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Moderating Effects of Trait Hope and Coping Styles on Perceived Personal Control in Genetic Counseling

THESIS

submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

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DEDICATION

To my husband: Thank you for your support. Thank you for your trust in my unconventional way of doing life. Thank you for letting me partner with you in a marriage; for always putting the needs of me and of our children first; for agreeing to let me stay home with the children during their youngest years. Thank you for supporting my return to school; for supporting me moving out for graduate school; or taking care of everything while I have been away. Thank you for never complaining…ever.

To my children: Thank you for letting me be your mom. Thank you for being my biggest inspiration. Thank you for being guinea pigs for me; for letting my try out every strange thing on you. Thank you for supporting my return to school and graduate school. Thank you for letting me still be "Mom" on the weekends, even though you have proven you are more than capable of handling your own lives.

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ABSTRACT OF THE THESIS

Moderating Effects of Trait Hope and Coping Styles on Perceived Personal Control in Genetic Counseling

By

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Master of Science in Genetic Counseling

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Professor Virginia Kimonis, MD, Chair

Major goals of genetic counseling include promoting psychological well-being while educating patients about birth defects and genetic disorders, facilitating empowered health care choices. Perceived Personal Control (PPC) is an established measure of the benefit of genetic counseling. The primary purpose of this study was to examine change in PPC, trait hope, and coping following genetic counseling. A secondary purpose was to determine how trait hope and coping styles (Brief COPE) might moderate PPC in the setting of genetic counseling. Pre-and post-surveys were completed by 59 individuals who were either a patient or a loved one attending an initial genetic counseling session. The intervention was an hour-long initial genetic counseling session in the prenatal, cancer setting, or general genetics setting. Results showed that PPC is significantly increased after genetic counseling ($p<0.001$). Although trait hope and coping did not significantly moderate change in PPC, individuals with higher pre-test trait hope achieved bigger gains in PPC than those with lower hope ($p=0.16$); and those with lower pre-test coping scores (either adaptive or maladaptive) achieved bigger gains in PPC than those with higher coping skills ($p=0.29$). However, the study was underpowered to detect significant

moderator effects. These findings may encourage more research into the interaction between health behaviors and psychological health in improving the outcome of genetic counseling. Patients with the lowest coping and psychological skills may have the most to gain from the genetic counseling session. It will be valuable for counselors to be aware of this relationship.

1: INTRODUCTION

1.1 Purposes of Genetic Counseling

Genetic counseling is the process of helping individuals and families understand the meaning of and how to adapt to the implications of disease, whether they be medical or psychological in a family, and how genetic contributions might raise or lower those risks. This process involves collecting and evaluating medical histories to assess the chance of genetic disease or recurrence; educating individuals and families about inheritance of, testing for, management of conditions with a genetic component, including potential research opportunities; and counseling to support informed choices by families and individuals affected by conditions as well as adaptive strategies for managing risk (NSGC, 2005) .

The professionals who are trained to accomplish these tasks are called genetic counselors. They have earned a specialized graduate degree and training in the areas of medical genetics and counseling. They often hold previous degrees or have had training in nursing, biology, genetics, psychology or social work. They specialize not only in providing education and guidance for individuals and families with known genetic disorders, but also in identifying at-risk families, and researching clues in a family that may provide an answer to a family struggling with genetic disease. Genetic counselors provide risk assessments and analyze inheritance patterns to provide the family with the tools needed to evaluate all available options (NSGC, 2005).

In addition to the medical facts and factors surrounding a condition with genetic components, genetic counselors are tasked with providing emotional and social support to their patients. The types of information that must be gathered are often of a very sensitive nature. Obtaining accurate information on birth defects, miscarriages, biological parentage of offspring (including

consanguinity or non-paternity) and other highly personal and emotionally charged topics not often discussed due to societal concerns from the patient can be some of the most important pieces of a puzzle because they aid diagnosis of a patient, but allow for the calculation of recurrence risks for the entire family. Genetic counselors must practice candor and trustworthiness, and must inspire trust and openness in their patients in order to do the best job possible.

The counselor needs to be aware of the cultural differences among a wide variety of ethnic groups. A genetic counselor may see several families in a day from different countries, and must coordinate translation and cultural sensitivity into each session. It can sometimes be a challenge to accomplish the goals of education, support, and advocacy within the time allotted.

Genetic counselors see patients in various settings. The majority of patients are seen in pediatrics and prenatal clinics, but as the need for genetic counseling has grown with the knowledge of the genetic contribution to cancer, heart disease, and other mostly adult onset diseases, the need in other clinics has grown (Uhlman, 2009).

Patients must feel they are being heard, and must feel they are getting something out of the experience. The relationship between the counselor and the patient is very important to this end. This study explores some of the ways patients frame their lives (hope, coping, perceived personal control), and how those beliefs and strategies may be associated with the success of their encounter with genetic counseling.

1.2 Hope

When speaking of hope, many people recall the famous Greek myth of Pandora and her box. Pandora was the first woman, formed by the gods from clay. She was created as a vehicle of punishment to the Titan Prometheus, who had stolen fire from the gods. In his anger, Zeus

had the gods create a beautiful and cunning woman and named her Pandora. She was sent to be the bride of Prometheus' younger brother Epimetheus. She arrived with a pithos (storage jar) which she was told contained wondrous items, but was warned never to open the jar. Eventually her curiosity became overwhelming, and she opened the jar, unleashing a swarm of diseases and evil spirits, forever to plague mankind. As she went to return the lid to the jar, she found that there was one item left…hope. Many interpret that hope was the one blessing in the jar, left as a gift from Zeus as a salve to ease the pain caused by the evil now within the world. Others interpret that perhaps hope is not a blessing, but yet another curse, meant to fool us into believing in the illusion of a better tomorrow (Snyder, 1994). Empty, foolish hope may be considered a cheat, but hope with structure, a goal upon which to anchor hope, is a real thing indeed.

Hope, as defined by C.R. Snyder, is "the sum of the mental willpower and waypower that you have for your goals."(Snyder, 1994). He goes on to rename willpower to "agency" and waypower to "pathways."

These two measurable attributes (agency and pathways) are the measure of hope used in this research. Agency is the individuals' determination to reach goals, and is exemplified with statements such as "I energetically pursue my goals" or "My past experiences have prepared me well for my future." Pathways are the planning of the ways to reach those goals, and are exemplified by statements such as "There are lots of ways around any problem" or " I can think of many ways to get the things in life that are important to me" (Snyder et al., 1991).

As with many personality traits, individuals possess both trait hope and state hope. Trait hope is a stable component of one's personality, and does not generally change over time. State hope is more "of the moment", and can be changeable, depending on the circumstances. This is not to say that one is born with all the trait hope there is to be had. Hope can be taught, and it

can be destroyed. Lessons of perseverance in childhood and lessons of despair in the form of abuse and neglect can influence trait hope. Hope can be grown or diminished based upon life experiences and thought patterns. Interventions to teach agency and pathways can increase goal progress (Feldman & Dreher, 2012). Hopeful people have the ability to consider a wider range of goals than most people. In addition, they have the energy to pursue those goals. Hopeful people also have more positive emotions. They also are more confident, able to handle stress more successfully, and flexible enough to alter plans to continue to pursue the bigger goals (Rand, 2009).

Hope has been shown to positively correlate with improved decision making and better coping with stress. For example, college students given a single session of hope intervention showed increases in goal-directed thinking, hope, life purpose, and vocational calling over control participants (Feldman & Dreher, 2012).

Hope, in the form of will power, has been shown to be necessary to patients' progress and personal development after acute spinal cord injury (Lohne, 2006). Essences of those patients' experiences were analyzed from interviews one year after their injury. Recurrent important themes from the patients were the desire to not give up, do things independently, growing grateful through new experiences, meaning of struggling, growing, and new life perspectives.

Hope also has been shown to function as a mediator between proactive sociable style and functional ability for adventitiously blinded American military veterans. Participants answered questions on hope, behaviors including coping, and psychosocial and functional abilities. Veterans who scored higher on hope measurements had more social and less isolating ways of coping with stress (Jackson, Taylor, Palmatier, Elliott, & Elliott, 1998).

1.3 Coping

Coping mechanisms are the way we react to threats, real or perceived. Humans have varied ways of coping with different situations. Some of these may be viewed as active; for example, "I've been taking action to try to make the situation better", or denial, for example, "I've been refusing to believe that it has happened." One well-used coping inventory is the COPE (Carver, Scheier, & Weintraub, 1989a). This measure has 14 subscales, including mental disengagement, active coping, denial, substance use, and acceptance. Researchers have commonly divided the measure into adaptive and maladaptive subscales as well (Moore, 2011). Scales of this length are often prohibitively long, and subject the participant to response fatigue, which indicates a reduction in meaningful responses as the participant becomes fatigued. For this reason, the shorter version, the Brief COPE was developed (Carver, 1997) and utilized in the current study.

Coping activities can also differ depending on internal vs. external locus of control. Locus of control is the idea that people perceive a continuum of control over various parts of their lives. Locus of control can be either internal or external, and can vary for every life situation. The individual expectations relate to Rotter's Social Learning Theory, in which individual experiences over time teach when one can expect to have more or less control over reinforcement (Rotter, 1966). People with strong internal locus of control believe that their own success or failure is due to their own efforts. Those who have largely external locus of control believe that their lives are subject to chance, luck, or to others who have more power to wield. (Rotter, 1966). This is not to say that one is correct, and one is incorrect; these beliefs stem from individual experiences; which are influenced by our culture, social standing, and gender (Mohammadi & Honarmand, 2007). Locus of control differs by gender in employment, with women having higher external locus of control than men (Sharma, 2015). People with more

internal locus of control tend to be active in searching out information on disease and health maintenance when it is relevant to their wellbeing and are active in preventive behaviors, such as wearing seat belts and going to the dentist for checkups (Strickland, 1978).

Coping also has relevance in the literature in association with Perceived Personal Control. A recent study reported that passive coping predicted decreased perceived personal control in persons with type 1 diabetes

as compared with active coping (Rassart et al., 2016).

1.4 Perceived Personal Control

Studies show that Perceived Personal Control (PPC) is a valid measure for gauging the effectiveness of genetic counseling. Higher measurements of PPC are correlated with positive health outcomes and better functioning, including buffering declines in well-being while in terminal decline, meaning that the final decline in life before death was less severe, and took place later in those with high PPC, regardless of age, gender, or disability (Gerstorf et al., 2014). Researchers have examined the PPC in areas such as prenatal, cancer, and aging (Smets, 2006) (Gerstorf et al., 2014).

PPC is a measure designed for use in genetic counseling to measure success not only across education and decision making, but in helping people feel that they have the tools to make informed choices that are in line with what is right for individuals and their families (Berkenstadt et al., 1999). The original work establishing PPC as relevant to genetic counseling revolves around a study in which patients were given the PPC questionnaire (Appendix D) before and after a genetic counseling appointment. The measure evaluates four domains both before and after the session: cognitive, decisional, behavioral, and emotional.

Improving PPC may be associated with many benefits. Though genetic counselors can help their patients understand genetic disease in their family and how to minimize the risk of recurrence, they can't cure the disease, and certainly can't erase the fact that the disease, or risk of disease exists for the family. Counselors may not be able to control the fact that a person has a birth defect, but if they can understand why it happened, and how likely it is to happen again, it gives the patient a sense of control. Genetic counseling that improves PPC therefore can bring strength to an individual through understanding, acceptance, and coping skills. Patients who gain a better sense of control over an adverse health outcome after genetic counseling are more apt to make better decisions with regard to their individual family situation, and express satisfaction with the genetic counseling experience (Cuturilo et al., 2016).

When individuals are faced with uncontrollable pain and stress, they can become helpless and passive. The perception of control over pain and stress, even when the pain experience is identical, results in increased pain tolerance and reduced subjective helplessness. (Muller, 2012). Robinson et al. (2016) conducted a study of Genetic Counseling Satisfaction that evaluated the PPC for participants who received only a Conventional Risk Score (CRS, based upon conventional risk factors such as age, sex and cholesterol levels), in comparison with the PPC for participants who received both a CRS and a Genetic Risk Score (GRS, based upon personal genetic factors). The addition of GRS information corresponded to an increase in PPC for the participants. Similarly, Cuturilo et al. (2015) found that using the PPC measure, their prenatal patients had an increased sense of control both over their medical situation and their emotional response to it as compared to before the genetic counseling session. In that study, prenatal patients were surveyed three times: before a genetic counseling appointment, immediately

afterward, and finally 2-4 weeks after the initial session, when they come back for a follow up session (Cuturilo et al., 2015).

PPC is a measure that has been incorporated into other validated, published measures. The patient-reported outcome measure by McAllister, Wood, Dunn, Shiloh, and Todd (2011) created an 84-item scale to be used to measure health-related quality of life (HRQoL). In this measure, all 9 items of the PPC were integrated, in variations of their original format (McAllister, Wood, Dunn, Shiloh, & Todd, 2011).

Previous studies have examined combining the PPC and elements of coping and hope, but literature review did not reveal the specific combination of the PPC, the Trait Hope, and the Brief COPE. The construct of Empowerment combines PPC and hope, and is one that was examined by the same research team that developed the Genetic Counseling Outcome Scale in the UK. In 2011, participants were interviewed about their ideas of how genetic information and genetic counseling impact patient empowerment. Empowerment was defined by their responses as cognitive control, decision control, behavioral control, hope, and emotional regulation. This includes the dimension of PPC (cognitive, decisional, and behavioral control) and adds hope and emotional regulation (McAllister, Dunn, & Todd, 2011). The participants' qualitative responses explain how genetic counseling empowers patients by re-establishing control and confidence in the patients after their feelings of control have been taken away after a genetic diagnosis. The information and support provided by genetic counselors helped parents feel empowered to make decisions and to have the strength to move forward (in one instance, to try for another pregnancy after a trisomy 18 pregnancy termination.)

Measures of perceived control have been combined with measures of coping. In a study of women who were recovering from sexual assault, perceived control has been associated with

less distress due to reduced use of social withdrawal as a coping strategy than those who used more destructive methods of coping (Frazier, Mortensen, & Steward, 2005).

1.5 Study Objectives and Hypotheses

This current study combines the three measurements of PPC, Hope and Coping. The participants took a combination of pre-published, validated measures: Trait Hope (Snyder et al., 1991), Brief Cope (Carver, 1997), and Perceived Personal Control (Berkenstadt et al., 1999) Measures of hope and coping styles are designed to be stable in this study, and not expected to change after the intervention of genetic counseling as compared to before the session. As in previous research, it is expected that PPC scores will rise after the genetic counseling session. The hypotheses to be tested are that not only will hope be positively correlated with PPC, but that certain methods of coping will emerge among persons with higher or lower trait hope scores. If individuals with reduced trait hope and/or maladaptive coping skills can be identified prior to genetic counseling, the possibility exists to provide appropriate fostering of hope and adaptive coping skills to improve overall patient outcomes.

While perceived personal control has been examined individually with hope and coping, the three constructs have not been jointly examined. The aim of this study is to collect data to investigate these relationships by testing the four following hypotheses.

Hypotheses:

1. Measures of PPC will increase after an initial genetic counseling session as compared to before the session in patients or loved ones participating in the session.
2. Measures of Trait Hope and the Brief COPE will not change after the genetic counseling session as compared to before the session.

3. Those participants with higher Trait Hope will have significantly higher PPC and a significantly larger gain in PPC after the session, as compared with participants with low Trait Hope.
4. Different coping mechanisms will have specific correlations with higher and lower PPC.

2: RESEARCH DESIGN AND METHODS

This project was approved by the University of California, Irvine School of Medicine, Department of Pediatrics, as a thesis project within the Master of Science Genetic Counseling program. All research was conducted in accordance with the rules and regulations of the University of California, Irvine Office of Research, Institutional Review Board; UCI IRB HS#2015-2526 (Appendix A). The research was approved under expedited review, category 7.

2.1 Study Population

The study population comprised a convenience sampling of adult (age 18+) women and men who were either patients, or adult "loved ones" of patients seen for an initial genetic counseling appointment in the prenatal, cancer, or general genetics setting at the University of California (UCI) Medical Center, Pavilion 1 or one of the University's off site centers: The Center for Fetal Evaluation (CFE) in Orange, or Pacific Breast Center in Costa Mesa, CA. Inclusionary criteria were age and English literacy since the measures had not been validated in other languages.

The term "loved one" was used to avoid any concerns from participants of feeling the need to explain marital relationships in the prenatal clinic or any other setting. If the patient was interested in participating, any adults accompanying the patient were asked if they would also like to participate. If the patient was under age 18, the adult loved ones were asked if they

would like to participate. Given the shared nature of genetics, it is possible that the blood relative of a patient (or the spouse/partner of a patient in the event of a prenatal appointment) may have a personal vested interest in the information discussed during an appointment, either for their own genetic risk or for that of their children. Because of this, it is also valuable to gauge the pre and post survey values of those present in the appointment, in addition to those of the patient themselves.

2.2 Recruitment

Participants were recruited from February 2016 - April 2016. Recruitment was done at UCI, in the waiting rooms of Pavilion I, the CFE and Pacific Breast Center. Patients were approached by the lead researcher after signing in for their appointment and after completing any clinic paperwork. Patients and adult loved ones were told that because they were present for an initial genetic counseling session, they were eligible to participate in a research study to better understand the experience of genetic counseling. If the patient or loved one was interested, the approved UCI study information sheet (Appendix B) was used to explain the risks and benefits of participation and to obtain verbal consent. Written consent for this research was not required by the IRB. Loved ones were only asked to participate if the patient was participating. In the event that the patient was a minor, the adult loved one would be asked to participate.

Participants completed the pre-counseling surveys (Appendix D, Part A) before the session, and placed them in a locked box which was kept in in view on a countertop in the waiting room. Immediately after their genetic counseling session, which lasted approximately one hour, participants returned to the waiting room, completed the post-counseling surveys (Appendix D, Part B) and placed them in the locked box. Participants were thanked for their time, and given a $5.00 Target gift card at the completion of their participation.

The lead researcher remained in the waiting room at a distance to provide privacy (preferably at least 10 feet away) but was available to answer any questions; and was not involved in the genetic counseling session. The lead researcher was not present in the counseling session, which would take place in a private office away from the lead researcher, who remained in the waiting room.

2.3 Data collection

In accordance with the IRB approval, no personal information was collected when using the anonymous surveys. Surveys were numbered for the sole purpose of connecting the pre genetic counseling appointment survey packet (Part A) to the post survey packet (Part B).

Three pre-published, validated measures used in this study: Trait Hope (Snyder et al., 1991), Brief Cope (Carver, 1997), and Perceived Personal Control (Berkenstadt et al., 1999). In addition, two custom surveys were created to collect the reason for the appointment in genetics, and demographic information. All survey packets were presented to the participant in pen and paper format. Each individual measure was edited in size to fit on to its own sheet of paper (Appendix D).

2.3.1 Assessment of Custom Surveys (Appointment Reason and Demographics)

The custom Appointment Reason and Demographics surveys were created with the help of Kathryn Osann, PhD, Statistician, University of California, Irvine, and Pamela Flodman, MSc, MS, LCGC, Genetic Counseling Program Director, University of California, Irvine. The Appointment Reason survey asked the participant to indicate the reason for the appointment in genetics: prenatal (pregnant patient, or loved one); pediatric (loved one of minor patient – not cancer); adult (patient, or loved one – not cancer); cancer (patient with cancer diagnosis, or loved one; cancer (patient without diagnosis, or loved one); or other (fill in). The demographic survey

gathered information regarding the participant's age, ethnicity, education level, marital status, and employment status (Appendix D).

2.3.2 Assessment of the Hope Measure

The Trait Hope (Snyder et al., 1991) is a published, validated ordinal Likert-like measure with 12 statement variables. Each of the variables has eight response choices, ranging from "definitely false" to "definitely true." The Snyder Hope scale was used in this study to measure the "trait hope" of the respondents; a reflection of one's personality, which is predicted to remain stable from one measure to the next (as opposed to state hope). The scale was called "The Future Scale" for administration, and included 12 items, designed to measure the participant's overall hope, and the subscales of *agency* and *pathways*.

2.3.3 Assessment of the Brief COPE

The Brief Cope (Carver, 1997), is a published, validated ordinal Likert-like measure with 28 statement variables. Each of the variables has four response choices, ranging from "I didn't do this at all" to "I did this a lot." A sample statement is: "I tried to come up with a strategy about what to do." This measure contains 14 subscales of coping: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame. All sub scales have a Cronbach's alpha rating of between 0.50 to .90 (Mean = .68). which indicates the reliability of the items to accurately measure the construct. This measure is designed to capture an individual's coping mechanisms within a stated period of time. For this study, the timeframe of "over the last month" was specified in the surveys. Because it is asking about past behaviors, this measure is not expected to change significantly between a pre and post measure for any one individual (Appendix D). The Brief COPE is a shortened version of the

original COPE, which has 60 response variables in the same sub domains (Carver, Scheier, & Weintraub, 1989b). The length of the original COPE, in combination with the other measures selected for this study would have been prohibitively long and could have induced response fatigue, and would not have been appropriate for the time sensitive nature of the present study. For these reasons, we selected the Brief COPE.

2.3.4 Assessment of Perceived Personal Control

Perceived Personal Control (Berkenstadt et al., 1999) is a published, validated ordinal Likert-like measure with nine statement variables. Each of the variables has three response choices: "do not agree", "somewhat agree", and "completely agree." A sample statement is: "I feel I have the tools to make decisions that will influence my future." This measure was designed with genetic counseling in mind. In this study, we expect a change in this measure from pre genetic counseling appointment (Part A) to post counseling (Part B) (Appendix D).

2.3.5 Assessment of Combined Data Collection Tools

The five individual measures were combined and replicated to form a two-part survey: Part A and Part B. Part A included (in this order): Pre Appointment Survey, The Future Scale (Trait Hope), Coping Efforts (Brief COPE), Perceived Personal Control. Part B included (in this order): The Future Scale (Trait Hope), Coping Efforts (Brief COPE), Perceived Personal Control, Demographics. Each of the four Part A survey measures and each of the four Part B survey measures were printed on one sheet of paper, creating a stapled Part A and Part B packet. The sample packets were distributed to genetic counseling students and genetic counseling professors affiliated with the graduate program for genetic counseling at University of California, Irvine to evaluate the time needed, and the clarity of questions. It was determined that between 5-8 minutes were needed to complete each packet (Part A or B). The previously

published and validated surveys (Trait Hope, Brief COPE, and Perceived Personal Control) were not altered in any way, and the Pre Appointment Survey and Demographics questions were pilot tested, and found to be clear and easy to understand (Appendix D).

2.4 Data Analysis

Summary domain and subdomain scores were calculated for pretest and posttest measures of hope, coping and PPC according to previously published instructions. Pretest and posttest scores were compared for all participants using paired t-tests with two-sided significance level 0.05. Power analysis conducted for study design indicated that a sample size of 60 participants would have 80% power to detect a significant difference between paired means equal to 0.4 SD, a moderate sized difference that is typically considered clinically meaningful. Associations between measures were explored using Pearson correlation coefficients. Coping and hope scales were further dichotomized at the median to identify participants with high and low values. Analysis of variance for repeated measures with one grouping factor, high vs low coping or hope, was used to investigate the moderating effect of hope and coping on change in PPC. Because participants with high and low coping/hope differed with respect to pretest levels of PPC, analyses were further adjusted for pretest PPC. A significant time by coping (or hope) interaction effect indicates that the change over time in PPC differs between those with high vs low coping (or hope).

2.4.1 Survey Transcription

The lead researcher collected the completed anonymous surveys and matched Part A of each to Part B, then transcribed the data twice in its entirety in double-entry format with true/false verification programming to ensure the most accurate transcription into an Excel file. After cleaning the data to correct any entry discrepancies, the data were imported into IBM's

statistical package software, SPSS for analysis (IBM, 2014). Dr. Kathryn Osann and Pamela Flodman provided guidance for statistical analysis. No adjustments were made for multiple comparisons. The nominal significance for each statistical test is reported.

3: RESULTS

There were a total of 59 participants between February and April, 2016. Participants completed a two-part, 104 item survey (Part A = 50 items; Part B = 54 items). Surveys included the Trait Hope, Brief COPE, Perceived Personal Control, reason for appointment in genetics, and demographics. Six participants did not complete the demographics survey. Aside from the demographics, no survey included more than 2 missed items. No surveys were excluded from this analysis.

3.1 Descriptive Analysis of Reason for Appointments

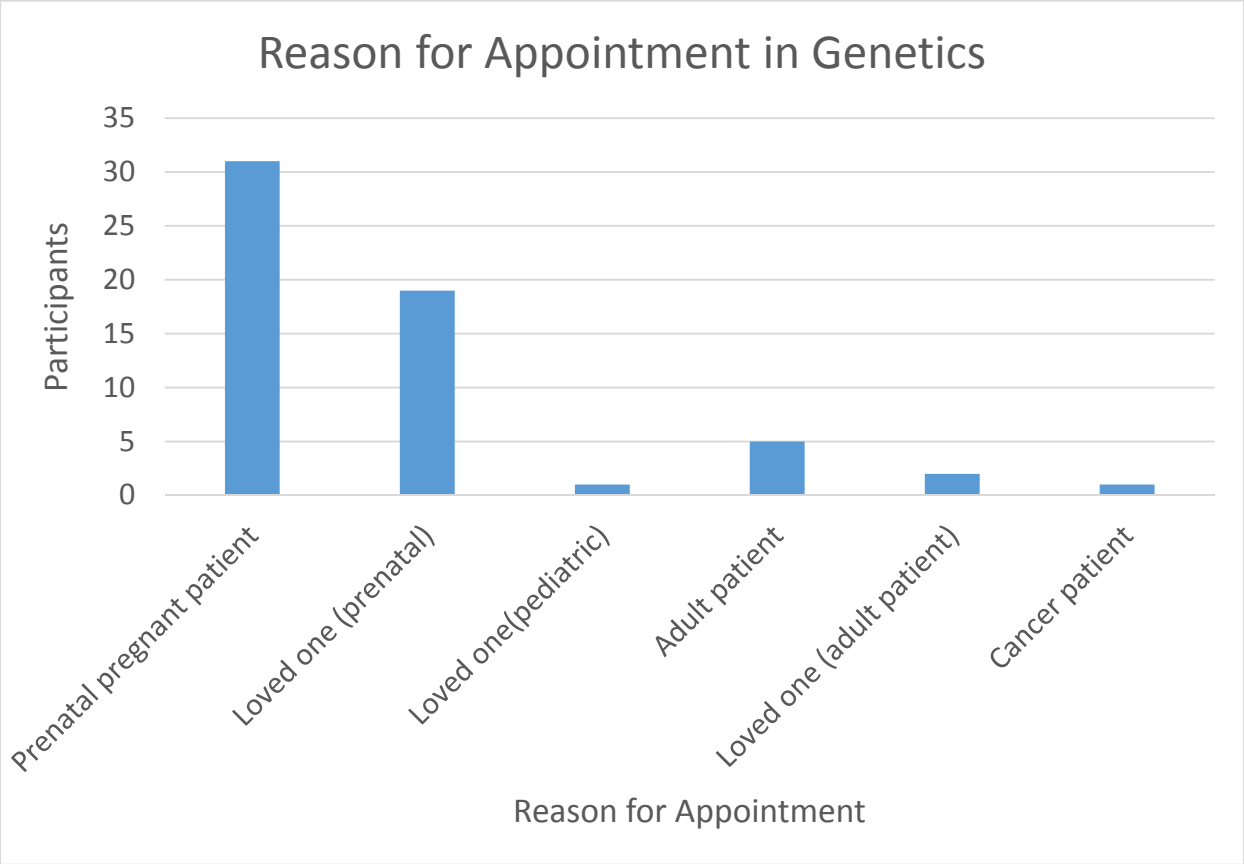
Out of 63 eligible individuals, only four declined to participate (93.65% participation rate). Of the 59 participants, 100% answered the "reason for appointment in genetics" survey. Many patients came to the appointments alone, but due to the anonymous nature of the data collected, it is not possible to determine the exact percentage of sole vs. accompanied patients; in addition, there were some cases in which a patient had more than one "loved one" with them for the appointment (though this was the exception rather than the rule). Categories from which participants could identify themselves were: Prenatal "I am pregnant, appointment is for me" (52.5%; n=31); Prenatal "Appointment is for a loved one who is pregnant" (32.2%; n=19); Pediatric "I am the parent/loved one of a **child** with a genetic counseling appointment – Not cancer" (1.7%; n=1); Adult "I am an adult with a genetic counseling appointment" (8.5%; n= 5) Adult "I am the parent/loved one of an **adult** with a genetic counseling appointment" (3.4%; n=2); Cancer "I have a cancer diagnosis" (1.7%; n=1); Cancer family history "I have not had

cancer, but a family member/loved one has" (0%; n=0); Other "please fill in" (0%; n=0). Thus, pregnancy was the modal reason for the appointment.

Table 1: Reason for Appointment in Genetics

Reason for Appointment in Genetics	Frequency	Percent
Prenatal Pregnant	31	52.5
Prenatal Loved One, Not Patient	19	32.2
Pediatric, Loved one of patient CHILD	1	1.7
Adult patient, not cancer	5	8.5
Adult, loved one, Not patient	2	3.4
Cancer, Patient	1	1.7
Total	59	100.0

Figure 1: Reason for Appointment in Genetics



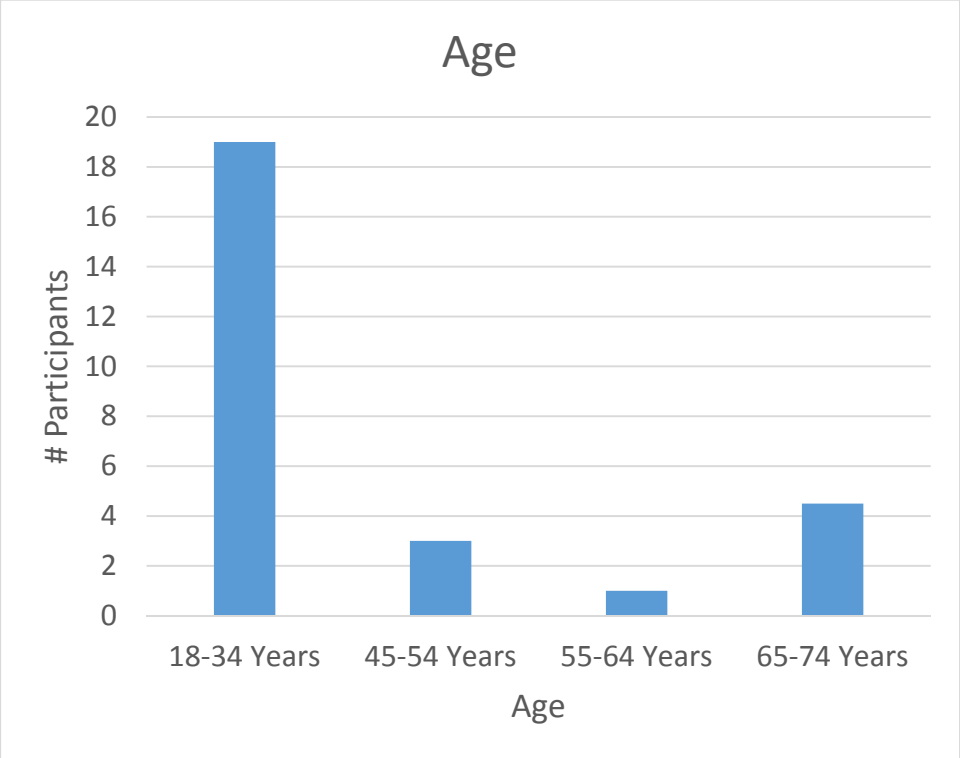
3.2 Descriptive Analysis of Age

Of the 59 participants, 53 answered for Age (89.83%). For those who responded: Age 18-31 (52.8%; n=28); age 35-44 (35.8%; n=19); age 45-54 (5.7%; n=3); age 55-64 (1.9%; n=1); age 56-74 (3.8%; n=2). Thus, the modal participant was 18-34 years of age and over 90% were 18-44 years.

Table 2: Age

Age		Frequency	Percent	Valid Percent (Excludes Missing)
Valid	18-34 years old	28	48	52.8
	35-44 years old	19	32	35.8
	45-54 years old	3	5	5.7
	55-64 years old	1	2	1.9
	65-74 years old	2	3	3.8
	Total	53	90	100.0
Missing	Did not answer	6	10	
Total		59	100	

Figure 2: Age


Age
20
18
16
14
12
10
8
6
4
2
0
Participants
18-34 Years
45-54 Years
55-64 Years
65-74 Years
Age

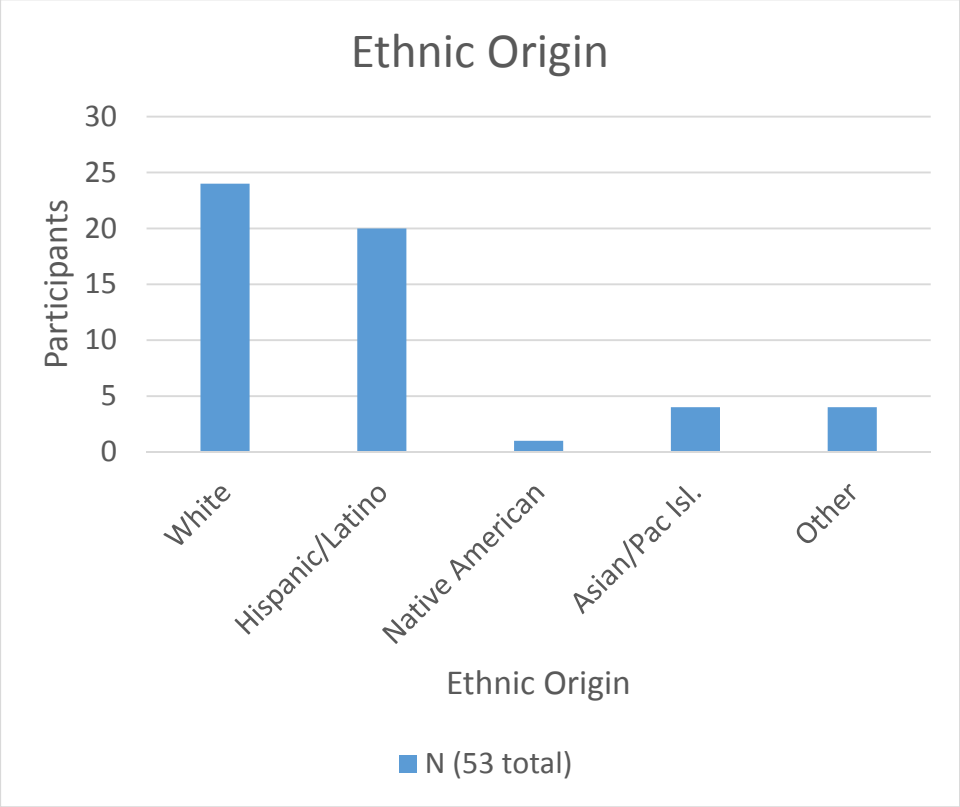
3.3 Descriptive Analysis of Ethnic Origin

Of the 59 participants, 53 answered for Ethnic Origin (89.83%). For those who responded, the vast majority was White or Hispanic/Latino. Specifically, the sample was: White (45.3%; n=24), Hispanic or Latino (37.7%; n=20); Native American or American Indian (1.9%; n=1); Asian or Pacific Islander (7.5%; n=4); Other (7.5%; n=4)

Table 3: Ethnic Origin

Ethnic Origin		Frequency	Percent	Valid Percent (Excludes Missing)
Valid	White	24	40.7	45.3
	Hispanic or Latino	20	33.9	37.7
	Native American or American Indian	1	1.7	1.9
	Asian/Pacific Islander	4	6.8	7.5
	Other	4	6.8	7.5
	Total	53	89.8	100.0
Missing	No response	6	10.2	
Total		59	100.0	

Figure 3: Ethnic Origin



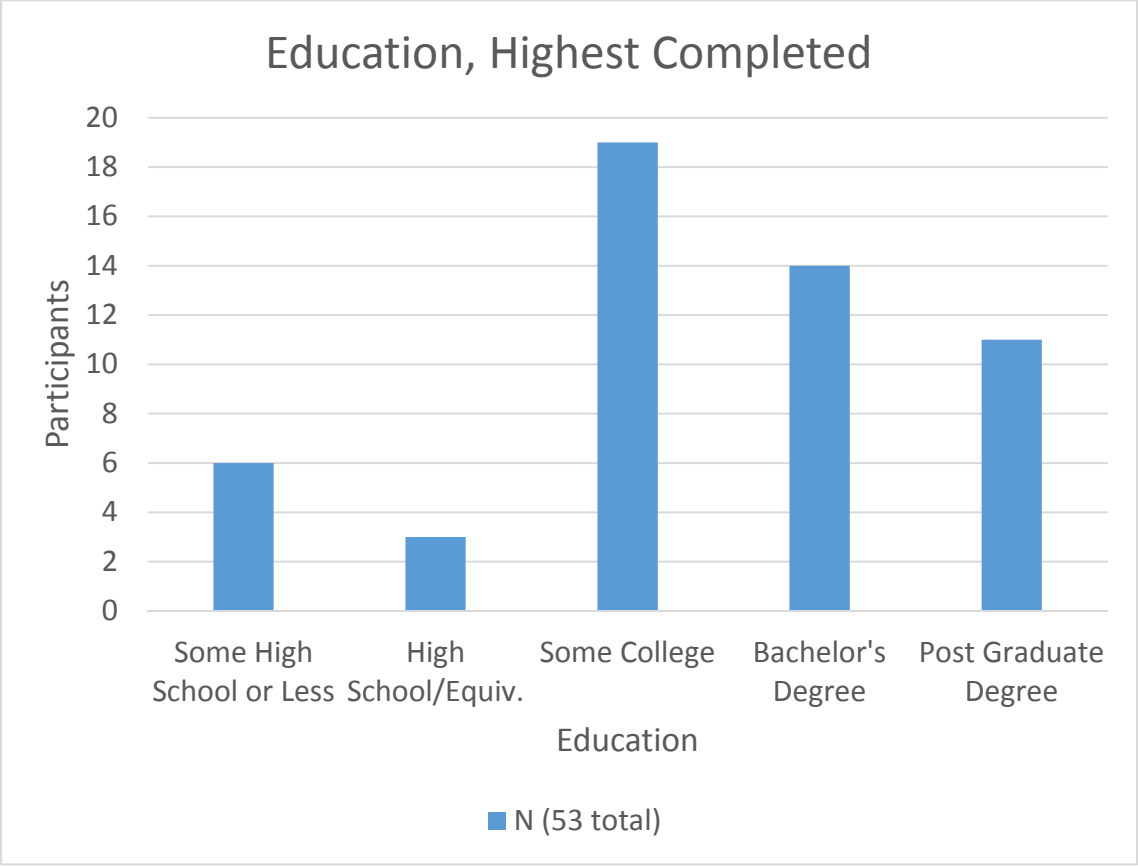
3.4 Descriptive Analysis of Education

Of the 59 participants, 53 answered for Education (89.83%). For those who responded: Some high school or less (11.3%; n=6), high school graduate or equivalent; (5.7%; n=3); some college; (35.8%; n=19) bachelor's degree; and (26.4%; n=14); post graduate degree (20.8%; n=11). Thus, the sample was largely well-educated.

Table 4: Education, Highest Completed

Highest Education Completed		Frequency	Percent	Valid Percent (Excludes Missing)
Valid	Some high school or less	6	10	11
	High School graduate or GED	3	5	6
	Some college	19	32	34
	Bachelor's degree	14	24	26
	Post graduate degree	11	19	21
	Total	53	90	100
Missing	Did not respond	6	10	
Total		59	100	

Figure 4: Education, Highest Completed



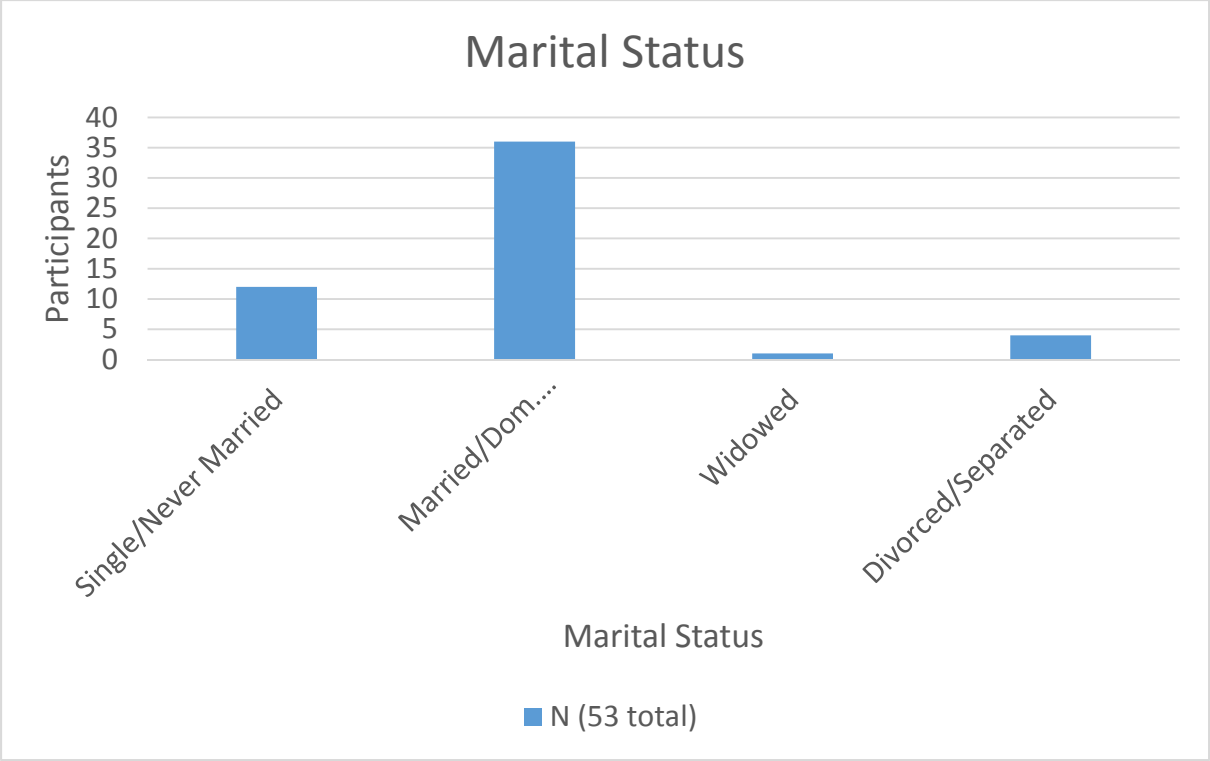
3.5 Descriptive Analysis of Marital Status

Of the 59 participants, 53 answered for Marital Status (89.83%). For those who responded: single/never married (22.6%; n=12); married or domestic partnership (67.9%; n=36); widowed (1.9%; n=1); divorced/separated (7.5%; n=4) as shown in Table 5. Thus, the majority were either married or in a domestic partnership.

Table 5: Marital Status

Marital Status		Frequency	Percent	Valid Percent (Excludes Missing)
Valid	Single, never married	12	20	22.6
	Married or domestic partnership	36	61	67.9
	Widowed	1	2	1.9
	Divorced/ separated	4	7	7.5
	Total	53	90	100
Missing	No response	6	10	
Total		59	100	

Figure 5: Marital Status



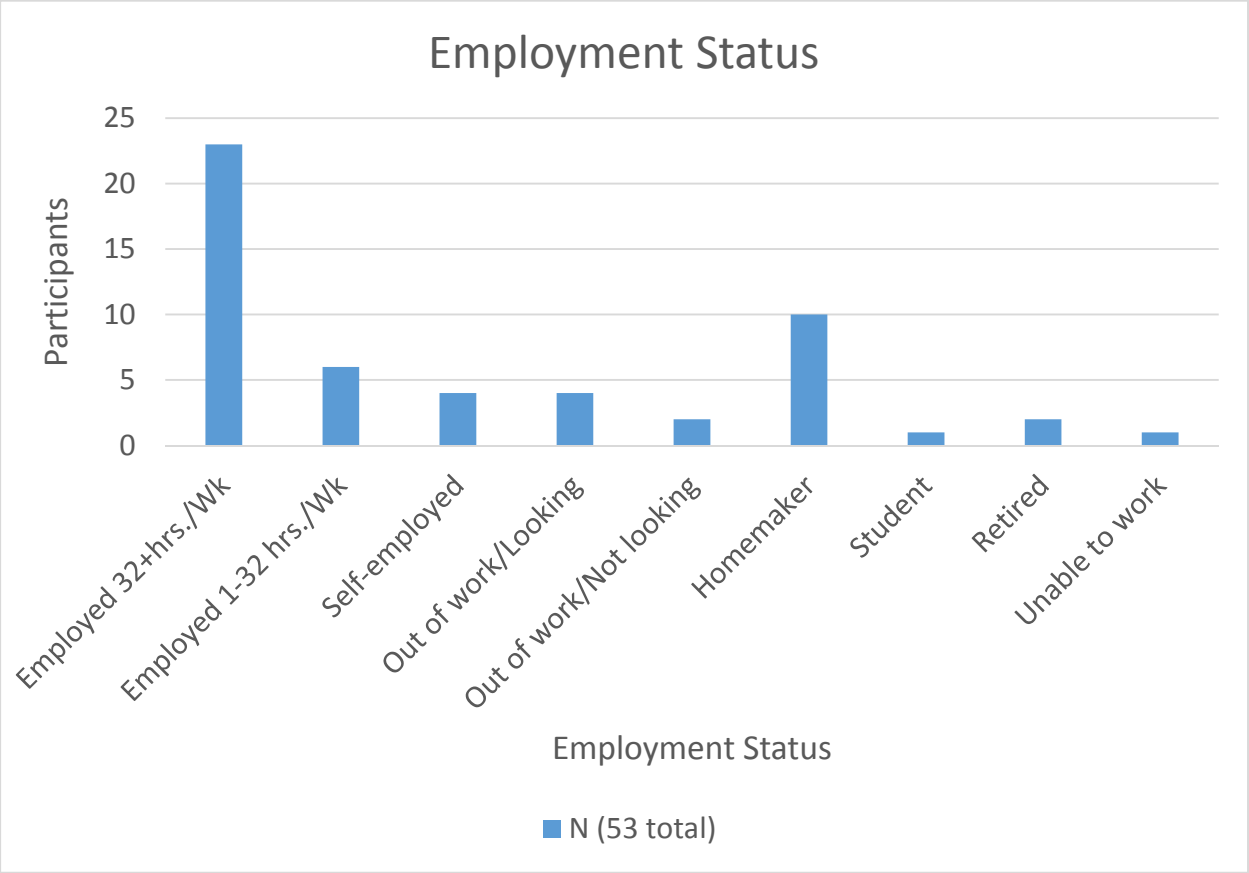
3.6 Descriptive Analysis of Employment Status

Of the 59 participants, 53 answered for Employment (89.83%). For those who responded: employed full-time 32+ hrs./week (43.4%; n=23) employed part-time 1-32 hrs./week (11.3%; n=6); self-employed (7.5%; n=4); out of work and looking for work; (7.5%; n=4); out of work, but not looking for work; (3.8%; n=2); homemaker (18.9%; n=10) student; (1.9%; n=1); military; (0%; n=0); retired (3.8%; n=2); and unable to work. (1.9%; n=1) as shown in Table 6. Thus, the majority were employed full-time.

Table 6: Employment Status

Employment		Frequency	Percent	Valid Percent (Excludes Missing)
Valid	Employed full-time (32+ hrs./week)	23	39	43.4
	Employed part-time (1-32 hrs./week)	6	10	11.3
	Self-employed	4	7	7.5
	Out of work and looking for work	4	7	7.5
	Out of work but not currently looking for work	2	3	3.8
	Homemaker	10	17	18.9
	Student	1	2	1.9
	Retired	2	3	3.8
	Unable to work	1	2	1.9
	Total	53	90	100.0
Missing	No response	6	10.2	
Total		59	100.0	

Figure 6: Employment Status



3.7 Descriptive Analysis of Hope Measure

Hypothesis 2 states: "Measures of Trait Hope and the Brief COPE will not change after the genetic counseling session as compared to before the session."

There was no significant difference in the pretest and posttest scores of sum Hope (Mean difference=0.56; p=0.37), or the subscores of Agency (Mean difference=0.38; p=0.18), or Pathways (Mean difference=0.26, p=0.56) as shown in the table below (Table 7). The sum Trait

Hope pretest and posttest were strongly positively correlated, r=.62, *p*=<.001. The Trait Hope Agency subscore pretest and posttest were strongly positively correlated, r=.80, *p*=<.001. The Trait Hope Pathways subscore pretest and posttest were less strongly correlated, r=.37, *p*=.005.

Table 7: Hope

Hope Paired Samples t-test					
	Mean	N	Std. Deviation	t	p-value
Hope Sum: Pretest	53.35	57	5.44	0.9	0.37
Hope Sum: Posttest	53.91	57	5.27		
Agency Subset: Pretest	26.43	58	3.38	1.4	0.18
Agency Subset: Posttest	26.81	58	3.24		
Pathways Subset: Pretest	26.78	57	3.08	0.6	0.56
Pathways Subset: Posttest	27.04	57	2.93		

3.8 Descriptive Analysis of Brief COPE Measure

The Brief COPE is not designed to have a sum score. Therefore, we analyzed the larger subscores by dividing the measure into Adaptive vs. Maladaptive coping styles. There was no significant difference in the pretest and posttest scores for Adaptive Coping (Mean difference=1.04; *p*=0.13) or for Maladaptive Coping (Mean difference=0.18; *p*=0.96) as shown in the table below (Table 8).

There was no significant difference in the pretest and posttest 14 categorical subdomain scores with the exception of Positive Reframing (Mean difference= - 0.3288, p=0.01) and Humor (Mean difference= - 0.3288, p=0.006), both of which were lower after genetic counseling as compared to before, as shown in the table below (Table 9).

Table 8: Brief COPE

Brief COPE Adaptive and Maladaptive Paired Samples t-Test					
	Mean	N	Std. Deviation	t	p-value
Adaptive Coping Pretest	48.37	52	8.69	1.56	0.13
Adaptive Coping Posttest	47.33	52	8.92		
Maladaptive Coping Pretest	17.57	56	4.79	0.05	0.96
Maladaptive Coping Posttest	17.55	56	5.25		

Table 9: Brief COPE Subdomains

Brief COPE Paired Samples 14 Subdomains Paired Samples t-test					
Coping Style	Mean	N	Std. Deviation	t	p-value
Self-Distraction Pretest	5.25	59	1.49	1.64	0.11
Self-Distraction Posttest	5.53	59	1.83		
Denial Pretest	3.33	58	1.68	1.20	0.24
Denial Posttest	3.14	58	1.55		
Substance Use Pretest	2.49	59	1.33	0.90	0.37
Substance Use Posttest	2.58	59	1.53		
Behavior Disengagement Pretest	3.00	57	1.24	0.33	0.74
Behavior Disengagement Posttest	2.95	57	1.32		
Active Pretest	5.98	58	1.54	1.34	0.18
Active Posttest	5.74	58	1.61		
Planning Pretest	5.81	58	1.48	0.21	0.84
Planning Posttest	5.78	58	1.55		
Positive Reframing Pretest	6.07	59	1.54	2.61	*0.01
Positive Reframing Posttest	5.69	59	1.56		
Acceptance Pretest	5.98	59	1.32	0.59	0.56
Acceptance Posttest	5.88	59	1.47		
Humor Pretest	4.03	59	1.89	0.63	*0.006
Humor Posttest	3.66	59	1.94		
Religion Pretest	5.10	58	2.06	1.34	0.19
Religion Posttest	5.24	58	2.16		
Emotion Support Pretest	5.88	58	1.67	0.31	0.76
Emotion Support Posttest	5.93	58	1.62		
Venting Pretest	4.51	57	1.76	0.58	0.57
Venting Posttest	4.42	57	1.81		
Instrumental Support Pretest	5.60	58	1.64	1.00	0.32
Instrumental Support Posttest	5.76	58	1.59		
Self-Blame Pretest	3.53	59	1.62	0.53	0.60
Self-Blame Posttest	3.46	59	1.47		

3.9 Descriptive Analysis of Perceived Personal Control

Posttest scores of sum Perceived Personal Control (PPC) are significantly higher than pretest scores (Mean difference=2.41; $p<0.01$), as are posttest scores for the subdomains of cognitive (Mean difference=0.83, $p<0.01$), decisional (Mean difference=0.57, $p<0.01$), and behavioral (Mean difference=1.02, $p<0.01$) subdomains, as shown in the table below (Table 10).

Table 10: PPC

PPC Sum or Subscore	Mean	N	Std. Deviation	t	p-value
Sum Pretest	11.28	58	4.09	5.44	<0.01
Sum Posttest	13.69	58	3.76		
Cognitive Pretest	3.48	58	1.98	4.10	<0.01
Cognitive Posttest	4.31	58	1.66		
Decisional Pretest	3.67	58	1.82	4.42	<0.01
Decisional Posttest	4.69	58	1.45		
Behavioral Pretest	4.12	58	1.59	2.98	<0.01
Behavioral Posttest	4.69	58	1.33		

3.10 Descriptive Analysis of Moderation Effects of Hope on Perceived Personal Control

We compared change in PPC over time between participants with pretest levels of Hope above the median to those with pre-test levels of hope below the median. Those are given the names high and low sum hope. There was no significant moderation of PPC change over time by Hope. Those with low Hope had an adjusted increase in PPC after genetic counseling as compared to before of 1.9 points, and those with high Hope had an adjusted increase of 3.08 points ($p=0.16$) as shown below (Table 11)

Table 11: Change in PPC over time by Sum Hope

Unadjusted Scores	**Sum Hope**					
		Low Hope		**High Hope**		**Change Over Time by Hope Level**
		Mean	**SE**	**Mean**	**SE**	**p-value**
	Pretest	10.58	0.72	12.20	0.78	
	Posttest	12.87	0.64	14.84	0.71	
	Increase in PPC over Time	2.29		2.64		**0.71**
Adjusted Scores		**Mean**	**SE**	**Mean**	**SE**	**p-value**
	Pretest	11.30	0	11.30	0	
	Posttest	13.25	0.53	14.38	0.59	
	Increase in PPC over Time	1.95		3.08		**0.16**

We also compared change in PPC over time between participants with pretest levels of the Hope subdomains Agency and Pathways above the median to those with pre-test levels of hope below the median. Those are given the names high/low Agency, and high/low Pathways. There was no significant moderation of PPC by Agency or Pathways over time. For the Agency subdomain, the mean adjusted increase in PPC after genetic counseling for low Agency was 2.08 points, and for high Agency was 2.5 points (p=0.85). For the Pathways subdomain, the mean adjusted increase in PPC after genetic counseling for low Pathways was 1.91 points, and for high Pathways was 2.92 points (p=0.14), as shown below (Table 12).

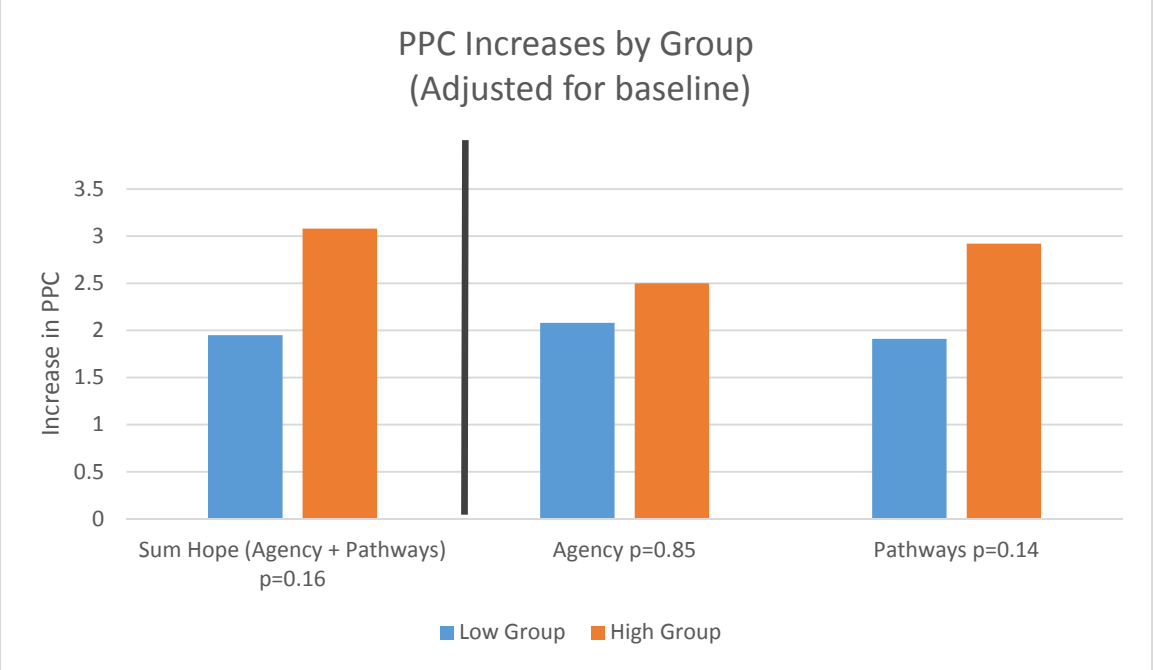
Table 12: Changes in PPC after genetic counseling by Agency or Pathways

Unadjusted Scores	**Agency**						**Pathways**				
		Low Agency		**High Agency**		**Change Over Time by Coping Level**	**Low Pathways**		**High Pathways**		**Change Over Time by Coping Level**
		Mean	**SE**	**Mean**	**SE**	**p-value**	**Mean**	**SE**	**Mean**	**SE**	**p-value**
	Pretest	10.67	0.71	12.09	0.81		10.45	0.71	12.36	0.79	
	Posttest	13.27	0.66	14.24	0.75		12.77	0.63	14.96	0.70	
	Increase in PPC over Time	2.60		2.15		**0.62**	2.32		2.60		**0.77**
Adjusted Scores		**Mean**	**SE**	**Mean**	**SE**	**p-value**	**Mean**	**SE**	**Mean**	**SE**	**p-value**
	Pretest	11.28	0	11.28	0		11.30	0	11.30	0	
	Posttest	13.63	0.52	13.78	0.60		13.21	0.53	14.22	0.59	
	Increase in PPC over Time	2.08		2.50		**0.85**	1.91		2.92		**0.14**

We adjusted for the difference in mean pretest PPC score between groups to address the concern for a possible ceiling effect. After adjusting, the differences between the posttest PPC over time by sum Hope or the subdomains Agency or Pathways became less significant, as

shown in Table 12, and Figure 7. The increase in PPC was larger for those with high sum Hope (Mean difference = 3.08) than for those with low sum Hope (Mean difference=1.95; p=0.16. Increase in PPC were also higher for those with higher Agency (Mean difference = 2.5) than low Agency (Mean difference = 2.08, p=0.85) and those with high Pathways subscores (Mean difference = 2.92) than those with low Pathways (Mean difference = 1.91, p=0.14) than before genetic counseling, as shown in Figure 7.

Figure 7: Increases in PPC increases by group after genetic counseling session, adjusted for baseline.



3.11 Descriptive Analysis of Moderation Effects of Coping on Perceived Personal Control

We compared change over time in PPC between participants with high and low adaptive and maladaptive coping defined as above or below the median pre-test level. Again, there was no

significant difference in change in PPC over time in either the Adaptive or Maladaptive subscores, but the trend showed that those participants who scored below the median in either Adaptive or Maladaptive coping before the counseling session had larger gains in PPC than those whose scores in Adaptive or Maladaptive coping were above the median before the counseling session, (p=.089; p=.091 respectively). Because participants with low coping differed from those with high coping with respect to pre-test levels of PPC, we adjusted for pretest PPC scores. After adjusting the pretest PPC scores, there was reduced significance for the difference in increase of PPC over time between groups defined by high and low Adaptive coping (p=0.29), and between groups defined by high and low Maladaptive coping (p=0.10) as shown in Table 13.

Table 13: Changes in PPC after genetic counseling by High/Low Adaptive or Maladaptive Coping

Unadjusted Scores	**Adaptive Coping**					**Maladaptive Coping**				
		Low Adaptive Coping		**High Adaptive Coping**		**Change Over Time by Coping Level**	**Low Maladaptive Coping**		**High Maladaptive Coping**		**Change Over Time by Coping Level**
		Mean	**SE**	**Mean**	**SE**	**p-value**	**Mean**	**SE**	**Mean**	**SE**	**p-value**
	Pretest	10.57	0.74	12.31	0.80		11.03	0.73	11.58	0.81	
	Posttest	13.60	0.70	13.80	0.75		14.13	0.67	13.16	0.74	
	Increase in PPC over Time	3.03		1.49		**0.091**	3.10				**0.089**
Adjusted Scores		**Mean**	**SE**	**Mean**	**SE**	**p-value**	**Mean**	**SE**	**Mean**	**SE**	**p-value**
	Pretest	11.38	0	11.38	0		11.28	0	11.28	0	
	Posttest	14.09	0.54	13.24	0.59		14.27	0.51	12.98	0.74	
	Increase in PPC over Time	2.71		1.86		**0.29**	2.99		1.70		**0.10**

Though not statistically significant, the trend suggests that those with lower coping scores (either Adaptive or Maladaptive) have larger increases in PPC after genetic counseling, as shown in Figure 8 and 9.

Figure 8: Lower Coping may be associated with larger gain in PPC after genetic counseling

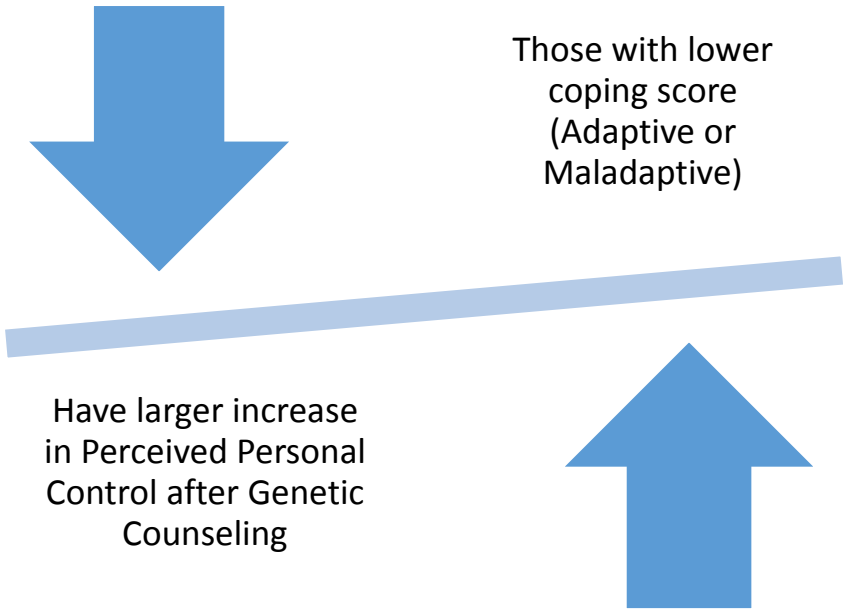
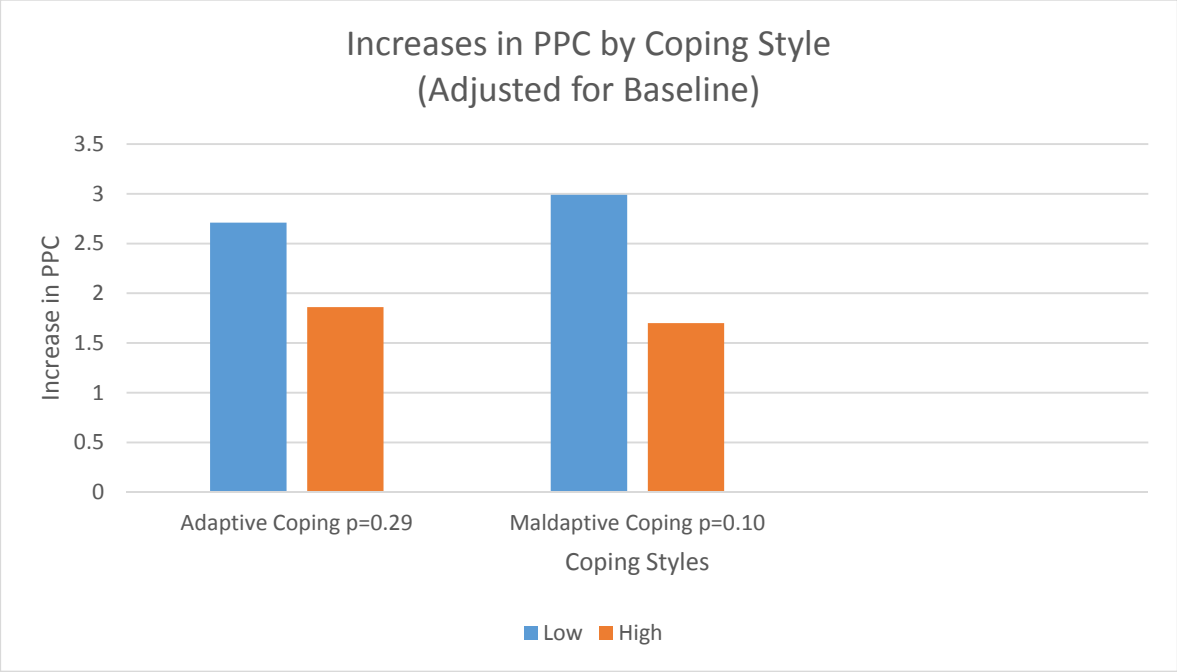


Figure 9: Increases in PPC after genetic counseling by coping style



4: DISCUSSION

4.1 Hypotheses Discussion

Hypothesis 1: Data support hypothesis 1: "Measures of PPC will increase after an initial genetic counseling session as compared to before the session in patients or loved ones participating in the session". This was expected, as PPC is designed to measure the effects on patients of quality genetic counseling: Cognitive Control, Behavioral Control, and Decisional Control (Berkenstadt et al., 1999).

Hypothesis 2: Data support hypothesis 2: "Measures of Trait Hope and Brief COPE will not change after the genetic counseling session as compared to before the session". Trait Hope is a measure of stable Hope, and was not expected to change in the short interval of this study. Brief COPE asked participants how they have used coping in the last 30 days, and the time between before counseling and after would not be expected to influence a change in responses.

For Hope, even though it was expected that values for Hope would be highly correlated before and after the genetic counseling session, the subscore for Pathways within the hope measure of Hope had lower correlation than that of the Agency subscore. It could be speculated that either the physical layout of the instrument (Agency items are more clustered than Pathways items), or the ways people think about the items in the subscales could influence the way participants responded to the items before and after the counseling session.

While the original author of the Brief COPE encourages users of the measure to reference the 14 subscores, he does not encourage use of the subdomains Adaptive and Maladaptive, as he did not originally assign variables to these domains (Carver, 1997). However, many researchers use Adaptive and Maladaptive subdomain scores on a regular basis (Conklin, 2015). The Adaptive subdomain score includes the following domains: Active, planning, positive reinforcement, acceptance, humor, religion, emotional support, venting, instrumental support, and adaptive coping. The Maladaptive subdomain score contains the following domains: Self-destructive, denial, substance use, behavioral disengagement, and self-blame. It could be argued that not all of the adaptive or maladaptive variables are inherently good or bad; but that they are necessarily context dependent. For example, if one is waiting for a test result over which they have no control, engaging in short term maladaptive behaviors like denial could be perfectly rational behavior, since the test has been taken, and the waiting is where the anxiety lies. No amount of adaptive coping such as positive reframing will change the outcome of the test. For these reasons, adaptive and maladaptive coping are interesting subdomain scores to consider, but they may not be mutually exclusive.

There were two significant differences within in the 14 subdomains of the Brief COPE, where the score after genetic counseling were slightly lower than before the session. These

subdomains were Positive Reframing (Mean difference = - 0.37, p=0.01) and Humor (Mean difference= - 0.37, p=0.006). Although the Brief COPE is a validated survey with good internal consistency (Mean=0.73 for Cronbach's alpha), the results of any measure are subject to error (Carver, 1997). The fact that two of the 14 subdomains had a significantly different score after genetic counseling is within the normal range for error within a measure of this size. In addition, the nonsignificant changes in the 14 subscales after genetic counseling as compared to before the session were split between increases (43%) and decreases (57%), which are also split between adaptive (44% increase; 56% decrease) and maladaptive (40% increase; 60% decrease), which further suggests that the small differences in pre and posttest scores is likely due to some other factor such as response fatigue, and not the intervention of genetic counseling.

Hypothesis 3: Data did not support Hypothesis 3: "Those participants with higher Trait Hope will have significantly higher PPC and a significantly larger gain in PPC after the session, as compared with participants with low Trait Hope". The lack of support for this hypothesis may be due to the limited nature of the scale (three scale choices per variable), as there is limited ability to measure an increase in PPC for a participant who already had a high score before the counseling session. It is also possible that a lack of power to detect the difference observed as "statistically significant" is the reason the hypothesis was not supported. Those with higher Trait Hope did have a bigger change, just not to the level of significance. Alternatively, change in PPC following the counseling session may not be influenced by pre-test level of Trait Hope.

For Hope, the idea of the hypothesis was correct. Those with higher levels of Hope (Sum, Agency, Pathways) did see a bigger gain in PPC after the genetic counseling session as compared to before. The data is in the anticipated direction, but significance was not achieved. The idea for this expected direction comes from the literature, which supports high levels of hope

with high levels of coping and functional ability. Previous research supports activities which foster hope as a positive force for patients struggling with health concerns. Hope defined as will power, which approximates Agency, was shown to be important to all patients, providing power and energy for the struggles associated with spinal cord injury one year after the event (Lohne, 2006). Hope has been shown as a mediator between proactive sociable coping and perceived level of functioning in American military veterans who had lost their vision during the course of their lives (Jackson et al., 1998). Hope has also been shown to predict goal progress in college students (Feldman & Dreher, 2012). Their research not only showed that hope can predict goal progress, but that hope can be taught, as evidenced by an increase in hope, life purpose, and vocational calling after a single 90-minute session designed to increase levels of hope (Agency and Pathways) with regard to a previously selected personal goal. Though the present study did not attempt to shape Hope, it is encouraging to know that the positive benefits of hopefulness can be cultivated in a brief period of time. Perhaps further studies can add to the knowledge of how this can benefit those in need of genetic counseling. Hope has long been believed to promote wellness and influence adaptation to disease. Hope and coping are shown to correlate hope with survival rates in metastatic cancers (Gottschalk, 1985). Other hope measures exist as well. Kaye Herth, PhD, RN knew that hope was important to the healing process, and developed the Herth Hope Index to provide a stable instrument to be used in the clinical setting (Herth, 1992)

For coping, these data suggest that those with lower coping (either Adaptive or Maladaptive) have larger gains in PPC after genetic counseling, though statistical significance was not achieved. This could be due to reduced power once the coping styles were stratified into high and low subgroups. Another reason could be that this model of coping was not amenable to measurement by PPC. Though not at the level of significance, the trend suggested that those

with the lowest levels of coping had the most gains in PPC after counseling. This was not the direction that was anticipated, but it is very interesting. It was hypothesized that "Different coping mechanisms will have specific correlations with higher and lower PPC." Instead, an overall low score in coping (Adaptive or Maladaptive) was associated with a bigger gain in PPC. This may be because those with the lowest ability to cope (whatever they style) are less equipped with the skills needed to function in the face of a potential crisis.

Hypothesis 4: Data did not support Hypothesis 4: "Different coping mechanisms will have specific correlations with higher and lower PPC". The lack of support for this hypothesis may be due to the null hypothesis being correct, or due to other factors not examined in this study. We did see a larger increase in PPC among participants with low Adaptive coping and low Maladaptive coping after genetic counseling as compared to before the session. Although these differences did not reach statistical significance, it approached significance with adjusted Adaptive ($p= 0.29$) and adjusted Maladaptive ($p=0.10$). These results were in the opposite direction of what was anticipated. They are very interesting, nonetheless. It is suspected that those with fewer coping skills may have the most room to grow in PPC simply because they started out lower than those with higher coping scores before the counseling session. Future research with more participants may achieve the power necessary when stratifying the coping mechanisms, and help clarify the trend in a statistically significant way.

4.2 Operational Discussion

There were many details of the logistics of the operational data collection which warrant discussion. When preparing for data collection, the researcher made the acquaintance of the office staff, and obtained the permission of the managers with the help of the UCI Genetic Counseling program professors and staff. During data collection, the researcher asked the front

office staff daily to discreetly help her identify initial genetic counseling patients as they came in for their appointments. Daily thanking the front office staff both verbally and by providing a small treat as a token of appreciation (a piece of candy) improved attention and helpful participation of the office staff.

If participant(s) agreed to complete the questionnaires, the researcher gave each a pen and a clipboard which held the IRB approved study information sheet, and the two surveys, stapled separately (part A from part B). Only four eligible participants declined to participate in the study. Part A was face up and open. Part B was folded in half so that only the title (Pre appointment survey, Part A) was immediately visible to the participant. Participant was instructed both in writing and verbally by the researcher to complete Part A immediately, before the counseling session, and to keep hold of the rest of the items until just after the session, when they were to complete Part B. Once the participant completed Part A, they placed that part in a locked box provided by the researcher and placed visibly on the reception desk daily. This supported the anonymous nature of survey collections. Part A contained some identical measures as Part B; collecting Part A before the genetic counseling session allowed the participant to complete Part B after the appointment without access to, or the burden of the answers already provided in Part A. After completing Part A, participant proceeded to their genetic counseling session, taking their clipboard and pen with them. Because these were pre and post measures of an individual participant, it was important to align the answers of the pre counseling session with the answers of the post counseling session for a single individual while maintaining anonymity. This was attempted by using three techniques. First, the researcher discreetly and identically numbering each page of the pre and post survey packet in the corner of the back of each sheet so that pre and post could be matched after collection. Each page was marked in the event they

became separated. Second, brightly colored paper was purchased for surveys. If at all possible, the researcher would give a different color survey packet (each packet one color) to each member of a patient group. Third, the researcher had two different colors of clipboards. The researcher also asked the participants to try and remember the color of the survey packet so that they could keep track of their own individual surveys (if in a group). These tactics evolved after the researcher saw one couple stack the clipboards after completing Part A. This was noticed before the surveys were deposited in the box, and thus they were able to be sorted and kept to their original authors. The researcher informed participants she would be present in the waiting room, a respectable distance away from the participants to allow for privacy during the entirety of the data collection process, in the event of questions from the participants, which was rare.

Immediately following the genetic counseling session, the participants returned to the waiting room to complete Part B of the survey. When complete, the surveys were placed in the locked box, the materials collected (pen, clipboards) and the participants were handed their $5 Target gift cards and thanked for their time and their help. Only two participants refused the gift cards.

It was noticed that some participants were neglecting to complete the final page of Part B of the survey one day when the researcher was emptying the collection box. It was theorized that the reason for this was likely that though Part A and Part B of the surveys contained some the identical surveys in the identical order, there was one unique sheet on the first page of Part A (Reason for appointment in Genetics) and one for the last page of Part B (Demographics). It is likely that the participants may have accidentally skipped the Demographics page, as it was after (what had been) the last page in Part A. To remedy this problem, the researcher slightly wrinkled the last page of Part B, so that it would be more obvious to the participant that there

was indeed another page to the packet, and also if the participant handed the completed packet to the researcher instead of putting it in the box (a frequent occurrence, perhaps to ensure receipt of the promised gift card), then the researcher would give a cursory glance to be sure all the papers were completed without actually reading the responses. One was caught by the last method, and the researcher gently reminded the participant that there was one more page, which the participant quickly completed without concern.

During the course of the study, only three potential participants declined to participate. In order to achieve a high compliance rate, the lead researcher employed several tactics: She approached the potential participant with a smile and knelt or sat about 5 feet away, at or below the eye level of the participant when introducing herself. This positioning is less threatening and more respectful than standing over the participant (Tiedens, 2003). The first thing she did after introducing herself was to ask for the participant's help. Persons who are asked directly for help are more likely to comply, due to the psychological "cost of saying no." (Flynn, 2008). Once they were "asked if they could help", even if they did not verbally answer, a nod was usually observed, which seemed to pave the way for agreeing to participate in the study.

A $5.00 Target gift card was offered to every participant during explanation of the study, which was promised to be distributed when the two-part survey was completed. Even though the cost of the cards was borne by the researcher ($5 x 59 participants = $295.00), it seemed to be a valuable incentive and a worthwhile investment. Not one participant who began the study failed to complete both parts of the survey (one before the session, and one after). This was true even for one participant who was taken immediately to her prenatal ultrasound before she could complete Part B of her surveys. The participant did not return to the waiting room for at least one hour, and the lead researcher had to leave the site. The lead researcher handed the gift card

to the staff, in the unlikely event that the participant returned. The next day the researcher was told that the participant had returned the surveys hours later, after complications during her ultrasound session. The participant had been given the gift card, and the completed surveys were in the secure box. The entirety of the motivation of the participants to complete they surveys with such dedication is uncertain, but it can be presumed to be a combination of social norms related to "agreeing to help" and the small monetary incentive. Since this type of study required the researcher to invest at least one hour per appointment to collect both surveys, the concern was quite high that participants may slip out the door of the busy clinics before completing the post-counseling surveys. Research shows that though large monetary incentives can be manipulative and create an unfair allure to vulnerable populations participate in research, small appropriate monetary incentives improve participation and completion of surveys by participants (Rose, 2007).

In the busy prenatal clinic where the majority of the data was collected, many of the patients have an ultrasound scheduled after their genetic counseling appointment. The ideal arrangement was to have the post survey (Part B) completed immediately after the genetic counseling appointment. In this way, the measurements collected post counseling session would be most likely influenced only by the information received and the interaction between the participant and the genetic counselor, and not by any other events which might occur between the pro and post measures. The flow of the prenatal clinic is designed in such a way to expect just that. Generally, once the patient is done with the genetic counselor, they are returned to the waiting room, and the counselor moves the chart down the hall to the ultrasound technician's chart box. As soon as is feasible, the technician reviews the chart, prepares the room, and then calls for the patient from the waiting room. This process often takes between 10 and 20 minutes.

On two occasions, the patient was called away to their ultrasound before they completed their post counseling survey (Part B). Because the anonymous nature of the data collection, there is no way to know: A) to which patients this occurred, or B) if the information obtained during the ultrasound influenced the outcome of the post measure (Part B). This scenario was unique to the prenatal patients in the study, who were the majority of participants. Other participants, such as adult loved ones of pediatric patients, adult or cancer patients, did not have any additional intervening experiences between pre and post measure other than the intended genetic counseling session.

4.3 Limitations

A strength of the study was that it was large enough to have 80% power to detect moderate differences between paired measures from the pretest and posttest. The absence of differences between pretest and posttest for coping and hope therefore likely reflect the fact that these measures do not change over the counseling session, as expected.

The study was not large enough to detect significant differences between those classified high vs low coping (or hope). With approximately 25 per subgroup, the study had 80% power to detect differences in PPC change between high and low coping (or hope) of 0.8 SD. Observed differences were smaller than this. Thus the study lacked sufficient power to detect as significant the observed differences. The subscales of the Brief COPE have internal reliability Cronbach's alpha ratings of between 0.5 – 0.90 (Mean=0.68) which indicates a less than optimal internal reliability for some subscales.

The original study was adequately powered to test for change in the PPC measure over time. When stratifying participants by high and low scores of Trait Hope, and Adaptive and Maladaptive Coping, adequate power to detect differences between subgroups in change in PPC

was not achieved with the sample size recruited to the study. A larger study with adequate power might detect statistically significant differences. The results that participants who began the study with the lowest scores in Coping (Adaptive or Maladaptive) had the largest gains in PPC after genetic counseling as compared to do not support our expectation (hypothesis 3) that it would be the participants with higher Trait Hope who would have a larger gain in PPC, but they are very encouraging.

The participants in the present study were from a convenience sample of mostly prenatal patients at one medical center, in one region of southern California. Though there was diversity in ethnic, education, and employment demographics, it is important to consider the limitations of a sample from a single geographic region when considering generalization of findings. The sample was restricted to initial genetic counseling appointments, which has the benefit of not confounding the sample with patients receiving genetic test results, which may influence their survey responses. It is important to consider, however, that the majority of patients in the prenatal setting are low overall risk for negative genetic outcomes. The results may have been different if the primary reason for being seen in genetics was for cancer or a child with a serious medical condition. Further research in those settings would be valuable to examine those outcomes to similar surveys.

When hypotheses are not supported, it is important to consider the reason. The reason for these results could be simply that those with the highest pretest scores in PPC simply had no room to improve. Adjusting for a proposed ceiling effect, in which the gain in score is halted due to a topping out of the measure, has been accounted for in this analysis. This leaves us to consider other options.

Previous research emphasizes the importance of coping in the face of genetic risk, and the different coping methods and theories in existence. It has been demonstrated that the style of coping is important depending on the stressor. Problem focused coping is best matched with controllable situations, and emotion-focused coping works better when the situation is uncontrollable, in what is known as the "goodness of fit hypothesis" (Zakowski, Hall, Klein, & Baum, 2001). The present study did not lend itself to this particular type of analysis, though associating coping and genetic counseling is made in both the current study and Zakowski et al. In Jackson et al. (1998), it was shown that those with high Agency and Pathways of Hope were more likely to have higher scores in the sociable and confident coping styles. The coping scale used in Jackson et al. was different than the one used in the present study, but it is encouraging to see a correlation between coping style and high Hope. When researching women's anxiety and coping styles in the face of BRCA mutation testing in families with known cancer syndromes, Tercyak et al (2001) was able to demonstrate a difference in anxiety between women in high vs. low monitoring styles, in that women who were high monitors exhibited higher stress anxiety than those who used more distraction techniques (low monitors). The coping styles in the Tercyak study were not the ones analyzed in the present study, but may be useful in future studies of genetic counseling. With regard to the present study, if the trend is accurate that those with the lowest coping scores have the most to gain from genetic counseling, then the low coping group may be those in the greatest need of quality genetic counseling when medically necessary. This is important information for genetic counselors to consider when working with patients who may show signs of low coping. If these new hypotheses are shown to be supported in future research, perhaps efforts could be made to identify those with low coping skills prior to the

genetic counseling appointment so that additional efforts could be made to reach those who may need the help of genetic counselors most.

Perceived Personal Control (PPC) is the measure around which the present study was built. The findings of the present study demonstrate that PPC increases after an initial genetic counseling session. These findings are consistent with the relevant literature. The original scale by Berkenstadt et al. (1999) was designed to measure the change in the subdomains of cognitive, decisional and behavioral control by providing to the patient knowledge, satisfaction, and fulfillment of expectations about genetic risk information. In another study, higher PPC after genetic counseling has been shown to be a mediator between genetic counseling and reduced use of emotional coping strategies (Shiloh et al., 1997). The coping scale used in the Shiloh et al. study differed from the one used in the present study. Increasing perceived control can reduce stress and pain, as evidenced in a study of pain intensity where participants reports of pain from electric stimuli was increased as subjective helplessness was increased (Muller, 2012). As further evidence of the validity of the PPC measure in genetic counseling, the National Society of Genetic Counselors the PPC to their newest larger measure discussed at the 2015 conference: The Genetic Counseling Outcome Scale (McAllister, Wood, et al., 2011).

4.4 Conclusion

In conclusion, there is more to be learned about the interactions between Hope, Coping and Perceived Personal Control. The present study confirms that PPC increases after genetic counseling, providing our patients with valuable insight for gaining cognitive behavioral and decisional control over their health. The present study suggests that higher levels of Hope may allow bigger gains in PPC after genetic counseling. In addition, the present study suggests that those with lower coping abilities may have the most to gain from medically necessary genetic

counseling. By returning to the story of Pandora and her unintentional unleashing of ills upon the world, only to be comforted by hope as a means of coping with the fallout, it is not unreasonable to consider our patients' emotions as they arrive in our clinics. They may feel that they have unwittingly unleashed some sort of genetic storm upon their families. Perhaps using our toolbox of skills as genetic counselors, we can help our patients identify the hope and coping strategies they already possess to build upon their resources to make their own best decisions.

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APPENDIX A: UCI IRB Approval Letter

January 22, 2016

MICHELLE HACKBARDT
PEDIATRICS

RE: UCI IRB HS# 2015-2526 *Moderating Effects of Trait Hope and Coping Styles on Perceived Personal Control in Genetic Counseling*

The above-referenced human-subjects research project has been approved by the University of California, Irvine Institutional Review Board (UCI IRB). This approval is limited to the activities described in the approved Protocol Narrative, and extends to the performance of these activities at each respective site identified in the Application for IRB Review. In accordance with this approval, the specific conditions for the conduct of this research are listed below, and informed consent from subjects must be obtained unless otherwise indicated below. Additional conditions for the general conduct of human-subjects research are detailed on the attached sheet.

NOTE: Approval by the Institutional Review Board does not, in and of itself, constitute approval for the implementation of this research. Other institutional clearances and approvals may be required (e.g., EH&S, Radiation Safety, School Dean, other institutional IRBs). Research undertaken in conjunction with outside entities, such as drug or device companies, are typically contractual in nature and require an agreement between the University and the entity. Such agreements must be executed by an institutional official in Sponsored Projects, a division in the UCI Office of Research. The University is not obligated to legally defend or indemnify an employee who individually enters into these agreements and investigators are personally liable for contracts they sign. **Accordingly, the project should not begin until all required approvals have been obtained.**

Questions concerning the approval of this research project may be directed to the Office of Research, 5171 California Avenue, Suite 150, Irvine, CA 92697-7600; 949-824-6068 or 949-824-2125 (biomedical committee) or 949-824-6662 (social-behavioral committee).

Expedited Review: Category 7

Alyssa A Brewer, MD, PhD
Vice Chair, Institutional Review Board

Approval Issued: 1/22/2016
Expiration Date: 1/21/2019
UCI (FWA) 00004071, Approved: January 31, 2003

IRB Determinations as Conditions of Approval:

1. STUDY STATUS: Three-Year Extended IRB Approval Granted[1]

Informed Consent Determinations:

2. Waiver of Signed Consent Granted
    a. Study Information Sheet Required

[1] *Research posing no more than minimal risk to human subjects (Expedited review), is not subject to federal oversight (e.g. federally-supported) and is not subject to UCI COIOC review qualifies for Extended IRB Approval. If during the extended approval period the study becomes ineligible for Extended IRB Approval immediately contact the HRP staff for instructions on how to reset to a one-year (no more than 365 days) approval cycle.*

APPENDIX B: UCI IRB Study Information Sheet

University of California, Irvine
Study Information Sheet

Pre and Post Genetic Counseling Survey

Lead Researcher
Michelle Hackbardt, Genetic Counseling Intern
Pediatrics, Division of Genetic and Genomic Medicine
714-456-5837 | mhackbar@uci.edu

Faculty Sponsor
Pamela Flodman, MS, LCGC
Pediatrics, Divison of Genetic and Genomic Medicine
(714) 456-5789 | pflodman@uci.edu

- You are being asked to participate in a research study to better understand the experience of receiving genetic counseling.
- You are eligible to participate in this study if you are over 18 years of age and are a patient, adult parent of a patient/participant, or a loved one of a patient who is seeing a genetic counselor for a first appointment today.
- The research procedures involve a 5-8 minute anonymous survey, to be taken just before (Part A) and again just after your appointment (Part B) today. **No identifiable information will be collected. The survey will NOT become a part of your medical record.**
- Possible risks/discomforts associated with the study are psychological stress caused by answering the questions of the survey.
- There are no direct benefits from participation in the study. However, this study may explain how we can improve the experience of genetic counseling.
- You will receive a $5.00 gift card to Target as compensation for your participation in this research study. You will receive the gift card when you turn in the second part of the survey (Part B)
- All research data collected will be stored securely and confidentially. There will be no identifiable information gathered that could be traced back to you.
- If you have any comments, concerns, or questions regarding the conduct of this research please contact the researchers listed at the top of this form.
- Please contact UCI's Office of Research by phone, (949) 824-6662, by e-mail at IRB@research.uci.edu or at 5171 California Avenue, Suite 150, Irvine, CA 92617 if you are unable to reach the researchers listed at the top of the form and have general questions; have concerns or complaints about the research; have questions about your rights as a research subject; or have general comments or suggestions.
- **Participation in this study is voluntary.** There is no cost to you for participating. Your decision to participate (or not participate) will not affect your status or care as a patient of the Genetic Counseling Center. You may choose to skip a question or a study procedure. You may refuse to participate or discontinue your involvement at any time without penalty. You are free to withdraw from this study at any time.

UCI IRB Approved: 01-22-2016 | APP # 9779 | HS# 2015-2526

APPENDIX C: UCI Chao PRMC Exemption Memorandum

Chao Family Comprehensive Cancer Center
A National Cancer Institute-Designated Comprehensive Cancer Center

Protocol Review and Monitoring Committee
Exemption Memorandum

Date:	01/26/2016
To:	Michelle Hackbardt, BS Pediatrics, Division of Genetic and Genomic Medicine
Re:	UCI 16-03 / HS#2015-2526: Moderating Effects of Trait Hope and Coping Styles on Perceived Personal Control in Genetic Counseling

The above protocol is exempt from PRMC review due to the following reason(s):

- [ ] Chart and/or database review protocol
- [ ] Registry/repository banking study with no scientific objectives
- [ ] Expanded access study
- [ ] Non-cancer study
- [ ] Closed to accrual
- [X] Other: Protocol does not involve access to subject identifiable information.

Protocols that have received PRMC exemption do not require PRMC review at the time of IRB renewal. However, if any modifications affect the scientific design during the course of the renewal period, submission to the PRMC for review is required at CancerCenter_Committees@health.uci.edu.

Thank you.

APPENDIX D: Survey

Pre Appointment Survey – Part A

Q. Reason for your appointment in Genetics: (Check correct box)

- ❑ 1. Prenatal (I am pregnant, appointment is for me.)
- ❑ 2. Prenatal (Appointment is for a loved one who is pregnant)
- ❑ 3. Pediatric (I am the parent/loved one of a **child** with a genetic counseling appointment – Not cancer)
- ❑ 4. Adult (I am an adult with a genetic counseling appointment - Not cancer)
- ❑ 5. Adult (I am the parent/loved one of an **adult** with a genetic counseling appointment – Not cancer)
- ❑ 6. Cancer (I have a cancer diagnosis)
- ❑ 7. Cancer Family History (I have **not** had cancer, but a family member/loved one has)
- ❑ 8. Other (Please fill in)

_____

_____

Pre Appointment Survey – Part A

The Future Scale

Directions: Read each item carefully. Using the scale shown below, please circle the number that best describes YOU.

	1. Definitely False	2. Mostly False	3. Somewhat False	4. Slightly False	5. Slightly True	6. Somewhat True	7. Mostly True	8. Definitely True
1. I can think of many ways to get out of a jam.	1	2	3	4	5	6	7	8
2. I energetically pursue my goals.	1	2	3	4	5	6	7	8
3. I feel tired most of the time.	1	2	3	4	5	6	7	8
4. There are lots of ways around any problem.	1	2	3	4	5	6	7	8
5. I am easily downed in an argument.	1	2	3	4	5	6	7	8
6. I can think of many ways to get the things in life that are important to me.	1	2	3	4	5	6	7	8
7. I worry about my health.	1	2	3	4	5	6	7	8
8. Even when others get discouraged, I know I can find a way to solve the problem.	1	2	3	4	5	6	7	8
9. My past experiences have prepared me well for my future.	1	2	3	4	5	6	7	8
10. I've been pretty successful in life.	1	2	3	4	5	6	7	8
11. I usually find myself worrying about something.	1	2	3	4	5	6	7	8
12. I meet the goals that I set for myself.	1	2	3	4	5	6	7	8

COPING EFFORTS

The next items deal with ways you've been coping **over the past month** or so with your concern that brought you to genetic counseling. Each item says something about ways of coping. We want to know **how much or how frequently** you've been doing what the item says--not whether it seems to help or not, but how much or how frequently you've been doing it lately. Try to rate each item separately in your mind from others. Circle the best choice.

Over the past month:	I didn't do this at all	I did this a little bit	I did this a medium amount	I did this a lot
1. I turned to work or other activities to take my mind off things……	1	2	3	4
2. I concentrated my efforts on doing something about the situation I'm in..	1	2	3	4
3. I said to myself "this isn't real"……	1	2	3	4
4. I used alcohol or other drugs to make myself feel better……	1	2	3	4
5. I got emotional support from others……	1	2	3	4
6. I gave up trying to deal with it……	1	2	3	4
7. I took action to try to make the situation better……	1	2	3	4
8. I refused to believe that it has happened……	1	2	3	4
9. I said things to let my unpleasant feeling escape……	1	2	3	4
10. I got help and advice from other people……	1	2	3	4
11. I used alcohol or other drugs to help me get through it……	1	2	3	4
12. I tried to see it in a different light, to make it seem more positive……	1	2	3	4
13. I criticized myself……	1	2	3	4
14. I tried to come up with a strategy about what to do……	1	2	3	4
15. I got comfort and understanding from someone……	1	2	3	4
16. I gave up the attempt to cope……	1	2	3	4
17. I looked for something good in what is happening……	1	2	3	4
18. I made jokes about it……	1	2	3	4
19. I did something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping……	1	2	3	4
20. I accepted the reality of the fact that it has happened……	1	2	3	4
21. I expressed my negative feelings……	1	2	3	4
22. I tried to find comfort in my religion or spiritual beliefs……	1	2	3	4
23. I tried to get advice or help from other people about what to do……	1	2	3	4
24. I learned to live with it……	1	2	3	4
25. I thought hard about what steps to take……	1	2	3	4
26. I blame myself for what happened……	1	2	3	4
27. I prayed or meditated……	1	2	3	4
28. I made fun of the situation……	1	2	3	4

Perceived Personal Control Questionnaire:

To what extent do you agree with the following statements? Please circle the number that best describes YOU.

	0 Do Not Agree	1 Somewhat Agree	2 Completely Agree
1. I think I understand what problem brought me to genetic counseling.	0	1	2
2. I feel I know the meaning of the problem for my family's future and me.	0	1	2
3. I feel I know what caused the problem.	0	1	2
4. I feel I have the tools to make decisions that will influence my future.	0	1	2
5. I feel I can make decisions that will change my family's future.	0	1	2
6. I feel there are certain things I can do to prevent the problem from recurring.	0	1	2
7. I feel there are certain things I can do to ease the situation.	0	1	2
8. I feel I know what to do to ease the situation.	0	1	2
9. I think I know what should be my next steps.	0	1	2

Please put this survey in the box.
Please complete Part B IMMEDIATELY after your counseling session, before leaving the clinic.

Post Appointment Survey, Part B

The Future Scale

Directions: Read each item carefully. Using the scale shown below, please circle the number that best describes YOU.

	1. Definitely False	2. Mostly False	3. Somewhat False	4. Slightly False	5. Slightly True	6. Somewhat True	7. Mostly True	8. Definitely True
1. I can think of many ways to get out of a jam.	1	2	3	4	5	6	7	8
2. I energetically pursue my goals.	1	2	3	4	5	6	7	8
3. I feel tired most of the time.	1	2	3	4	5	6	7	8
4. There are lots of ways around any problem.	1	2	3	4	5	6	7	8
5. I am easily downed in an argument.	1	2	3	4	5	6	7	8
6. I can think of many ways to get the things in life that are important to me.	1	2	3	4	5	6	7	8
7. I worry about my health.	1	2	3	4	5	6	7	8
8. Even when others get discouraged, I know I can find a way to solve the problem.	1	2	3	4	5	6	7	8
9. My past experiences have prepared me well for my future.	1	2	3	4	5	6	7	8
10. I've been pretty successful in life.	1	2	3	4	5	6	7	8
11. I usually find myself worrying about something.	1	2	3	4	5	6	7	8
12. I meet the goals that I set for myself.	1	2	3	4	5	6	7	8

COPING EFFORTS

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6. I gave up trying to deal with it.	1	2	3	4
7. I took action to try to make the situation better.	1	2	3	4
8. I refused to believe that it has happened.	1	2	3	4
9. I said things to let my unpleasant feeling escape.	1	2	3	4
10. I got help and advice from other people.	1	2	3	4
11. I used alcohol or other drugs to help me get through it.	1	2	3	4
12. I tried to see it in a different light, to make it seem more positive.	1	2	3	4
13. I criticized myself.	1	2	3	4
14. I tried to come up with a strategy about what to do.	1	2	3	4
15. I got comfort and understanding from someone.	1	2	3	4
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26. I blame myself for what happened.	1	2	3	4
27. I prayed or meditated.	1	2	3	4
28. I made fun of the situation.	1	2	3	4

Perceived Personal Control Questionnaire:

To what extent do you agree with the following statements? Please circle the number that best describes YOU.

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2. I feel I know the meaning of the problem for my family's future and me.	0	1	2
3. I feel I know what caused the problem.	0	1	2
4. I feel I have the tools to make decisions that will influence my future.	0	1	2
5. I feel I can make decisions that will change my family's future.	0	1	2
6. I feel there are certain things I can do to prevent the problem from recurring.	0	1	2
7. I feel there are certain things I can do to ease the situation.	0	1	2
8. I feel I know what to do to ease the situation.	0	1	2
9. I think I know what should be my next steps.	0	1	2

For each question, please check the appropriate box.

Q. Age: What is your age?

- ❑ 1. 18-34 years old
- ❑ 2. 35-44 years old
- ❑ 3. 45-54 years old
- ❑ 4. 55-64 years old
- ❑ 5. 65-74 years old
- ❑ 6. 75 years or older

Q. Ethnicity origin (or Race): Please specify your ethnicity.

- ❑ 1. White
- ❑ 2. Hispanic or Latino
- ❑ 3. Black or African American
- ❑ 4. Native American or American Indian
- ❑ 5. Asian / Pacific Islander
- ❑ 6.Other _____

Q. Education: What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*

- ❑ 1. Some high school or less; no diploma
- ❑ 2. High school graduate, diploma or the equivalent (for example: GED)
- ❑ 3. Some college
- ❑ 4. Bachelor's degree
- ❑ 5. Post graduate degree

Q. Marital Status: What is your marital status?

- ❑ 1. Single, never married
- ❑ 2. Married or domestic partnership
- ❑ 3. Widowed
- ❑ 4. Divorced/Separated

Q. Employment Status: Are you currently…?

- ❑ 1. Employed full time (32+ hrs./week)
- ❑ 2. Employed part time (1-32 hrs./week)
- ❑ 3. Self-employed
- ❑ 4. Out of work and looking for work
- ❑ 5. Out of work but not currently looking for work
- ❑ 6. A homemaker
- ❑ 7. A student
- ❑ 8. Military
- ❑ 9. Retired
- ❑ 10. Unable to work

Thank you for taking my surveys. I appreciate your help. Please put the survey in the box and collect your $5.00 gift card.