & Dieckmann, 2009). Numeracy becomes particularly relevant in the context of healthcare and medical decision-making. While there is no widely agreed upon definition of health numeracy, Golbeck, Ahlers-Schmidt, Paschal, and Dismuke (2005) suggest that it is "the degree to which individuals have the capacity to assess, process, interpret, communicate, and act on numerical quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions." In this framework, health numeracy can be categorized into four major skills: Basic (ex: identification of numbers), Computational (ex: simple manipulation of numbers), Analytical (ex: inference, estimations, proportions,

percentages), and Statistical (ex: comparison of information, risk). This definition encompasses the numeracy skills that are necessary for patients to successfully navigate today's healthcare system (Golbeck et al., 2005).

## Patient Numeracy

There are a wide variety of health-related tasks that require some level of numeric ability. Reading nutritional labels, interpreting medication dosage, measuring clinical data such as blood pressure or glucose levels, and understanding health risks all require the use of numbers. However, in order to complete these tasks, patients must first determine which mathematical skills are necessary to manipulate these numbers and then apply those skills in a multi-step fashion (Rothman, Montori, Cherrington, & Pignone, 2008).

Therefore, health numeracy is important to several aspects of patient healthcare. First, numeracy has been shown to be associated with overall health differences. For example, individuals with low numeracy are more likely to have greater body mass index (Huizinga, Beech, Cavanaugh, Elasy, & Rothman, 2012), higher prevalence of comorbidities, and more prescribed medications (Garcia-Retamero, Andrade, Sharit, & Ruiz, 2015). Second, health numeracy is necessary for the management of chronic conditions such as diabetes, HIV, and hypertension due to the necessity of selfadministered treatments. Research has shown that individuals with low numeracy tend to have poor adherence to these treatments, putting them at higher risk for adverse health outcomes (Cavanaugh et al., 2008; Ciampa et al., 2012; Estrada, Martin-Hyrniewicz, Collins, Byrd, & Peek, 2004; Rao et al., 2015). Finally, health numeracy, specifically the

ability to understand and apply probability and risk information, is vital to the process of informed decision-making. Research has demonstrated that patients with lower numeracy have difficulty with this type of information in a variety of settings. For example, in a study assessing the ability of women to gauge the risk reduction of mammography when given quantitative data, researchers found that numeracy was strongly related to accuracy. Only 5.8% of women with a numeracy score of 0 (on a scale of 0 to 3), were able to accurately apply the risk reduction information to estimate her risk of death from breast cancer with and without mammography (Schwartz, Woloshin, Black, & Welch, 1997). Lower numeracy has also been associated with lower comprehension of the risks and benefits for screening (Petrova, Garcia-Retamero, Catena, & van der Pligt, 2016), attaching inappropriate emotional meaning to risk magnitudes, and decreased sensitivity to different levels of numerical risks (Garcia-Retamero et al., 2015; Petrova, Garcia-Retamero, Catena, & van der Pligt, 2014). Another study found that individuals who had lower numeracy were less able to accurately understand the risk of experiencing side effects from medication (Gardner, McMillan, Raynor, Woolf, & Knapp, 2010). All of these factors reduce the ability of individuals with low numeracy to make informed decisions about their health. However, individuals with low numeracy prefer to have less involvement in the decision-making process in the first place, leaving more responsibility to the physician or healthcare provider (Galesic & Garcia-Retamero, 2011). Physician Numeracy

The importance of health numeracy has been well established in patient populations; however, physicians have not been adequately studied. The ability of physicians to understand risk estimates in order to effectively summarize and communicate the risks and benefits of medical interventions for patients is critical, particularly in the era of shared decision making. However, research has demonstrated that physicians can be susceptible to low numeracy (Anderson & Schulkin, 2011; Rao, 2008). Anderson and Schulkin (2014) reported that 53-75% of physicians are not able to answer questions assessing basic probabilities. Furthermore, in a study of over 300 medical students across 4 institutions, only 70% had complete numeracy (3 out of 3 questions answered correctly, 21% of students correctly answered 2 items and 9% of students correctly answered 0 to 1 items). Research from this study also demonstrated that low numeracy amongst physicians is a significant predictor of poor comprehension of risk reduction (Johnson et al., 2014). In addition, research has also found that low physician numeracy can have significant impacts on risk communication to patients.

A study on how German gynecologists communicate the risks and benefits of mammography revealed that they often relied on incomplete and potentially misleading information such as relative risks and verbal qualifiers (Wegwarth & Gigerenzer, 2011). Further studies focused on risk communication within the context of cancer screening, demonstrated that this type of information was more likely to be provided by physicians with low levels of numeracy. Data from this study even suggest that these physicians may not be equipped to perform tasks that rely on the consideration of numerical information such as facilitation of informed decision making or recommendation of medical treatments (Petrova, Kostopoulou, Delaney, Cokely, & Garcia-Retamero, 2018). Genetic Counselor Numeracy

Research has established that health numeracy is important for both patients and physicians in order to successfully use quantitative information in a healthcare environment (Ancker & Kaufman, 2007). However, there is little to no information on health numeracy in other healthcare providers such as current and future genetic counselors. Several key elements of genetic counseling require the ability to understand and apply numeric information on a daily basis including identifying appropriate genetic testing options and interpretation of genetic testing results. A major component of genetic counseling is determining risks for genetic or medical conditions in a patient. This can include assessing the likelihood of having a disease-causing genetic variant given a family history, the risk of passing a genetic condition to future offspring, the risk of inheriting a genetic condition from a parent, or even the risk of developing a disease related to having a disease-causing genetic variant. Genetic counselors with low numeracy may not be able to accurately interpret risk numbers which could potentially compromise their ability to effectively communicate this information to patients. Risk communication relies on the genetic counselor's numeric ability with regards to format as well. An observational study regarding risk communication in genetic counseling revealed that quantitative and qualitative expressions were used an approximately equal amount of times, 47% and 53% respectively (Michie et al., 2008). However, qualitative probabilities have a high degree of variability in interpretation and vary widely depending on context, most likely in relation to the judges' personal knowledge, opinion, and experience (Brun & Teigen, 1988; Lipkus, 2007). Research on the best format for

quantitative risk communication remains inconsistent. One study that compared three numeric formats for communicating risk (percentages, frequencies, and 1 in n) found that the percentage and frequency formats had higher overall accuracy rates than the 1 in n format when it came to mathematical operations that might be encountered in discussions of risk. However, when compared to each other, the two formats were roughly equivalent with 57% and 55% accuracy respectively (Cuite, Weinstein, Emmons & Colditz, 2008). In contrast, other studies suggest that using frequencies rather than percentages helps physicians with communication and patients with understanding (Hoffrage & Gigerenzer, 1998; Kessler, Levine, Opitz, & Reynolds, 1987).

In addition, there are a number of studies that demonstrate a wide variety of preferences between individuals when it comes to risk communication. For example, in a study on the presentation of risk information during genetic counseling sessions for breast and ovarian cancer, participants found numeric formats for risk to be informative and helpful. In fact, 73% of participants preferred when risk was presented numerically (Hallowell, Statham, Murton, Green, & Richards, 1997). This is in direct contrast to other studies in which participants describe quantitative risk estimates as "confusing," "meaningless," and "add[ing] nothing" when receiving information about risk for Duchenne Muscular Dystrophy (Green & Murton, 1993). Therefore, genetic counselors must have the ability to provide risk figures in multiple different formats (both qualitative and quantitative), sometimes requiring conversion from one to another on the spot. This ability is important to ensure that the patient has the chance at understanding the information being presented in order to make informed decisions.

7

Given that genetic counselors must understand and work with numbers in a multitude of different capacities, it is important that their health numeracy is evaluated. As the need for genetic counselors continues to grow worldwide, it is essential to ensure that current and future genetic counselors have the skills to successfully understand, apply, and communicate numeric information in order to provide patients with the necessary components to make informed decisions about their health.

#### The Current Study

The primary aim of this study is to assess the numeracy of genetic counselors (GCs) and genetic counseling trainees (GCTs), measured using both objective and subjective numeracy scales. While objective numeracy evaluates an individual's performance on mathematical problems (Lipkus, Samsa, & Rimer, 2001; Schwartz et. al, 1997), subjective numeracy evaluates an individual's confidence or preference for numbers (Fagerlin et al., 2007). Most objective and subjective numeracy scales show some degree of correlation, suggesting that these two constructs are related. However, the degree of correlation is not enough to conclude that they are identical (Dolan, Cherkasky, Qinghua, Chin, & Veazie, 2015).

The second aim of this study is to explore the relation of numeracy with GCs' and GCTs' preference for the format of communicating statistical risk information to patients and other healthcare providers. Increased subjective numeracy, but not objective numeracy, has been associated with the likelihood that a physician will provide quantitative information to patients when giving a diagnosis of Down Syndrome (Anderson, Obrecht, Chapman, Driscoll, & Schulkin, 2011). Lastly, the third aim of this

study is to examine the relation of numeracy on GCs' and GCTs' interpretation of and sensitivity to risk information for patients.

#### Chapter 2. Methods

All study procedures were approved by the institutional review board of The Ohio State University. Certified GCs were recruited through the National Society of Genetic Counselors (NSGC). Survey links and study information were distributed by NSGC via a weekly digest to members who opted-in to receive emails requesting participation in student-generated research studies. A follow-up email was also sent two weeks after the initial email. We estimated a response rate of approximately 10% (n=400) based on response rates to previously conducted student research using NSGC's membership as a sampling frame. To sample current GCTs, a request was sent to the Association of Genetic Counseling Program Directors (AGCPD) asking program directors to forward survey links and study information to their students. Recruitment materials are available in Appendix B.

An anonymous online survey of 50 items was created using Qualtrics, an OSUsupported, online survey software provider. The full text of the survey is available in Appendix C. An answer to each question was required to move forward with the survey. All participants were offered the opportunity to enter a raffle to receive a \$50 Amazon gift card via email. Subjective Numeracy

Subjective Numeracy was assessed using the 8-item Subjective Numeracy Scale (SNS) (Fagerlin et al., 2007). The SNS can be divided into two distinct sections: SNS ability and SNS preference. Four of the items in this scale (SNS ability) measure a person's beliefs about their own ability to perform mathematical operations on a scale from not at all good (1) to extremely good (6). The remaining four questions (SNS preference) assess how individuals prefer numbers to be presented. Response options were measured on 6-point scales.

Preference for Format of Risk Communication

To explore GCs' and GCTs' preference for the format of communicating statistical risk information, the authors created four questions for this study. The first two questions assessed the individual's general preference for the format of risk communication. The first question asked, "In general, when communicating genetic risk information to **patients**, do you use . . .? (select all that apply)." The second question was the same as the first, but instead asked about communication of genetic risk information to **other healthcare providers**. The response options for these questions were "Numeric values (frequencies, percentages, decimals, fractions, etc.)," "Evaluative labels such as 'high,' 'moderate,' or 'low' risk," "Relative labels such as 'increased/decreased' or 'higher/lower' risk," and "I do not communicate genetic risk information to [patients/other healthcare providers]." The remaining two questions assessed the individual's preference for the specific type of numeric format used when communicating risk information to both patients and other healthcare providers. The third question asked,

"In general, if you use numbers to communicate genetic risk information to **patients**, which of the following numeric formats do you use most often?" The fourth question was the same as the third, but instead asked about communication of genetic risk information to **other healthcare providers**. The response options for the third and fourth questions were "Frequencies (e.g., there is a 1 in 10 chance for you to have this genetic condition)," "Percentages (e.g., there is a 10% chance for you to have this genetic condition)," "Decimals (e.g., there is a 0.10 chance for you to have this genetic condition)," "Fractions (e.g., there is a 1/10 chance for you to have this genetic condition)," "I do not use numbers to communicate risk to patients," and "Other."

#### Assignment of Evaluative Labels

To assess GCs' and GCTs' interpretation of and sensitivity to risk information for patients, the authors created 8 questions. Each question presented a scenario in which the GCs and GCTs received a numeric risk figure for a fictitious patient, and were asked to describe the patient's risk using evaluative labels. The questions asked "You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is [numeric risk]. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain)." Each of the eight questions were "1 (almost no risk)," "2 (low risk)," "3 (moderate risk)," "4 (high risk)," and "5 (almost certain)." This section included two sets of four questions that presented the same magnitude of risk in different formats. The first four questions presented the following

equivalent risks: "1 in 500," "0.002," "9/4500," and "0.2%." The remaining four questions presented the following equivalent risks: "1 in 4," "0.25," "225/900," and "25%."

## Hypothetical Patient Scenario

A hypothetical patient scenario was created to assess GCs' and GCTs' use of technical information regarding genetic testing results. The scenario was as follows: "A 30-year-old female hears about a newly discovered genetic condition called "syndrome fictum geneticae" on the news. She is concerned about having this condition, so she sees her primary care physician who orders genetic testing. The patient is referred to you for genetic counseling for the result disclosure. You receive the following information from the patient's genetic test report: Sensitivity 70%, Specificity 90%, Positive Predictive Value 80%, Negative Predictive Value 95%." Two questions were asked regarding the scenario. The first question asked, "If your patient tested positive, what is the minimum information you need to tell them (choose between one and all of the options below)?". The second question asked, "If your patient tested negative, what is the minimum information you need to tell them (choose between one and all of the options below)?". The options were "Sensitivity," "Specificity," "Positive Predictive Value," and "Negative Predictive Value."

## **Objective Numeracy**

To address the concern that traditional scales are not difficult enough to adequately differentiate numeracy among highly-educated individuals, objective numeracy was assessed using a scale that combined harder items from the Berlin Numeracy Scale with easier items from the Rasch-based numeracy scale (Cokely et al., 2012; Weller et al., 2013). To prevent cheating, language from the original items was modified due to the widespread availability of items and their corresponding answers on the internet. In some cases, numbers were modified in a way that would not alter the question's difficulty. Participants were presented with seven items designed to test comprehension of probabilistic information ranging in difficulty. The last item asked, "You just answered 7 math questions. How many do you think you answered correctly?". Participants were instructed not to use a calculator, but were allowed the use of pen and paper if needed.

Objective numeracy check

To determine if participants followed instructions regarding the objective numeracy section, they were asked, "Did you use a calculator or any outside resources (anything other than a pen and paper) to answer any of the questions from the previous section?". In addition, to determine how much effort participants used to answer questions in the objective numeracy section, they were asked, "Overall, how much effort did you use to answer the questions in the previous section accurately and honestly?". Response options ranged from zero effort (1) to extreme effort (6).

Demographics

Background information about age, gender, race, years of practice as a genetic counselor, and specialty were collected.

Analyses

Subjective numeracy scores for all participants were calculated by averaging all items in the scale to produce an overall score. Of note, the item regarding weather forecasts was reverse coded. An independent samples t-test was conducted to compare subjective numeracy scores between GCs and GCTs. Objective numeracy scores for all participants were calculated as the sum of the total number of correct responses to 6 items (range from 0 to 6). Item number 2 of the objective numeracy scale (see Appendix C) was excluded from analyses due to a survey typo which made the correct answer to the question difficult to interpret. The wording of the question asked for the number of individuals who would win a prize out of 5000, while the answer space asked for the number of individuals out of 500. An independent samples t-test was conducted to compare objective numeracy scores between GCs and GCTs. All participants were categorized into four groups based on their objective numeracy and subjective numeracy levels. A chi-square test of independence was used to analyze any differences in participant type between categories.

We used Fisher's exact test to evaluate for differences in GCs' and GCTs' preferred format of communication for patients versus providers. Fisher's exact test was also performed to analyze differences in the preferred format of risk communication between higher and lower subjective numeracy groups when communicating with both patients and providers. Fisher's exact test was also performed to analyze differences in the preferred format of risk communication between higher and lower objective numeracy groups when communicating with patients and providers.

15

We used both the test of symmetry (asymptotic) and the test of marginal homogeneity (Stuart-Maxwell) to evaluate for differences in interpretation between the 6 separate format combinations using a risk of 0.002. These same analyses were also performed using a risk of 0.25. A chi-square test of independence was used to evaluate differences in consistency between formats of risk communication across higher and lower subjective numeracy groups. This test was also used to evaluate for the same differences across higher and lower objective numeracy groups.

#### Chapter 3. Results

## Demographics

Two hundred and seventy-seven individuals submitted responses for this study. However, only 217 participants completed the survey in its entirety. Participant demographics are listed in Table 1. This sample consisted of 98 (45.2%) certified GCs and 119 (54.8%) GCTs enrolled in a genetic counseling graduate program accredited by the Accreditation Council for Genetic Counseling (ACGC). At the time of this study, the "American Board of Genetic Counseling" (2019) reported a total of 5,172 certified GCs practicing in the United States. This is a response rate of 1.9%. According to "The Genetic Counseling Admissions Match" (2018, 2019), a total of 872 positions for GCTs were available from the two most recent match cycles. This is a response rate of 13.6% for GCTs.

Participants were 94% female and aged 21 to 56 (M = 28.0, SD = 6.6). Among practicing GCs, the mean years of experience was 6.2 (SD = 7.1). Within the sample, 186 (85.7%) participants were non-Hispanic Caucasian, 14 (6.5%) were Asian or Asian-American, 5 (2.3%) were Hispanic, 2 (0.9%) were African American and 10 (4.6%) were of mixed, other, or unspecified ethnic background. Cancer and prenatal were the most commonly reported specialties, chosen by 73.2% of practicing GCs. Counselors who selected "other" as a specialty reported practicing in the following areas of specialty: laboratory, preconception, artificial reproductive technology, neurogenetics, cardiology, molecular genetics, elective sequencing, and academia. In addition, 31.6% of practicing GCs reported having two or more areas of specialty.

Hypothetical Patient Scenario

Analyses using this data were not completed as they were not directly related to the primary aims of this study.

## Subjective and Objective Numeracy

Overall, participants scored a mean of 4.8 (SD = 0.64) out of 6 on the subjective numeracy scale. The mean score on the SNS Ability subscale was 4.8 (SD = 0.93) and the SNS preference subscales was 4.8 (SD = 0.69). Practicing GCs scored a mean of 5.0 (SD= 0.60), while GCTs scored a mean of 4.7 (SD = 0.65). Subjective numeracy scores and percentiles are presented in Table 2. Practicing GCs demonstrated significantly higher subjective numeracy scores when compared to GCTs, t(215) = 2.99 p = 0.003.

Given the high level of numeracy in this sample, groups for higher and lower subjective numeracy were determined by splitting participants between the median (4.9) and the 25th percentile (4.4) to separate out those who were least numerate from those who were highly numerate, but still below the median in this particular sample. Therefore, individuals were classified as higher subjective numeracy if they scored 4.5 or higher and lower subjective numeracy if they scored less than 4.5 total.

Overall, participants scored a mean of 3.9 (SD = 1.3) out of 6 on the objective numeracy scale. Practicing GCs scored a mean of 4.2 (SD = 1.3), while GCTs scored a mean of 3.7 (SD = 1.3). Objective numeracy scores and percentiles are presented in Table 2. Practicing GCs demonstrated significantly higher objective numeracy scores when compared to GCTs, t(215) = 2.46, p = 0.015). The percentage of GCs and GCTs who correctly answered each question in the objective numeracy scale is listed in Table 3. Again, because of the higher level of numeracy in this sample, we used a median split to classify individuals into higher (4, 5, or 6 correct) and lower (1, 2, or 3 correct) numeracy groups.

Using the classifications for both subjective and objective numeracy scales as described above, all participants were grouped into one of four categories. The number of participants, demographic characteristics (age, gender, ethnicity, and years of experience), and participant type for each category are displayed in Table 4. There did not appear to be any differences in age, gender, ethnicity, or years of experience between categories. However, there was a significant association between participant type between categories,  $X_2$  (3, N = 217) = 10.3, p = 0.016. Practicing GCs were significantly more likely than GCTs to be in category 1 (high objective, high subjective), making up 55% of participants compared to the expected 45%.

#### Preference for Format of Risk Communication

When communicating with patients, 47.9% (n = 104) of GCs and GCTs reported using percentages most often, followed by 31.3% (n = 68) of GCs and GCTs who use frequencies. When communicating with other healthcare providers, 65.4% (n = 142) of GCs and GCTs reported using percentages most often, followed by only 14.8% (n = 32) of GCs and GCTs who use frequencies (see Table 5). There was a significant difference in GCs' and GCTs' reported preference for the format of statistical risk information when communicating with patients versus providers (p < 0.0001).

There were no significant differences in the preferred format of risk communication between higher and lower subjective numeracy groups when communicating with both patients and providers (p = 0.86; p = 0.88). Additionally, there were no significant differences in the preferred format of risk communication between higher and lower objective numeracy groups when communicating with patients and providers (p = 0.91; p = 0.25).

Differences in Risk Interpretation across Format

Regardless of the magnitude of risk interpretation, GCs and GCTs would optimally choose the same label for each format of the same value. When presented with equal risks of 0.002 in differing formats, 151 (70%) participants were consistent in their risk interpretation. Among those who were not consistent, there was a significant difference in interpretation of frequencies (1 in 500) when compared decimals (0.002),  $X_2$ (3, N = 217) = 38.93, p = 0.0000). Participants were either consistent in their interpretation between these two formats or rated the risk as greater when the value was presented as a frequency. Statistically significant differences were also found in participants' interpretation of frequencies vs. fractions, decimals vs. fractions, and percentages vs. decimals. Results are included in Table 5.

When presented with equal risks of 0.25 in differing formats, 181 (83%) of participants were consistent in their risk interpretation. For this value, statistically significant differences were found in participants' interpretation of frequencies vs.

decimals, frequencies vs. fractions, decimals vs. fractions, percentages vs. decimals, and fractions vs. percentages. Results are displayed in table 6.

Differences in Risk Interpretation across Format in Relation to Numeracy

Of those with lower subjective numeracy, only 62% were consistent in their interpretation of the value 0.002, compared to 72% of those with higher subjective numeracy,  $X_2$  (1, 217) = 2.13, p = 0.14. Of those with lower objective numeracy, 62% of individuals were consistent in their interpretation of the value 0.002, compared to 74% of those with higher objective numeracy,  $X_2$  (1, 217) = 3.35, p = 0.07.

Of those with lower subjective numeracy, only 77% of individuals were consistent in their interpretation of the value 0.25, compared to 86% of individuals with higher subjective numeracy,  $X_2$  (1, 217) = 2.48, p = .12. Of those with lower objective numeracy, 73% of individuals were consistent in their interpretation of the value 0.25, compared to 89% of individuals with higher objective numeracy,  $X_2$  (1, 217) = 8.96, p = 0.003.

#### Chapter 4. Discussion

The present research adds to the growing body of literature on the role of healthcare provider numeracy in patient care. To our knowledge, it is the first study to evaluate either objective or subjective numeracy for current and future genetic counselors. The results of this study showed that GC and GCT subjective numeracy was high with means of 5.0 and 4.7, respectively. These scores are comparable to those of physicians, whose subjective numeracy scores from two different studies were 4.4 and 4.9 (Anderson, Obrecht, Chapman, Driscoll, & Schulkin, 2011; Gaissmaier, Anderson, & Schulkin, 2014). On average, GC and GCT objective numeracy was also relatively high with means of 4.2 and 3.7, respectively. In addition, 63.5% of the total sample scored 4 or more, and only 36.5% scored 3 or below. Due to differences in the scale used to assess objective numeracy in other studies, we are not able to directly compare the numeracy of GCs and GCTs to that of physicians or the general population. However, it is possible to compare the percentages of individuals who correctly answered questions designed to assess similar numeric tasks between studies. Eighty-two percent of GCs and GCTs in our sample were correctly able to answer a question that assessed an individual's ability to convert frequencies to percentages (see item 2 in Table 2). In comparison, Galesic and Garcia-Retamero (2010) found that only 23.5% of a national representative sample of the general population from the United States were able to answer a similar question

correctly. Among fellows of the American College of Obstetricians and Gynecologists, 88.5% of individuals were able to correctly convert a frequency to a percentage (Anderson & Schulkin, 2011). A basic probability problem (see item 4 in Table 2) was answered correctly by 75.1% of GCs and GCTs in our study, whereas similar questions ("Imagine that we rolled a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think the die would come up even (2,4, or 6)) were only correctly answered by 57.1% of the general population sample studied by Galesic and Garcia-Retamero (2010). In a sample of physicians studied by Anderson and Schulkin (2011), 88.0% of ACOG fellows correctly answered a similar question. Based on these simple comparisons, it appears that GCs' and GCTs' objective numeracy is higher than that of the general population, and could potentially be comparable to that of physicians. Given that genetic counselors must understand and work with numbers in a multitude of different capacities, it is encouraging that our study population had high numeracy.

In our sample, practicing GCs had significantly higher subjective and objective numeracy when compared to GCTs. These differences in numeracy could be a result of increased experience. As GCs practice for more years in the field, they may gain increased confidence in working with these types of numbers, and, as a result, increase their subjective numeracy. However, objective numeracy is a stable construct and should not change significantly over time. Therefore, these differences in objective numeracy may be attributed to other factors that are unrelated to years of experience.

Objective numeracy was not significantly related to GCs' and GCTs' preferred format of risk communication. Moreover, in contrast to a previous study on physicians conducted by Anderson, Obrecht, Chapman, Driscoll, and Schulkin (2011), GCs' and GCTs' subjective numeracy was also not significantly related to the format, quantitative or qualitative, that they preferred to use when communicating results to patients or other healthcare providers. In fact, GCs and GCTs in this study most often used a numeric format for risk communication regardless of their objective and subjective numeracy. This finding has implications on the quality of care that patients receive from current and future GCs. If GCs and GCTs are most often using numeric formats to communicate with patients, those patients with low objective numeracy might not be able to comprehend or interpret their risk in order to make an informed decision. In addition, GCs and GCTs who have lower numeric ability may be more susceptible to making errors when presenting risk information to patients in a numeric format, or, similar to physicians, may be more likely to provide incomplete and potentially misleading information, thus compromising optimal patient care (Petrova, Kostopoulou, Delaney, Cokely, & Garcia-Retamero, 2018). Research has already shown that individuals with lower numeracy are more likely to be influenced by factors unrelated to numeric information when making decisions (Peters et al., 2006; Reyna, Nelson, Han, & Dieckmann, 2009). This becomes particularly relevant when considering how GCs and GCTs are interpreting and then presenting and framing risks for lower numeracy patients.

Although we did not find any relationship between GC and GCT numeracy and preferred format of communication, this study does indicate that GCs and GCTs are using different numeric formats of risk communication depending on their audience. When communicating with other healthcare providers, it seems that GCs and GCTs are more likely to use percentages and less likely to use frequencies than with their patients. It is possible that GCs and GCTs are intentionally choosing a specific numeric format based on the perceived numeracy of their audience. While adapting communication strategies to the numeric ability of the intended audience seems ideal, there is little evidence that individuals, including healthcare providers, can accurately assess someone else's numeracy using their own assumptions or judgements. This could potentially lead to miscommunication or misunderstanding of risks if a patient or physician has lower objective numeracy than a GC or GCT might assume, particularly because physicians can be susceptible to low numeracy despite being part of a highly educated group (Anderson & Schulkin, 2011; Rao, 2008).

Most GCs and GCTs were consistent in their interpretation of two values when presented in different formats. However, our data does show that there were differences in interpretation between several numeric formats amongst GCs and GCTs who were inconsistent for both values presented (0.002 and 0.25). In particular, our data show that GCs and GCTs rated the magnitude of risk as greater when values were presented as frequencies in comparison to decimals. Of note, 31.3% of our sample reported using frequencies to communicate risk information to patients, and 14.8% reported using them with providers. These results suggest that differences in numeric format of the same risk value can affect how an individual interprets risk. Therefore, when using qualitative expression to describe risk to patients, GCs and GCTs may provide different interpretations of the same risk based on the specific numeric format on the test report. Even if GCs and GCTs are not directly providing qualitative information to patients, their own qualitative interpretation of the risk may unknowingly shape or frame their discussion of risks, options, and management. The results of this study may be important for informing the format for which laboratories present test results that include risk values to GCs. Providing multiple numeric formats of a given value may help to achieve a more consistent interpretation of results.

Although our calculations did not reach statistical significance, there is some suggestion that individuals with lower subjective numeracy may have been less likely to be consistent in their interpretations across numerical formats. However, our data does show that those who were higher in objective numeracy, were significantly more likely to be consistent in their interpretation than those with lower objective numeracy, particularly with the larger of the two values (0.25). These differences in numeracy suggest that the format of risk communication may be particularly important in risk interpretation for individuals with lower objective numeracy. It is possible that individuals with higher numeracy may have been able to convert one format to another more easily, recognizing that the values presented were equal. This is an important skill for GCs and GCTs to provide the most appropriate counseling for each individual patient. If a patient does not understand the risk presented in a particular format, a GC needs to be able to quickly and accurately transform this risk to another format. This type of adaptability could potentially be related to experience as well. Of note, with a mean of only 6.2 years of experience among our sample of practicing GCs, our sample is relatively inexperienced. GCs with more years of experience, and therefore more time working with these types of conversions, could be more likely to quickly convert these

different numeric formats, recognize that the values are equal, and ultimately be more consistent in their risk interpretation. However, an argument could also be made that GCs with less experience would have more recent exposure to these mathematical concepts, therefore, increasing their ability to make these adaptations.

Recent advances in technology and research have brought healthcare into an era of personalized medicine, where patients are increasingly asked to evaluate different options for their treatment and management. This requires patients to be more actively involved in the decision-making process, which may be difficult for patients with low numeracy given that they prefer to leave more responsibility to the physician or healthcare provider (Galesic & Garcia-Retamero, 2011). Historically, GCs have been trained to present information in a non-directive manner. However, GCs are moving away from non-directive counseling in favor of a shared decision-making approach, where the healthcare provider and the patient make decisions together. Low numeracy patients may rely more on GCs to help them with risk interpretation in the decisionmaking process. In these situations, a GC's own interpretation of the risk is important as it may inadvertently guide their discussion with the patient.

#### Limitations

While it is encouraging that our sample had both high objective and subjective numeracy, the individuals who completed our study may not be representative of GCs and GCTs overall. This could potentially be a result of voluntary response bias, where those who feel more comfortable with numbers or have high numeric ability may have been more likely to participate in this study. Whereas GCs and GCTs who are not comfortable with numbers or have low numeric ability may have intentionally avoided this study and, therefore, were not included in our sample. In addition, 60 participants started the survey, but failed to complete it. Some of this drop-out may have been due to difficulty or reduced confidence in answering the survey questions, especially given that many of the incomplete questions were from the objective numeracy portion of our survey. This could be a contributing factor to the lack of lower numeracy individuals in our sample. Our sample of 217 GCs and GCTs represents a very small percentage of the total population. Research on a larger sample may be more representative and, therefore, more generalizable to GCs and GCTs as a whole. In addition, the high levels of both objective and subjective numeracy in our sample may have masked some significant effects on our dependent variables. The individuals categorized into the "lower numeracy" group were not truly of low numeracy. Therefore, differences between the high and low groups may not have been apparent.

#### **Future Directions**

Future research should explore more specifically how GCs' interpretation of risk information influences their communication and, therefore, patient understanding. This could be accomplished by evaluating both patient and GC numeracy while monitoring the session for content, options presented, and overall themes. This could also include measures of patient satisfaction and decisional anxiety to examine the different effects of both patient and provider numeracy on a genetic counseling session. This could have important implications for patient decision-making regarding testing options, continuation of a pregnancy, risk-reducing surgeries, lifestyle modifications, and much more.

The era of personalized medicine has led to a more preventative approach to healthcare using genetic testing. We know that individuals with low numeracy have poor adherence to treatments (Cavanaugh et al., 2008; Ciampa et al., 2012; Estrada, Martin-Hyrniewicz, Collins, Byrd, & Peek, 2004; Rao et al., 2015). Given this information, it may be reasonable to explore whether low numeracy individuals are also less likely to pursue preventative measures when it comes to their heath. Future research may consider evaluating the numeracy of patients who present for preventative genetic testing, as they may have higher numeracy than the general population. This could have important implications for how GCs choose to communicate risk information and facilitate decision making.

While our study found that some GCs and GCTs interpret the same value with different magnitudes of risk when presented in different formats, we did not assess which formats may be more likely to be interpreted as higher or lower than others. This could be an interesting topic of further investigation with this specific population. Additionally, given differences in numeracy for GCs and GCTs compared to the general population, further research comparing risk interpretation differences between these two groups could be helpful to more specifically characterize the effects of numeracy on patient care.

## Bibliography

American Board of Genetic Counseling. (2019). Retrieved from https://www.abgc.net/

Ancker, J. S., & Kaufman, D. (2007). Rethinking health numeracy: A multidisciplinary literature review. *Journal of the American Medical Informatics Association*, *14*(6), 713-721.

Anderson, B. L., Obrecht, N. A., Chapman, G. B., Driscoll, D. A., & Schulkin, J. (2011). Physicians' communication of Down syndrome screening test results: The influence of physician numeracy. *Genetics in Medicine*, *13*(8), 744.

Anderson, B. L., & Schulkin, J. (2011). Physicians' perceptions of patients' knowledge and opinions regarding breast cancer: Associations with patient education and physician numeracy. *Breast care*, 6(4), 285.

Anderson, B. L., & Schulkin, J. (2014). Physicians' understanding and use of numeric information. *Numerical reasoning in judgments and decision making about health*, 59-79.

Brun, W., & Teigen, K. H. (1988). Verbal probabilities: Ambiguous, context-dependent, or both?. *Organizational Behavior and Human Decision Processes*, *41*(3), 390-404.

Cavanaugh, K., Huizinga, M. M., Wallston, K. A., Gebretsadik, T., Shintani, A., Davis, D., ... & Pignone, M. (2008). Association of numeracy and diabetes control. *Annals of internal medicine*, *148*(10), 737-746.

Ciampa, P. J., Vaz, L. M., Blevins, M., Sidat, M., Rothman, R. L., Vermund, S. H., & Vergara, A. E. (2012). The association among literacy, numeracy, HIV knowledge and health-seeking behavior: a population-based survey of women in rural Mozambique. *PLoS One*, *7*(6), e39391.

Cokely, E. T., Feltz, A., Ghazal, S., Allan, J. N., Petrova, D., & Garcia-Retamero, R. (2018). Decision making skill: From intelligence to numeracy and expertise. *Cambridge handbook of expertise and expert performance*, 476-505.

Cokely, E. T., Galesic, M., Schulz, E., Ghazal, S., & Garcia-Retamero, R. (2012). Measuring risk literacy: The Berlin numeracy test. *Judgment and Decision making*. Cuite, C. L., Weinstein, N. D., Emmons, K., & Colditz, G. (2008). A test of numeric formats for communicating risk probabilities. *Medical Decision Making*, *28*(3), 377-384. DeWolf, M., Grounds, M. A., Bassok, M., & Holyoak, K. J. (2014). Magnitude comparison with different types of rational numbers. *Journal of Experimental Psychology: Human Perception and Performance*, *40*(1), 71-82.

Dolan, J. G., Cherkasky, O. A., Li, Q., Chin, N., & Veazie, P. J. (2016). Should health numeracy be assessed objectively or subjectively? *Medical Decision Making*, *36*(7), 868-875.

Estrada, C. A., Martin-Hryniewicz, M., Collins, C., Byrd, J. C., & Peek, B. T. (2004). Literacy and numeracy skills and anticoagulation control. *The American journal of the medical sciences*, *328*(2), 88-93.

Fagerlin, A., Zikmund-Fisher, B. J., Ubel, P. A., Jankovic, A., Derry, H. A., & Smith, D. M. (2007). Measuring numeracy without a math test: development of the Subjective Numeracy Scale. *Medical Decision Making*, *27*(5), 672-680.

Galesic, M., & Garcia-Retamero, R. (2010). Statistical numeracy for health: A crosscultural comparison with probabilistic national samples. *Archives of internal medicine*, *170*(5), 462-468.

Galesic, M., & Garcia-Retamero, R. (2011). Do low-numeracy people avoid shared decision making?. *Health Psychology*, *30*(3), 336.

Garcia-Retamero, R., Andrade, A., Sharit, J., & Ruiz, J. G. (2015). Is patients' numeracy related to physical and mental health?. *Medical Decision Making*, *35*(4), 501-511.

Gaissmaier, W., Anderson, B. L., & Schulkin, J. (2014). How do physicians provide statistical information about antidepressants to hypothetical patients?. *Medical Decision Making*, *34*(2), 206-215.

Ghazal, S., Cokely, E. T., & Garcia-Retamero, R. (2014). Predicting biases in very highly educated samples: Numeracy and metacognition. *Judgment and decision making*.

Golbeck, A. L., Ahlers-Schmidt, C. R., Paschal, A. M., & Dismuke, S. E. (2005). A definition and operational framework for health numeracy. *American journal of preventive medicine*, 29(4), 375-376.

Green, J. M., & Murton, F. E. (1994). *Duchenne muscular dystrophy: The experience of 158 families*. Centre for Family Research, University of Cambridge.

Hallowell, N., Statham, H., Murton, F., Green, J., & Richards, M. (1997). "Talking about chance": the presentation of risk information during genetic counseling for breast and ovarian cancer. *Journal of Genetic Counseling*, 6(3), 269-286.

Handel, M. J. (2016). What do people do at work?. *Journal for Labour Market Research*, 49(2), 177-197.

Hoffrage, U., & Gigerenzer, G. (1998). Using natural frequencies to improve diagnostic inferences. *Academic medicine*, *73*(5), 538-540.

Huizinga, M. M., Beech, B. M., Cavanaugh, K. L., Elasy, T. A., & Rothman, R. L. (2008). Low numeracy skills are associated with higher BMI. *Obesity*, *16*(8), 1966-1968.

Johnson, T. V., Abbasi, A., Schoenberg, E. D., Kellum, R., Speake, L. D., Spiker, C., ... & Master, V. A. (2014). Numeracy among trainees: are we preparing physicians for evidence-based medicine?. *Journal of surgical education*, *71*(2), 211-215.

Kessler, S., Levine, E. K., Opitz, J. M., & Reynolds, J. F. (1987). Psychological aspects of genetic counseling: IV. The subjective assessment of probability. *American journal of medical genetics*, 28(2), 361-370.

Lipkus, I. M. (2007). Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations. *Medical decision making*, 27(5), 696-713.

Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making*, *21*(1), 37-44.

Michie, S., Lester, K., Pinto, J., & Marteau, T. M. (2005). Communicating risk information in genetic counseling: an observational study. *Health Education & Behavior*, *32*(5), 589-598.

Nelson, W., Reyna, V. F., Fagerlin, A., Lipkus, I., & Peters, E. (2008). Clinical implications of numeracy: theory and practice. *Annals of behavioral medicine*, *35*(3), 261-274.

Peters, E. (2012). Beyond comprehension: The role of numeracy in judgments and decisions. *Current Directions in Psychological Science*, 21(1), 31-35.

Peters, E., Västfjäll, D., Slovic, P., Mertz, C. K., Mazzocco, K., & Dickert, S. (2006). Numeracy and decision making. *Psychological Science*, *17*(5), 407-413. Petrova, D., Garcia-Retamero, R., Catena, A., Cokely, E. T., Heredia, A., Arrebola, A., Ramirez-Hernández, J. A. (2017). Numeracy predicts risk of pre-hospital decision delay: A retrospective study of acute coronary syndrome survival. *Annals of Behavioral Medicine*, *51*, 292–306.

Petrova, D., Garcia-Retamero, R., Catena, A., & Van der Pligt, J. (2016). To screen or not to screen: What factors influence complex screening decisions?. *Journal of Experimental Psychology: Applied*, 22(2), 247.

Petrova, D., Kostopoulou, O., Delaney, B. C., Cokely, E. T., & Garcia-Retamero, R. (2018). Strengths and gaps in physicians' risk communication: a scenario study of the influence of numeracy on cancer screening communication. *Medical Decision Making*, *38*(3), 355-365.

Petrova, D. G., van der Pligt, J., & Garcia-Retamero, R. (2014). Feeling the numbers: On the interplay between risk, affect, and numeracy. *Journal of Behavioral Decision Making*, 27(3), 191-199.

Rao, G. (2008). Physician numeracy: Essential skills for practicing evidence-based medicine. *Family medicine*, 40(5), 354.

Rao, V. N., Sheridan, S. L., Tuttle, L. A., Lin, F. C., Shimbo, D., Diaz, K. M., ... & Viera, A. J. (2015). The effect of numeracy level on completeness of home blood pressure monitoring. *The Journal of Clinical Hypertension*, *17*(1), 39-45.

Reyna, V. F., & Brainerd, C. J. (2007). The importance of mathematics in health and human judgment: Numeracy, risk communication, and medical decision making. *Learning and Individual Differences, 17*(2), 147-159.

Reyna, V. F., Nelson, W. L., Han, P. K., & Dieckmann, N. F. (2009). How numeracy influences risk comprehension and medical decision making. *Psychological bulletin*, *135*(6), 943.

Rothman, R. L., Montori, V. M., Cherrington, A., & Pignone, M. P. (2008). Perspective: the role of numeracy in health care. *Journal of health communication*, *13*(6), 583-595.

Schwartz, L. M., Woloshin, S., Black, W. C., & Welch, H. G. (1997). The role of numeracy in understanding the benefit of screening mammography. *Annals of Internal Medicine*, 127(11), 966-972.

Sidney, P.G., Thompson, C.A., Fitzsimmons, C., & Taber, J.M. (2019). Liking some kinds of math but not others: Evidence for adults' negative attitudes towards fractions but not whole numbers. *Manuscript under review*.

Siegler, R. S., & Lortie-Forgues, H. (2017). Hard lessons: Why rational number arithmetic is so difficult for so many people. *Current Directions in Psychological Science*, *26*(4), 346-351.

The Genetic Counseling Admissions Match. (2018). Retrieved from https://natmatch.com/gcadmissions/stats/2018stats.pdf

The Genetic Counseling Admissions Match. (2019). Retrieved from https://natmatch.com/gcadmissions/stats/2019stats.pdf

Wegwarth, O., & Gigerenzer, G. (2011). "There is nothing to worry about": gynecologists' counseling on mammography. *Patient education and counseling*, 84(2), 251-256.

Weller, J. A., Dieckmann, N. F., Tusler, M., Mertz, C. K., Burns, W. J., & Peters, E. (2013). Development and testing of an abbreviated numeracy scale: A Rasch analysis approach. *Journal of Behavioral Decision Making*, *26*(2), 198-21

# Appendix A. Tables

	n	%
Practicing Genetic Counselors	98	45.2%
Mean years of experience	6.2 years	
Specialty		
Prenatal	31	31.6%
Cancer	41	41.8%
Pediatric	18	18.4%
General Genetics	20	20.4%
Other	28	28.6%
Genetic Counseling Trainees	119	54.8%
% Female	204	94%
Mean age	28 years	
Ethnicity		
Non-Hispanic Caucasian	186	85.7%
Asian or Asian American	14	6.5%
Hispanic	5	2.3%
African American	2	0.9%
Mixed, other, or unspecified	10	4.6%

Table 1. Demographics (n=217)

Table 2. Distributions of Subjective and Objective Numeracy Scores

	Mean (sd)	25th percentile	50th percentile	75 <sup>th</sup> percentile
Subjective total	4.8 (0.64)	4.4	4.9	5.3
Subjective (GCs)	5.0 (0.60)	4.5	5.0	5.4
Subjective (GCTs)	4.7 (0.65)	4.3	4.9	5.1
SNS – ability	4.8 (0.93)	4.3	5.0	5.5
SNS – preference	4.8 (0.69)	4.5	4.75	5.3
Objective total	3.9 (1.3)	3	4	5
Objective (GCs)	4.2 (1.3)	3	4	5
Objective (GCTs)	3.7 (1.3)	3	4	5

Table 3. Objective Numeracy Questions Accompanied by the Percentage of Participants Who Responded Correctly to Each Numeracy Item

Question	Total (%)
1. Imagine that we flip a fair coin 700 times. What is your best guess	99.1
about how many times the coin would come up heads in 700 flips?	
times out of 700	
2. On WHEEL OF FORTUNE, the chance of winning a car is 2 in 1000.	81.6
What percent of players on WHEEL OF FORTUNE win a car?%	
3. Out of 50 villagers, 25 are members of a band. Out of these 25	61.8
members in the band, 15 are men. Out of the 25 villagers that are not in	
the band, 10 are men. What is the probability that a randomly drawn man	
is a member of the band?	
4. Imagine we are throwing a die (6 sides, numbered 1 to 6). The	49.3
probability that the die shows "3" is twice as high as the probability of	
each of the other numbers. Now imagine you would throw this die 70	
times. On average, out of 70 throws how many times would the die show	
the number 3?	
5. Imagine we are throwing a 12-sided die 100 times. On average, out of	75.1
100 throws, how many times would this 12-sided die show a number	
evenly divisible by 4 (4, 8, or 12)?	
6. In a field, 40% of snakes are striped, 30% brown and 30% black. A	26.7
striped snake is poisonous with a probability of 10%. A snake that is not	
striped is poisonous with a probability of 20%. What is the probability	
that a poisonous snake in a field is striped?	

	Ctg 1	Ctg 2	Ctg 3	Ctg 4
	n=112	n=26	n=44	n=35
Age	29.3	25.9	27.0	26.3
	(7.0)	(5.2)	(4.5)	(3.4)
Female gender	104 (93)	25 (96)	40 (91)	35 (100)
White, non-Hispanic	97 (87)	20 (77)	38 (86)	31 (89)
Years of experience	3.9 (6.3)	1.3 (4.7)	2.3 (5.9)	0.9 (2.1)
Participant Type				
Genetic Counselor (n=98)	62	8	17	11
Genetic Counseling Trainee (n=112)	50	18	27	24

Table 4. Demographics across Numeracy Categories

Category 1: higher objective, higher subjective (51.6%)

Category 2: higher objective, lower subjective (12.0%)

Category 3: lower objective, higher subjective (20.3%)

Category 4: lower objective, lower subjective (16.1%)

Table 5. Genetic Counselor and Genetic Counseling Trainee Communication Formats with Patients versus Providers

	Patients (%)	Providers (%)
Decimals	0 (0)	2 (0.9)
Fractions	16 (7.4)	22 (10.1)
Frequencies	68 (31.3)	32 (14.8)
Percentages	104 (47.9)	142 (65.4)
No numbers	13 (6.0)	14 (6.5)
Other	16 (7.4)	5 (2.3)

Table 6. Differences in Risk Interpretation across Formats for the Value 0.002

Format	Symmetry	Marginal homogeneity
	(asymptotic)	(Stuart Maxwell)
Frequency vs. Decimal	$X_2(4) = 41.00$	$X_2(3) = 38.93$
	p = 0.0000 * *	p = 0.0000 * *
	n = 217	<i>n</i> = 217
Frequency vs. Fraction	$X_2(3) = 14.78$	$X_2(3) = 14.78$
	p = 0.0020*	p = 0.0020*
	n = 217	n = 217
Frequency vs. Percentage	$X_2(6) = 6.97$	$X_2(4) = 3.42$
	p = 0.3240	p = 0.4902
	<i>n</i> = 217	<i>n</i> = 217
Decimal vs. Fraction	$X_2(3) = 20.87$	$X_2(3) = 20.85$
	p = 0.0001 **	p = 0.0001 **
	<i>n</i> = 217	<i>n</i> = 217
Percentage vs. Decimal	$X_2(6) = 34.10$	$X_2(4) = 33.57$
	p = 0.0000 * *	p = 0.0000 * *
	<i>n</i> = 217	<i>n</i> = 217
Fraction vs. Percentage	$X_2(4) = 8.19$	$X_2(4) = 8.19$
	p = 0.0848	p = 0.0848
	<i>n</i> = 217	n = 217

Frequency = 1 in 500; Decimal = 0.002; Fraction = 9/4500; Percentage = 0.2% \*p < 0.05, \*\*p < 0.001

Table 7. Differences in Risk Interpretation across Format for the Value 0.25

Format	Symmetry	Marginal homogeneity
	(asymptotic)	(Stuart Maxwell)
Frequency vs. Decimal	$X_2(3) = 12.33$	$X_2(3) = 11.67$
	p = 0.0063*	$p = 0.0086^*$
	n = 217	<i>n</i> = 217
Frequency vs. Fraction	$X_{2}(3) = 22.17$	$X_{2}(3) = 22.17$
	p = 0.0001 **	p = 0.0001 **
	n = 217	n = 217
Frequency vs. Percentage	$X_2(3) = 3.78$	$X_2(3) = 3.78$
	p = 0.2865	p = 0.2865
	<i>n</i> = 217	<i>n</i> = 217
Decimal vs. Fraction	$X_2(4) = 17.89$	$X_2(3) = 17.05$
	p = 0.0013*	p = 0.0007 **
	<i>n</i> = 217	<i>n</i> = 217
Percentage vs. Decimal	$X_2(4) = 9.80$	$X_2(3) = 9.34$
	p = 0.0439*	p = 0.0251*
	<i>n</i> = 217	<i>n</i> = 217
Fraction vs. Percentage	$X_2(2) = 18.00$	$X_2(3) = 18.00$
	p = 0.0001 **	p = 0.0004 **
	<i>n</i> = 217	<i>n</i> = 217

Frequency = 1 in 4; Decimal = 0.25; Fraction = 225/900; Percentage = 25% \*p < 0.05, \*\*p < 0.001

## Appendix B. Participant Recruitment Materials

## **Email Sent through NSGC**

Subject Line: Student Research Surveys & Reminders - <<current date>> Title: An Assessment of Genetic Counselors' Numeracy and its Relationship with Risk Assessment and Communication Practices Description: The purpose of this study is to explore the **numeracy** (numeric ability) of genetic counselors and how it may be related to a both risk assessment and communication practices. Participation should take approximately **30-minutes.** Survey Link: https://osu.az1.qualtrics.com/jfe/form/SV\_1RCBy1FU48dA8oB

# Study Information for Genetic Counselors and Genetic Counseling Students

Dear Genetic Counselor or Fellow Genetic Counseling Student,

You are invited to participate in a research study to explore the numeracy (numeric ability) of genetic counselors and genetic counseling students and how it may be related to a genetic counselor's assessment of a patient's risk and communication of that risk.

As the need for genetic counselors continues to grow worldwide, it is essential to ensure that current and future genetic counselors have the skills to successfully understand, apply, and communicate numeric information in order to provide patients with the necessary components to make informed decisions about their health.

You were selected as a possible participant for this research study because you are listed as a genetic counselor who is a member of NSGC or you are enrolled in an ACGC accredited graduate program in genetic counseling.

If you agree to be in this study, we would ask you to take a 30-minute survey. There are no direct benefits to you for participating in this survey. At the end of the survey, you will be prompted to provide your email to enter into a raffle for a \$50 Amazon gift card. 9 raffle winners will be selected at the conclusion of participant recruitment.

We ask that you read this e-mail and ask any questions you may have before agreeing to be in the study.

For questions about the study, you may contact Samantha Choi by email (samantha.choi@osumc.edu). You may also contact Kate Shane-Carson, MS, LGC by email (kate.shane@osumc.edu).

This study is being conducted by Samantha Choi, Genetic Counseling graduate student, in partial fulfillment of requirements for her master's degree at The Ohio State University.

Survey Link: https://osu.az1.qualtrics.com/jfe/form/SV\_1RCBy1FU48dA8oB

### Appendix C. Survey

## Instructions

We are interested in understanding factors that influence how genetic counselors understand, apply, and communicate risk information to patients. We greatly appreciate your time spent participating in this study, and your responses are valued and important. Please pay attention and answer all questions thoughtfully and honestly. An answer to each question is required to proceed with the survey.

## **Subjective Numeracy**

For each of the following questions, please select the number that best reflects how good you are at doing the following things on a scale of 1 (not at all good) to 6 (extremely good).

	1 = Not at	all good	6 = Extremelying	emely good	
How good are you	ı at working	with fractions?			
1 Not at all good	2	3	4	5	6 Extremely good
How good are you	ı at working	with percentage	es?		
1 Not at all good	2	3	4	5	6 Extremely good
How good are you	ı at calculati	ng a 15% tip?			
1 Not at all good	2	3	4	5	6 Extremely good

How good are you at figuring how much a shirt will cost if it is 25% off?

1	2	3	4	5	6
Not at all					Extremely
good					good

For each of the following questions, please select the number that best reflects your answer.

When reading the newspaper, how helpful do you find tables and graphs that are parts of a story?

1	2	3	4	5	6
Not at all					Extremely

When people tell you the chance of something happening, do you prefer that they use words ("it rarely happens") or numbers ("there's a 1% chance")?

1	2	3	4	5	6
Always					Always
prefer words					prefer
					numbers

When you hear a weather forecast, do you prefer predictions using percentages (e.g., "there will be a 20% chance of rain today") or predictions using only words (e.g., "there is a small chance of rain today")?

1	2	3	4	5	6
Always					Always
prefer					prefer words
percentages					

How often do you find numerical information to be useful?

1	2	3	4	5	6
Never					Very often

#### **Preference for Format of Risk Communication**

1. In general, when communicating genetic risk information to patients, do you use. . . ? (Select all that apply)

a. Numeric values (frequencies, percentages, decimals, fractions, etc.)

b. Evaluative labels such "high," "moderate," or "low" risk

c. Relative labels such as "increased/decreased" or "higher/lower" risk

d. I do communicate genetic risk information to patients

2. In general, when communicating genetic risk information about patients to other healthcare providers, do you use. . . ? (Select all that apply)

a. Numeric values (frequencies, percentages, decimals, fractions, etc.)

b. Evaluative labels such "high," "moderate," or "low" risk

c. Relative labels such as "increased/decreased" or "higher/lower" risk

d. I do not communicate genetic risk information to other healthcare providers

3. In general, if you use numbers to communicate genetic risk information to patients, which of the following numeric formats do you use most often?

a. Frequencies (e.g., there is a 1 in 10 chance for you to have this genetic condition)

b. Percentages (e.g., there is a 10% chance for you to have this genetic condition)

c. Decimals (e.g., there is a 0.10 chance for you to have this genetic condition)

d. Fractions (e.g., there is a 1/10 chance for you to have this genetic condition)

e. I do not use numbers to communicate risks to patients

f. Other

4. In general, if you use numbers to communicate genetic risk information to other healthcare providers, which of the following numeric formats do you use most often?

a. Frequencies (e.g., there is a 1 in 10 chance for you to have this genetic condition)

b. Percentages (e.g., there is a 10% chance for you to have this genetic condition)

c. Decimals (e.g., there is a 0.10 chance for you to have this genetic condition)

d. Fractions (e.g., there is a 1/10 chance for you to have this genetic condition)

e. I do not use numbers to communicate risks to other healthcare providers

f. Other

#### **Assignment of Evaluative Labels**

1. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 1 in 500. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

<ul><li>1 = Patient has almost no risk of having this condition</li><li>5 = Patient almost certainly has this condition</li></ul>						
1	2	3	4	5		
Almost no risk	Low risk	Moderate risk	High risk	Almost certain		

2. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 0.002. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

1 = Patient has almost no risk of having this condition 5 = Patient almost certainly has this condition

1	2	3	4	5
Almost	Low	Moderate	High	Almost certain
no risk	risk	risk	risk	

3. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 9/4500. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

<ul><li>1 = Patient has almost no risk of having this condition</li><li>5 = Patient almost certainly has this condition</li></ul>						
1	2	3	4	5		
Almost no risk	Low risk	Moderate risk	High risk	Almost certain		

4. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 0.2%. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

<ul><li>1 = Patient has almost no risk of having this condition</li><li>5 = Patient almost certainly has this condition</li></ul>						
1	2	3	4	5		
Almost no risk	Low risk	Moderate risk	High risk	Almost certain		

5. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 1 in 4. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

<ul><li>1 = Patient has almost no risk of having this condition</li><li>5 = Patient almost certainly has this condition</li></ul>						
1	2	3	4	5		
Almost no risk	Low risk	Moderate risk	High risk	Almost certain		

6. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 0.25. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

1 = Patient has almost no risk of having this condition 5 = Patient almost certainly has this condition

1	2	3	4	5
Almost	Low	Moderate	High	Almost certain
no risk	risk	risk	risk	

7. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 225/900. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

<ul><li>1 = Patient has almost no risk of having this condition</li><li>5 = Patient almost certainly has this condition</li></ul>						
1	2	3	4	5		
Almost no risk	Low risk	Moderate risk	High risk	Almost certain		

8. You are seeing a patient for genetic counseling. He is at risk for having a newly discovered condition. Based on the patient's demographic information and family history, the patient's risk is 25%. Please describe the patient's risk of having this condition on a scale of 1 (almost no risk) to 5 (almost certain).

## 1 = Patient has almost no risk of having this condition 5 = Patient almost certainly has this condition

1	2	3	4	5
Almost	Low	Moderate	High	Almost certain
no risk	risk	risk	risk	

### **Hypothetical Patient Scenario**

A 30-year-old female hears about a newly discovered genetic condition called "syndrome fictum geneticae" on the news. She is concerned about having this condition, so she sees her primary care physician who orders genetic testing. The patient is referred to you for genetic counseling for the result disclosure. You receive the following information from the patient's genetic test report:

Test Information:

Sensitivity	70%
Specificity	90%
Positive Predictive Value	80%
Negative Predictive Value	95%

If your patient tested positive, what is the minimum information you need to tell them (choose between one and all of the options below)?

Sensitivity Specificity Positive Predictive Value Negative Predictive Value

If your patient tested negative, what is the minimum information you need to tell them (choose between one and all of the options below)?

Sensitivity Specificity Positive Predictive Value Negative Predictive Value

## **Objective Numeracy**

Please answer the following questions. Do not use a calculator. You may use a piece of paper and pen if needed.

1. Imagine that we flip a fair coin 700 times. What is your best guess about how many times the coin would come up heads in 700 flips? \_\_\_\_\_times out of 700.

2. In the CONNECTICUT LOTTERY, the chance of winning a \$5 prize is 1%. What is your best guess about how many people would win a \$5 prize if 500 people each buy a single ticket to the lottery? \_\_\_\_\_ person(s) out of 500.

3. On WHEEL OF FORTUNE, the chance of winning a car is 2 in 1000. What percent of players on WHEEL OF FORTUNE win a car? \_\_\_\_\_%

4. Out of 50 villagers, 25 are members of a band. Out of these 25 members in the band, 15 are men. Out of the 25 villagers, that are not in the band 10 are men. What is the probability that a randomly drawn man is a member of the band?

5. Imagine we are throwing a die (6 sides, numbered 1 to 6). The probability that the die shows "3" is twice as high as the probability of each of the other numbers. Now imagine you would throw this die 70 times. On average, out of 70 throws how many times would the die show the number 3?

6. Imagine we are throwing a 12-sided die 100 times. On average, out of 100 throws how many times would this 12-sided die show a number evenly divisible by 4 (4, 8, or 12)?

7. In a field 40% of snakes are striped, 30% brown and 30% black. A striped snake is poisonous with a probability of 10%. A snake that is not striped is poisonous with a probability of 20%. What is the probability that a poisonous snake in the field is striped?  $\_$  %

8. You just answered 7 math questions. How many do you think you answered correctly?

\_\_\_\_ questions.

#### **Objective Numeracy Check**

1. Did you use a calculator or any outside resources (anything other than a pen and paper) to answer any of the questions from the previous section?

Yes No

2. Overall, how much effort did you use to answer the questions in the previous section accurately and honestly?

1	2	3	4	5	6
Zero Effort					Extreme
					Effort

#### **Demographics**

Please answer the following questions about yourself.

1. What is your current age? \_\_\_\_\_ years.

2. What is your gender? Please select the option your MOST identify with.

Male Female Other [DISPLAY 2c] I would rather not report this

2c. What is your gender?

3. What race do you consider yourself to be? Select all that apply.

White Black or African American American Indian or Alaska Native Asian or Asian-American Native Hawaiian or Pacific Islander Other [DISPLAY 3f] I would rather not report this

3f. What is your race?

4. Are you Hispanic or Latino?

Yes No Unsure I would rather not report this

5. How long have you been practicing as a genetic counselor? Please enter the number 0 if you are a current student. \_\_\_\_\_ years.

6. In which specialty(s) of genetic counseling are you currently practicing? Select all that apply.

Prenatal Cancer Pediatric General Genetics Other [DISLPAY 6e] I am currently a student I would rather not report this

6e. In which specialty(s) of genetic counseling are you currently practicing?

## Closing

Thank you for your participation! You have now completed the study. If you would like to be offered the opportunity to receive a \$50 Amazon gift card, please enter your email in the box below. If you would like to decline, please leave the box blank.