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Cancer Genetic Counselors' Perceptions of Nutritional Recommendations

by

Breann Reinsch

Submitted in Partial Fulfillment of the Requirements
For the Degree of Master of Science in Human Genetics and Genetic Counseling
School of Pharmacy and Health Sciences
Keck Graduate Institute

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Abstract

Objective: The purpose of this research study is to understand the perspectives of genetic counselors who work with patients in the cancer setting and explore if nutrition is a consideration when counseling patients.

Background: Evidence on the influence of nutrition on cancer risk is increasing with retrospective cohort studies. The American Cancer Society states that smoking, body mass index (BMI), poor nutrition, and excess alcohol consumption are directly linked to cancer occurrences, therefore some cancers may be preventable through lifestyle changes (American Cancer Society, 2016). In cancer genetic counseling sessions, patients are often inquiring about nutritional recommendations. A majority of patients have at least one modifiable lifestyle risk factor that increases their risk of developing cancer (Albada, et al., 2013; Quillin, 2016).

Method: Eight genetic counselors in Southern California working in the cancer specialty were interviewed to explore their perceptions of nutritional recommendations during counseling sessions. Transcripts were reviewed, coded, and analyzed using conventional content analysis.

Result: All genetic counselors participating in this study (8/8) expressed that they believe nutrition can contribute to cancer risk. Variability in the cohort regarding who regularly offered nutritional recommendations and the factors that influenced their perceptions of nutrition in this setting was explored.

Conclusion: Initial research shows that genetic counselors could benefit from additional education regarding nutritional impact on cancer risk in their formal training. A larger cohort study is recommended to determine if a majority of genetic counselors working in oncology have similar attitudes towards nutritional recommendations in their current practice.

Key Words: nutrition, cancer risk, genetic counseling, attitudes, hereditary, hereditary cancer

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Introduction

Cancer is one of the leading causes of morbidity and mortality in the world today. According to the National Cancer Institute, 39.3% of people in the United States will be diagnosed with some type of cancer in their lifetime, based on data collected from 2014 to 2016 (National Cancer Institute, 2019a). In the United States, the World Cancer Research Fund estimates that 20% of cancers are preventable (World Cancer Research Fund/American Institute for Cancer Research, 2018). The American Cancer Society states that smoking, body mass index (BMI), poor nutrition, and excess alcohol consumption are directly linked to cancer occurrences, therefore some cancer occurrences may be preventable through lifestyle changes (American Cancer Society, 2016). Approximately 5 to 10% of all cancers are inherited through a single gene mutation (National Cancer Institute, 2019b). Patients are often referred to a genetic counselor for further evaluation when there is suspicion of a hereditary cancer condition.

Genetic counseling traditionally follows a three-step model beginning with a risk assessment, followed by pre-test counseling, and finally, results disclosure. This practice includes management and prevention recommendations for counselees based on guidelines created for specific hereditary cancer syndromes and associated phenotypes. Cancer genetic counseling typically focuses on management and prevention recommendations that are limited to increased screenings, drug specific interventions, and prophylactic surgeries (Vig & Wang, 2012). Guidelines for hereditary and familial cancer risk assessment provide specific suggestions for early detection and cancer risk reduction as outline by the National Comprehensive Cancer Network (NCCN). Recommendations are provided based on cancer location, type, family

history, and mutation status. These guidelines do not include nutritional or lifestyle recommendations (National Comprehensive Cancer Network, 2020).

The Health Information National Trends Survey (HINTS 4) collected in 2013 asked questions to determine the public's understanding of cancer related information. Of the 3016 responses, 135 participants had genetic testing for hereditary cancer conditions. Cancer risk factors related to lifestyle were identified for the cohort that had undergone genetic testing based on the American Cancer Society nutrition and physical activity guidelines (American Cancer Society, 2016; Quillin, 2016). Among them, 58% were found to be overweight or obese, 63% drank non-diet soda, and 36% ate less than the recommended amount of fruits and vegetables per day (Quillin, 2016). These percentages were similar to individuals in the study who had cancer-focused genetic counseling but chose not to undergo genetic testing. In this population, genetic counselors did not specifically address modifiable lifestyle risk factors in their management and prevention recommendations for clients. Talking with patients about proven cancer risk factors, misconceptions, and modifications of lifestyle for reduction of cancer risks can help both people at average population risk level for cancer and those with hereditary cancer risks alike (Quillin, 2016).

In 2013, a study focused specifically on genetic counseling for breast cancer found that 60% of clients raised questions about lifestyle changes they could incorporate to decrease their risk of developing cancer (Albada, et al., 2013). Even more astoundingly, after counseling, there was a 14% increase in belief that lifestyle habits played a causal role in getting breast cancer. As a whole, lifestyle risk factors were not regularly offered in the counseling sessions. The authors concluded that genetic counseling for the indication of breast cancer should integrate lifestyle risk factors and recommendations including healthy eating habits and exercise regimens into

their sessions (Albada et al., 2013). Similarly, a study of 113 men undergoing genetic counseling for prostate cancer determined that 82.3% were either overweight or obese and that genetic counseling sessions provided a unique opportunity to address these risk factors (Milliron, et al., 2019). Proper nutritional practices can help mitigate risk for first cancers, second cancers, and increase overall cancer survival rates (Bodai, et al., 2018). Dietary and lifestyle recommendations are important for individuals affected with many cancer types including colon and prostate cancer as well as cancer survivors.

The American Cancer Society (ACS) has compiled evidence from research involving vitamin supplements, nutrient popularity, and availability in regions to geographic cancer incidence rates and dietary differences. The ACS has formulated recommendations to be used by the general public as guidelines for lifestyle cancer prevention methods. These recommendations include nutritional guidelines such as recommending diets high in vegetable and fruit servings, limiting foods high in fat, salt, and carbohydrates, and reducing sugar intake (American Cancer Society, 2016). Resources, like those available through the ACS, offer evidence-based guidelines that patients can utilize on a daily basis for cancer prevention and better health practice. These guidelines are relevant for unaffected individuals, as well as those who have developed cancer.

The purpose of this qualitative research study is to understand the perspectives of cancer genetic counselors to explore as to what extent nutrition is or is not a consideration when counseling patients. Participants were interviewed in a semi-structured method, utilizing a questionnaire to identify current practices and perceptions of nutrition in their practice. This study hopes to highlight the reasons nutrition is or is not incorporated into cancer genetic counseling sessions, with the goal of expanding these findings into future research studies and professional practices.

Background

Cancer is the result of a process in which multiple pathogenic genetic changes result in unrestricted abnormal cell growth. The disease is termed “genetic” however the causes for these genetic changes, be it environmental or inherited, are still not fully understood. Approximately 5-10% of cancers are hereditary, due to germline mutations in genes involved in DNA repair mechanisms including *BRCA1*, *BRCA2*, *MLH1*, among others (National Cancer Institute, 2019a). These genes are involved in the body’s natural defense against the development of cancer and therefore mutations confer a higher risk of developing cancer. The cause of cancer in the remaining 90-95% of cases is thought to be the result of environmental exposure, genetic causes not yet discovered or, more likely, a combination of the two, which contribute to disease progression over time. The role of genetic counselors is to elicit and evaluate individual health and family histories in an effort to provide a holistic assessment and tailored disease risk estimate (National Society of Genetic Counselors, 2019). An assessment of genetic cancer risk should therefore include evaluation of diet and nutrition in order to fully determine environmental considerations.

A landmark study published in 1981 included statistics of the different factors contributing to cancer development based on epidemiology (Doll & Richard Peto, 1981). The authors concluded that approximately 35% of cancers can be attributed to factors such as carcinogens including smoking and alcohol use and another 30% of all cancers can be attributed to diet. These findings help to explain variance in specific cancer incidences across different

racial and ethnic groups, and how the cancers types alter with geographical migration and dietary changes (Doll & Richard Peto, 1981). Diet is estimated to increase individual cancer risk by approximately 30%, however, publications vary in reported risk from 20% to 70%. For example, the World Cancer Research Fund quotes that 20% of cancer may be attributed to lifestyle factors including body fatness, poor nutrition, and alcohol consumption (American Cancer Society, 2016). Alcohol has long been an established risk factor for upper digestive tract, breast, and colorectal cancers (Bagnardi V. , et al., 2015). Likewise, the positive association between colorectal cancer incidence and increased red meat intake has well been established throughout cancer research (Norat, et al., 2005). While exact risk estimates vary, the association between diet and cancer remains undeniable.

Body Weight/Fat and Cancer

Nutrition affects body weight in that the difference in energy intake and energy expenditure, termed “energy balance”, largely determines how much fat is stored or metabolized in the body. This is commonly measured through the body mass index (BMI) or the ratio of height to body weight. A BMI above 25 is considered overweight, and above 30 is considered obese. Of note, physical activity is another important contributor to BMI/weight. While physical activity is undoubtedly connected to a healthy lifestyle, this remains outside the scope of this study with the exception of its capacity to influence BMI and healthy weight. BMI has been established as a risk factor for many cancer types including breast and colon cancer (American Cancer Society, 2016). Reviews of meta-analysis studies of predominantly white women found that those who were obese had a 1.5 to 2-fold higher risk for developing breast cancer after menopause (Gaudet, et al., 2014; Amadou, Hainaut, & Romieu, 2013). Visceral fat releases substances, including inflammatory markers, free fatty acids, locally produced estrogens,

adipokines, and insulin-like growth factors into the blood. These substances eventually permeate breast tissue through circulation. While the association of specific nutritional components and breast cancer is not defined in this study, there remains a positive correlation between higher BMI and breast cancer (Gaudet, et al., 2014). A review of literature published after 2002 identified that insulin signaling pathway is the subject of many breast cancer risk studies including the European Prospective Investigation into Cancer and Nutrition or EPIC study (Kaaks, et al., 2014). This determined that circulating insulin like growth factor-1 (IGF-1) levels were positively correlated with risk of estrogen receptor positive (ER+) and progesterone receptor positive (PR+) breast cancer at postmenopausal ages (Wang, et al., 2017; Kaaks, et al., 2014; ASCO, 2018). Energy balance has a direct effect on circulating IGF-1 and estrogen, as well as BMI and fat distribution. Therefore, energy balance likely plays a significant role in breast cancer risk. Another perspective on weight and cancer involves the location of fat distribution in women and its association with breast cancer receptor status. BMI as discussed above, is a measurement used to determine if a person is overweight. The waist to hip ratio is a measurement to determine how much fat is stored on someone's buttocks, waist and hips by dividing the waist measurement by the hip measurement. High BMI and waist to hip ratios less than one, were overall positively associated with ER+/PR+ breast cancer risk, while central obesity is more commonly associated with ER-/PR- breast cancer risk in post-menopausal women (Wang, et al., 2017).

Body fatness is associated with cancers beyond breast cancer in overweight/obese woman. In 2014, researchers from the Women's Health Initiative Observational Study followed 65,838 women for an average of 12.6 years, noting cancer incidences and collecting data using questionnaires that investigated specific factors like nutrition, physical activity, smoking, and

other lifestyle factors. To assess the impact of nutrition on cancer development, the research team assigned participants a score between 0 and 8, with higher scores based on close/complete adherence to the American Cancer Society's (ACS) lifestyle recommendations. Overall, the study determined that those who had the highest ACS scores reduced their risk of developing any cancer by 17%. Of those who did develop cancer, higher scoring individuals had a 20% lower risk of dying from cancer. Further analysis revealed that scores of 7-8 had the most cancer risk reduction in breast cancer (22% lower risk), colorectal cancer (52%) and endometrial cancer (27%) (Thomson, et al., 2014; American Cancer Society, 2016). The World Cancer Research Fund and American Institute for Cancer Research updated recommendations in 2018 that state: "Greater body fatness is a cause of cancers of the esophagus (adenocarcinoma), pancreas, liver, colorectum, breast (postmenopausal) and kidney." This report declares that other cancers are also likely caused by having more body fat (World Cancer Research Fund/American Institute for Cancer Research, 2018).

Nutrition and *BRCA1/BRCA2* Pathogenic Mutation Carriers

Breast cancer risk in people who carry *BRCA1* and *BRCA2* pathogenic mutations has been modified by weight loss and diet. In general, women with mutations in either *BRCA1* or *BRCA2* have a 50% to 80% lifetime risk of developing breast cancer (National Comprehensive Cancer Network, 2020). Kotsopoulos et al. (2005) looked at weight loss in early adult life (ages 13-18) and found that it was protective against *BRCA*-associated cancers and weight gain of more than ten pounds between ages 18 and 30 increased breast cancer risk. This study concluded that maintaining a healthy weight, while important for all women, is particularly critical for women harboring pathogenic *BRCA1* mutations (Kotsopoulos, et al., 2005). A separate pilot study looked at the French-Canadian population to determine diet quality and its effect on breast

cancer in women with *BRCA* mutations. Diet scores were calculated using four diet quality assessment tools; the results showed that two of these assessments, the Diet Quality Index-Revised and Canadian Healthy Eating Index, were able to predict breast cancer risk for individuals with and without *BRCA* mutations. This study found that individuals with high scores on either of these indexes had significant reduction in breast cancer risk of up to 82% for *BRCA*-related breast cancers (Nkodjok & Ghadirian, 2007). A review of literature published prior to 2015 looked at research regarding factors that may influence risk of developing breast cancer in *BRCA*-mutation carriers. The review concluded that diet and lifestyle can have an impact on the age of onset and risk level for breast and ovarian cancers in *BRCA*-mutation carriers, and maintaining a healthy body weight may reduce breast cancer risk for women who choose not to proceed with prophylactic surgery (Pettapiece-Phillips, Narod, & Kotsopoulos, 2015).

Nutrition and Colon Cancer

Colon cancer is the cause of 8.4% of cancer-related deaths in the United States and it is estimated that there will be 145,600 new cases in 2019. (National Cancer Institute, 2019c). A meta-analysis of 13 studies determined that a daily increase of 100 grams of red meat is associated with 12-17% increased risk for colon cancer (Sandhu, White, & McPherson, 2001). More recently, a prospective study of the European Prospective Investigation into Cancer and Nutrition (EPIC) study also found a positive correlation between red meat consumption and higher colorectal cancer incidence (Norat, et al., 2005). A retrospective study of patients with stage III colon cancer 7 years after diagnosis reported a 13% reduction of cancer recurrence when patients substituted one cup of refined grains with one cup of whole grains daily (Brown, et al., 2018). Patients who consumed a western style diet high in refined grains and red meats had a hazard ratio for cancer recurrence or death of 3.9, as opposed to those who ate a prudent diet

low in refined grains, high in vegetables and fruits who had a hazard ratio reported at 1.3. Further analysis of this group of stage III colon cancer patients utilized a scoring system to represent compliance with ACS guidelines for nutrition and exercise. Those that followed guidelines had a 42% lower risk of death during the 7 year follow up as opposed to those that were least compliant with the ACS recommendations (Van Blarigan, et al., 2018). The association between colon cancer and increased red meat consumption has been well described, and more recently, other foods have been shown to have an effect on incidence of colon cancer.

Alcohol and Cancer

Alcohol consumption was estimated to account for 2%-4% of cancer deaths in 1978 (Doll & Richard Peto, 1981). Several decades of research have produced consistent evidence regarding the positive correlation of drinking alcohol and cancer risk. A meta-analysis of 572 studies defined heavy drinking as consumption of 50 or more grams of alcohol a day. Heavy drinkers have a relative risk of 5.13 for oral and pharyngeal cancer, and 4.95 for esophageal squamous cell carcinoma; individuals also had increased risk for other cancers including stomach cancer, colorectal cancer, breast cancer, and others (Bagnardi V. , et al., 2015). Another meta-analysis of 222 studies that specifically assessed light alcohol consumption, determined one drink per day increases risks for oral cavity and pharynx cancers, esophageal and female breast cancers (Bagnardi V. , et al., 2013). In contrast, a meta-analysis performed in 2016 determined that light drinking was only associated with slight increase in breast cancer in women and colorectal cancer in men (Choi, Myung, & Lee, 2018). The mechanism by which alcohol causes damage to cells thereby increasing cancer risk is still not well defined. One hypothesis is that the toxic metabolite of alcohol, acetaldehyde, which damages DNA, may lead to cancer when the enzymes that break down this compound do not work properly (Yu, et al., 2010). Alcohol consumption

also can contribute to weight gain which has been associated with increased risk for many cancers as discussed earlier. Until the exact mechanism by which alcohol contributes to cancer risk has been determined, research has not shown any level of alcohol consumption to be safe and therefore the current recommendation for reduction of cancer risk is abstinence (Rehm, Soerjomataram, Ferreira-Borges, & Shield, 2019).

Other Nutrition Factors and Cancer

A number of studies have addressed the mechanisms of how diet influences cancer risk (Campbell, 2017). One such study looked at how diet affects inflammation. This study determined that higher gastric inflammation is associated with higher red meat consumption; inversely, low gastric cancer risk is associated with increased fruit and vegetable intake. Fruits and vegetables are rich in flavonoids and carotenoids, such as alpha-tocopherol and retinol; these components of nutrition are associated with anti-inflammatory effects on the digestive system. High levels of these circulating nutrients may help explain this lowered gastric cancer risk (Agudo, et al., 2018). Another study analyzed inflammatory markers and tumorigenesis. They determined that these markers (NF-kB factors) are typically precursors to tumor progression and can be regulated by certain chemicals found in plant-based foods. Therefore, increased consumption of these foods can reduce cancer risks by stopping tumor progression and activating apoptosis (Anand, et al., 2008). Furthermore, studies have analyzed how nutrition can directly affect epigenetic changes in the genome and contribute to the epigenetic regulation of cancer (Teegarden, Romieu, & Lelievre, 2012). Nutrient-gene interactions are bi-directional in that gene expression is regulated by nutrient intake, and response to nutrients may be determined by an individual's genotype. (Paoloni-Giacobino, Grimbale, & Pichard, 2003). One such example is that of pregnant women and folate deficiency. It has been well established that folate deficiency can

cause neural tube defects in embryonic development. The recommendation for woman who have had a previous pregnancy affected with a neural tube defect is to take increased amounts of folic acid supplements to aid development in the fetus which reflects nutrient-gene interaction (MRC Vitamin Study Research Group, 1991). Likewise, other nutrients such as vitamins found in food may influence DNA regulation of cell growth and proliferation, as well as the DNA damage response (Campbell, 2017).

Rationale for Current Study

Genetic counselors serve as liaisons in identifying medical specialties that may improve patient's well-being and care as necessary (Quillin, 2016). In fact, the scope of practice for genetic counselors includes discussing "management of risk for genetic/medical conditions and diseases" (National Society of Genetic Counselors, 2019). In cancer genetic counseling sessions, 59.6% counselees desired discussion of lifestyle risk factors on cancer development. Of affected participants, 29% state they believe their lifestyle is the cause of their breast cancer in post-counseling sessions (Albada, et al., 2013). Genetic counselors have the ability to educate patients on the current understanding of nutrition and its impact on cancer risk. Multiple studies like those previously discussed have shown the benefits of increased fruit and vegetable intake, lowered red meat consumption, lower fat consumption, and reduction of alcohol intake significantly reduce cancer risk through various mechanisms. Another study showed that a majority of patients who received cancer genetic counseling and testing could benefit from healthier eating habits and increased physical activities. Results from this study showed 58% of counselees were overweight meaning they could be counseled on modifiable lifestyle factors (Quillin, 2016). This provides a unique opportunity for counselors to use their knowledge of

evidence-based risk reduction strategies to counsel patients on factors that are within their control.

Methods

Study Design

A qualitative research method was used to explore cancer genetic counselors' perceptions of nutritional recommendations in counseling sessions. Through semi-structured interviews, the study aimed to explore many aspects of these sessions including patient driven discussions, resources used, understanding of nutritional impact on cancer, and driving factors for genetic counselors' choices for incorporating (or not) nutritional recommendations. This study was approved by the Claremont Graduate University's Institutional Review Board (IRB).

Study Recruitment

The study aimed to develop a preliminary understanding of genetic counselors' acuties of nutritional recommendations in cancer settings. Eligible participants were genetic counselors currently providing cancer genetic counseling services in Southern California. Participants were chosen based on snowball recruitment technique, starting with genetic counselors that had been introduced throughout Keck Graduate Institute's Master in Human Genetics and Genetic Counseling training program. Additional counselors were recruited through introductions from interviewees. Each additional recruited counselor was emailed using a standard template (see Appendix A) and those who responded were provided interview questions and consent forms (see Appendix B and Appendix C). Final interview details such as dates and times were set after the interviewees agreed to participate. In total, eight genetic counselors were interviewed from

four unique institutions. Recruitment took place from August through November of 2019 and interviews were conducted from August through December of 2019.

Data collection

The interview questions were created and revised by the author, advisors, and peers. Final approval was obtained from the Claremont Graduate University Institutional Review Board.

Interviews were conducted in a semi-structured format, lasting between 6 and 23 minutes. Eight interviews were conducted either in person, over the phone, or through Zoom video conferences, depending on the participants choice. These were performed beginning in August of 2019 through December of 2019 by the lead author (BR), a genetic counseling graduate student at the time of the study. Interviews were recorded using a digital recording device, transcribed verbatim by the author (BR) and then each audio recording was deleted. Each interview was randomly assigned a number 1-8 to deidentify the participants. Demographics were obtained in the beginning of the interviews including the institution from which the participant obtained their genetic counseling masters, graduation year, and the number of years the participant had been providing cancer genetic counseling.

Questions used to guide the interview

- How much do you feel nutrition affects cancer risk?
- What is your current stance on incorporating nutritional recommendations into genetic counseling sessions for cancer risk?
- How do you feel about genetic counselors giving nutritional recommendations as cancer risk-reduction options during genetic counseling sessions?
- How do you currently incorporate nutritional recommendations into your cancer genetic counseling sessions?

- What resources do you use for nutrition recommendations specifically associated with cancer risk reduction?
- If you do not incorporate these recommendations, why don't you?
- What type of exposure have you had with nutritional causes or risk reduction in cancer? (ex. Taught in graduate school, learned through research, other)
- Do you feel your exposure to nutrition (either high or low) affects whether you choose to offer it as a risk reduction technique?
- What would you say your confidence level when making nutritional recommendations in cancer genetic counseling sessions is?

Data Analysis

Interviews were transcribed verbatim and then reviewed by the author (BR). Transcripts were edited to aid in accuracy and readability of statements. Conventional content analysis was used to identify themes throughout, within, and across interviews. The researcher began by reading through interview transcripts to derive initial codes from exact words used by interviewees. Next, initial analysis and first impressions of each interview was noted and then labels for the initial codes emerged that encompassed impressions and key words. These codes were then sorted into categories in effort to group codes into approximately 11 clusters. After careful consideration and analysis, clusters were further grouped together and four themes arose under one major premise. The analysis technique was based on conventional content analysis as described by Hsieh and Shannon (Hsieh & Shannon, 2005). The analysis was framed using overall themes that best represent genetic counselors' responses in the interviews. The central message of each of the four themes is further subdivided based on clusters and each theme is emphasized using the most representative data extracts.

Results

Participant Characteristics

Participant characteristics are outlined in Table 1. The institutions from which participants received their genetic counseling master's degree from are included in Table 2. This list has been randomized in an effort to keep participants identities confidential. The number of years participants practiced cancer genetic counseling ranged from 2 to 25 years and graduation dates ranged from 1983 to 2017. Six out of eight participants have provided exclusively cancer genetic counseling services while the other two counselors worked within general genetics clinics that included cancer genetic counseling services. Five participants have nutritionists whom they could refer patients to. One participant had a nutritionist with whom they worked with at their first cancer genetic counseling position, but currently does not have one on staff for referral within the institution. Two participants did not have a nutritionist with whom they worked closely. Three out of eight participants stated that they regularly incorporate nutrition into counseling sessions.

Table 1

Participant characteristics

Participant #	% Cancer *	Years practicing cancer genetic counseling	Graduation Year	Nutritionist within Institution	Consistently Addressing Nutrition in Sessions
1	100%	4	2015	Yes	No
2	100%	3-4	2016	Yes	No
3	100%	21	1997	No	Yes
4	20-50%	4	2015	Yes	No
5	100%	2	2017	Yes/No**	Yes
6	100%	7	2012	No	No
7	25-50%	25	1983	Yes	No
8	100%	8	2011	Yes	Yes

*Percentage of patients seen in practice for cancer-specific counseling. ** Indicates a participant who has worked for two institutions, one that had a nutritionist within the institution and one that did not.

Table 2

Institutions from which participants obtained master’s training and degrees

Institution
California State University, Northridge (1)
Mount Sinai (1)
Sarah Lawrence (1)
Stanford (2)
University of British Columbia (1)
University of California, Irvine (1)
University of South Carolina (1)

Thematic Analysis- Genetic counselors’ value nutritional impact on cancer risk

All (8/8) counselors stated that they understand the impact of nutrition on cancer risk.

Likewise, participants felt that this information is important in cancer genetic counseling.

Statements reflected that although the participants did not know exact cancer-risk percentages,

they felt that nutritional impact on cancer risk is important. One participant related nutrition and healthy life habits to the medical profession at large, with genetic counselors falling under this umbrella:

I think it's really important. I think it's important for any healthcare provider to be knowledgeable in some general terms and at least be able to point to, and make comments about, the importance of good nutrition, good sleeping habits, good health habits, and avoidance of certain harmful habits. Anytime you have an opportunity to share that kind of information with a patient. I think it's very important. – Participant 3

This sentiment was often followed with a statement regarding patient-driven discussions of nutrition. Outside of the participants that incorporated nutrition into their everyday practice (3/8), every other interviewee (5/8) expressed that patients bring up diet or nutrition in their sessions regularly.

Another similarity in this cohort was that each participant stated that this information was not covered in their genetic counseling training program. Of participants who reported actively giving nutrition recommendations, the resources utilized were self-sought by the counselors. Some participants work with nutritionists closely and utilize resources vetted by these experts while others perform their own research to obtain information.

The interviews revealed that all of the participants feel that nutrition does impact cancer risk, however, the significance of nutritional impact on cancer risk and its incorporation into cancer genetic counseling sessions was highly variable. The interviews included questions to better understand why nutrition was or was not incorporated into sessions and if it was discussed, what other factors influenced these discussions. Through further analysis, four themes emerged

with further sub-themes listed in Table 3 giving further insight into the value of diet for the eight participants and where these tenets may have come from.

Four themes identified:

1. *Information conveyed during genetic counseling visits,*
2. *Resources utilized by genetic counselors to ascertain nutritional information and recommendations for patients,*
3. *Case-specific influences on nutritional recommendations or discussions, and*
4. *Challenges with giving nutritional recommendations*

Table 3

Themes and Sub-Themes

Theme	Sub-Theme
I. Information conveyed during genetic counseling visits	1. Well known influences/healthy diet 2. Body weight or BMI 3. Specific nutrients
II. Resources utilized by genetic counselors to ascertain nutritional information and recommendations for patients	1. Institutional influence 2. Personal interests 3. Handouts/research/conferences
III. Case-specific influences on nutritional recommendations or discussions	1. Patient interest/persistence 2. Patient disease status/type
IV. Challenges with giving nutritional recommendations	1. Lack of training 2. Not a doctor/expert 3. Counselors' comfort level

Theme I: Information Conveyed During Genetic Counseling Visits

Nutrition is a word that can have many different meanings depending on the context in which it is used and personal experience. This variability is reflected in the examples in participants' responses to many of the interview questions. These major categories of responses are discussed below.

Well known influences/healthy diet. Every participant mentioned at least one of the following as something they would feel comfortable discussing with patients: red/processed meat consumption, alcohol, smoking and exercise. The evidence linking these specific topics to increased cancer risks is not explicitly expressed in interviews, but in general these were assertions that participants felt comfortable when discussing with patients.

I will mention, and [I will] agree with them that nutrition could play a role in cancer risk reduction, or increase risk, and that nutritional components, exercise, reducing alcohol, not smoking, all of those lifestyle factors can play a role. – Participant 2

Another piece of nutritional advice that many (5/8) participants mentioned was that a healthy diet in general may be protective against cancer. When patients asked further questions about specific diets, many participants did not delve into specifics. To elaborate on healthy diet without giving particular endorsements, one participant stated:

The general thing I tell patients' sort of a good rule of thumb is eat the rainbow so to speak. So, a colorful diet, low in fat, everything in moderation. But I don't really get into great detail with that. – Participant 6

For patients that are currently in treatment, the discussions regarding diet are different. In these situations, participants stated they often refer patients back to their oncologists. They further stated that this was due to oncologists giving nutritional advice themselves or incorporating a referral to a nutritionist or dietician when patients in these situations inquire about nutritional recommendations. Participants stated that in these cases, the treatment of the cancer was most important and that patients needed to seek advice of those in charge of their medical care first.

Body weight or BMI. A few (2/8) participants mention body weight or BMI. Their approach to this is to talk about healthy lifestyle and weight in general or give blanket statements like healthy habits may be protective. “General things like having a healthy BMI may be somewhat protective or things like that. But for the most part, not like eat this many cup [sic] of vegetables.” (Participant 4)

Specific nutrients. Most (6/8) genetic counselors avoid advising patients to incorporate specific nutrients or food. Many refer patients out to experts for these types of discussions.

I would say, go over some general things, for most patients... anything more specific than that is really entirely delved into by [the geneticist], who goes into things like blueberries, and soy, and really specific recommendations. Mine are definitely more general based on the info that I know. – Participant 8

Theme II: Resources Utilized by Genetic Counselors to Ascertain Nutritional Information and Recommendations for Patients

All participants in this study stated that nutrition was not explicitly discussed in their graduate programs. Therefore, the genetic counselors that did bring up nutrition regularly in sessions were motivated to do so by other means. Participants were also tasked with finding resources for themselves without guidance from experts or training programs.

Institutional influence. Some (3/8) of the participants stated that the institutions in which they worked encouraged providers to include nutrition and lifestyle into their practice. Participant 5 stated that in their first cancer genetic counseling position, nutritional habits were discussed during the basic medical and social history intake for patients. This participant continues this practice in a new position with all of their patients, while keeping social issues, such as economic means, and cancer status in mind when discussing recommendations. This

participant frequently asks questions like “what does your diet look like” and “how many servings of red meat do you get”.

Another participant mentions the availability of the dietician within their institution multiple times throughout a session. This participant relies on the nutritional experts to give resources to pass on to patients, as well as act as a resource who the genetic counselor can refer patients to for more in depth conversations. Likewise, one participant works closely with a geneticist who has special training on the subject. This has inevitably influenced the practice in that nutritional recommendations are always given as stated by the participant:

We work with [geneticist] who has gone through an integrative medicine training program where they focus a lot on diet and lifestyle and nutrition. So, if a patient is seeing her, I always defer [nutritional recommendations]. – Participant 8

Personal interests. Beyond institutional influence, two participants describe their personal interest in nutrition having a strong influence on their recommendation decisions. They described that they have placed high value on the importance of good nutrition in daily life which then influences their recommendations in the cancer counseling setting.

I learn a lot on my own because of my own nutritional preferences and the things I’ve learned over many years that I’ve experimented with or have incorporated pretty religiously into my own diet. And so that’s a lot of self, just self-learning. – Participant 3

Another participant stated that their interest in nutrition began early on in life:

I feel like I’ve always had an interest in nutrition, since teenage years, because it was a big part of family life growing up and I think that made me feel more aware of it. I took a nutrition class in undergrad which I thought was really interesting. So yes, I think the fact

that I've been exposed to it and does make me feel more inclined to talk about it during a session especially when a patient brings it up. – Participant 2

Conferences, handouts, research. Four participants mentioned using American Cancer Society's recommendations as a resource they use for patients. Three participants talked about specific papers they have found that they utilize for research-based evidence on the reduction of cancer risk through healthy nutrition. Two participants expressed that their knowledge was furthered by conferences and talks where nutrition was a topic in conjunction with cancer:

There was a [Institute] conference a couple years ago that we attended where they had some talks that talked about lifestyle factors in relation to cancer risks and there were a couple talks relating to nutrition. They didn't go through details but they did address how nutrition can play into the familial cancer risk. – Participant 2

Theme III: Case Specific Influences on Nutritional Recommendations or Discussions

The decision to incorporate nutrition for participants, is influenced by case-specific details. These include a patients' cancer status, mutation status, and economical circumstances. Psychosocial considerations were also brought up by participants.

Patient empowerment vs patient guilt. Participants expressed that this is a difficult topic when it comes to discussing nutrition with patients that are found to carry a high-risk genetic mutation in genes such as *BRCA1* or *MLH1*. One participant stated that they are especially careful with recommendations and discussions in those sessions because they don't want to add to patients' level of guilt.

The deck is stacked against them to start out, and so, realize that this was something that is a predisposition that you carried. Your good habits are helpful and your bad habits might

not have been super great about some aspects, but don't beat yourself up over those things.

– Participant 3

In another perspective, one counselor stated that nutrition could be a tool to help a patient feel like they have more control over their circumstances.

Nutritional recommendations are one of those things that can make patients potentially feel more empowered because they feel like they have some sort of control over their own risk, and some sort of control over what they are putting into their bodies and how that might incorporate into risk in the future. – Participant 8

Patient circumstances. Three genetic counselors mentioned that patient circumstances influence whether or not they incorporate nutritional recommendations into the session or not. These circumstances included testing status (pre or posttest), cancer type, cancer stage, and economic status. One such participant stated “I would say that I take a different approach depending on if they are pretest, posttest, and then what their test results are and the types of cancers in their family.” (Participant 8).

Similarly, another participant identified that their reservation stemmed from circumstance. If a patient was past the preventative stage and already in treatment, affected with a late stage cancer, and especially those with a poor prognosis, participants would avoid discussing nutrition.

Patient circumstances also matter. For instance, if my patient has stage four pancreatic cancer or stage four for anything in general, I'm probably not going to harp on their diet and exercise habits because of their disease status. – Participant 5

Theme IV: Challenges with Giving Nutritional Recommendations

Participants differed in their choice to include nutrition in sessions. All counselors stated that there was a lack of formal training on the subject. This had different effects on counselors' thoughts regarding the subject of nutrition.

Lack of training. All genetic counselors in this cohort stated that their programs did not cover nutrition in their cancer training in any capacity, yet all agreed that it is an important part of their practice. Without the proper guidance of what can and should be discussed for this topic, counselors are uncomfortable giving these recommendations. As one counselor stated:

I think it's well within our purview to at the very least discuss [nutrition] on some level... my sort of take on it is that it is pretty lacking as far as being incorporated in to our training about what to discuss right? We are trained on how to discuss, encourage healthy behavior modifications and things like that and motivational interviewing, so to speak, to encourage people to change health habits, but we aren't necessarily taught what constitutes a sort of yes, this is the diet that people should ascribe to, and I think it can be a little dangerous. –

Participant 6

Not a doctor or an expert. Genetic counselors are trained to explain formal management recommendations created for specific genetic diagnoses. Typically, these recommendations are used as a baseline to guide which medical care specialists a patient should see. Nutritional recommendations are not an exception to this standard of practice. Many participants (5/8) identified a lack of basic knowledge about nutrition in the context of cancer, while some (3/8) felt confident enough to give some information before referring a patient to a specialist.

I feel like I am fairly confident when I am making these recommendations because I'm not over stepping or saying anything that is inappropriate right? They are very safe recommendations so I do feel I am not reluctant to share them and I don't feel like I am

hesitant to discuss them, so I am fairly confident. I would say if a patient is going to ask more specific recommendations then that is why I would say 'you know these are great questions, I'm not qualified to make those but I'm happy to find you someone who can'.

– Participant 6

The complexity of nutrition and its effect on health as a whole compounds the uncertainty in giving recommendations. While all counselors acknowledge that it is a factor in cancer risk, there is not a clear picture surrounding the topic. One participant stated that nutrition is a piece of the puzzle but how big that piece is remains unclear.

I think that it definitely impacts cancer risk...I don't know that I necessarily would know how to quantify it because I think so much of it relates to other factors that either modify or interact with nutrition but I think it is definitely part of the story. – Participant 6

Counselors comfort level. The participants' formal training appeared to correlate with their confidence on the subject of nutrition.

Probably in the sense that I guess I haven't had that much training on it, it's not something I feel incredibly confident talking about with a patient one on one, but I will say that I am totally confident in being able to say 'okay you know that's not my area but we have two wonderful dieticians who were here at the cancer center, do you want to talk to them about that?'. – Participant 1

Furthermore, participants stated that if the topic of nutrition was discussed during their training, their ability to speak on the subject would benefit.

I think that if it was something that was standardly a part of my training then I would for sure incorporate it because that was how I learned to carry out a cancer counseling session, but since it wasn't, it's just not a routine part of what I do. – Participant 4

Discussion

To date, this is the first identified study that explores how genetic counselors feel about discussing nutrition as it pertains to cancer risk with patients during genetic counseling sessions. Little to no information on the protective or preventative aspects of healthy nutritional habits is given during classroom training for genetic counseling in the cancer setting. Yet, in a study of 192 cancer genetic counseling sessions, genetic counselors discussed nutrition 27% of the time, and this was initiated by patients 60% of the time (Albada, et al., 2013). The current study mirrored this finding. Three participants regularly spoke about the topic while all stated that genetic counselors are often asked about the benefits of certain diets on cancer prevention. As stated by one participant:

I think a lot of patients are asking about these things so if it's not really taught then I think it would be really important to implement that into programs on top of everything else we learn. – Participant 5

If patients are consistently asking about this topic as the participants in this study convey, genetic counselors ought to be prepared to address concerns. The researcher (BR) had some exposure to cancer genetic counseling prior to the interviews as well as a course in cancer genetics. With these experiences, it was clear that nutrition was a topic that often came up in cancer genetic counseling sessions, but one that was not part of her formal classroom training. Because of the lack of training, as well as the patient driven discussions about nutrition which are all too common in the cancer setting, this study looked to determine genetic counselors'

perceptions of nutritional recommendations in cancer genetic counseling sessions. The goal was to interview genetic counselors in Southern California to get a general understanding of their thoughts on the topic. Though the region in which participants were interviewed was relatively limited, the counselors received training from programs across the nation and therefore provided a more diverse population with varied training backgrounds and experiences.

As a whole, the interviews revealed that all of the participants feel that nutrition does impact cancer risk. Participants differed in the value they placed on nutritional impact on cancer risk. The discussion was also highly variable regarding incorporation of nutritional discussions into cancer genetic counseling sessions. It is possible that this discrepancy stems from the lack of formal training on the subject. Without exposure in a formal setting, participants differed in their understanding and approaches to nutrition in sessions. An interesting aspect of the study was the differences surrounding the word nutrition. Nutrition can refer to specific foods, nutrients, diet as a whole, as well as BMI. In some interview's "nutrition" was even used to describe lifestyle. It is a word that derives its meaning depending on the context in which it is used and the person using its' personal experiences. This was reflected in the interviews. Some participants who interpreted nutrition to mean specific foods, discussed the influence of specific items in a person's diet, and how that may have an impact on cancer risk. Regularly nutrition was grouped into the category of lifestyle and participants would mention it along with exercise, tobacco, and diet. A formal framework regarding the meaning of nutrition and what it specifically refers to in someone's' life, be it foods, or lifestyle, would be useful to get a baseline for discussion with patients. It would provide the participants in this study better groundwork from which to expand these talks as well as what resources may be appropriate.

The discussions regarding resources used by participants brought up another interesting point. While it would be intuitive to think that all of the participants would utilize a nutritionist to enrich patient discussions, not all that had access to this resource utilized it. In fact, many preferred to do their own research on the topic as opposed to reaching out to the experts in their institutions. This may show the complexity regarding diet on health, and the lack of confidence in previous nutritional models. Those that did regularly utilize the nutritionists in their institutions (2/8) seemed to have a good relationship with these professionals. This could have been the factor that explained the discrepancy among the cohort studied here. The American Cancer Society and other well-established cancer experts have put out evidence-based guidelines written for the general public that include dietary recommendations to decrease cancer risk (American Cancer Society, 2016). Interestingly, half of the participants mentioned these guidelines (4/8) and even less (3/8) utilized them. Others utilized research papers or well-known cancer risk correlations like red meat consumption and colon cancer risks.

The other aspect that came up was that participants were often placed in situations where this topic was brought up by patients and therefore participants were forced to determine best practices in how they would respond. If lack of formal training lowered the value placed on nutrition in participants minds, it would explain the reluctance to regularly incorporate it in sessions for the five participants that did not do so. The three participants that do regularly broach the topic, explained that their choice to do so was based on personal exposure through their institutions and colleagues. The high value placed on this topic by others directly influenced their confidence in speaking about nutrition with patients. In examining what influences impacted discussions on the topic, one participant recalled the following:

When I was working in [state] I was working in a breast only clinic and that is where I was exposed to the ACS recommendations for breast cancer risk reduction lifestyle recommendation... anything beyond that in terms of turmeric and colon cancer or avoiding processed meats, all of those things are Dr. [sic] tidbits that she has brought back from her integrative medicine course. – Participant 8

The decision to incorporate nutrition for participants, is influenced by case specific details. These authorities include a patients' cancer status, mutation status, and economical circumstances. Psychosocial considerations were also brought up by participants. It is curious that perhaps assumptions made by the genetic counselors could limit their discussions regarding nutrition even though they did value its influence. It could be possible that in order to keep rapport with patients and ensure that they did not feel blamed for developing cancer, counselors avoid the topic of nutrition. One counselor states the importance of diet for health, but then when reflecting on discussions with patients that are affected with cancer, they state “We try to get them away from the idea that they ever were fully culpable because they drank two glasses of wine a day” (Participant 3).

Interestingly, the association between alcohol consumption and increased cancer risk is well established (American Cancer Society, 2016; Bagnardi V. , et al., 2015; Doll & Richard Peto, 1981). It is curious that counselors are remiss to make statements that could cause patients to feel responsible for their cancers when it comes to nutritional choices. This does not seem to be the case for other well-known influences on cancer risk like smoking. Perhaps the difference comes from the lack of public knowledge on the risk of cancer in association with alcohol consumption. One study determined that only 31% of woman ages 15-44 were aware of the

increased risk for breast cancer with alcohol consumption (Khushalani, Qin, Ekwueme, & White, 2020).

Comfort with the subject matter as well as patient's responses proved to be an important consideration for participants. If there was a possibility that patients would feel disheartened by the topic of nutrition counselors would avoid the subject. This could be because patients would feel that they were to blame for their disease in some situations. Interestingly, no participants discussed specific instances when this reaction occurred. Most talked about the possibility, which may instead be a projection of personal thoughts/feelings of the counselors onto patients. On the other hand, personal discomfort was experienced by counselors with the topic. This was due to lack of training, limited understanding/expertise and lack of clear guidelines regarding the subject. Interestingly, four participants stated they were comfortable with their level of knowledge on the topic of nutrition, yet only three of these regularly included it into their sessions. For the other four that did not feel comfortable with discussing nutrition, two regularly referred patients to nutritionists in their institutions. Perhaps they found comfort in having experts on the topic on-hand. Therefore, they did not feel the need to research or discuss this with patients on their own, when someone who had extensive understanding was nearby and an available resource.

In light of the absence of formal training on nutritional impact on cancer risk, the framework in which genetic counselors in this study viewed and offered nutritional advice in practice was highly influenced by the resources available, personal exposures, as well as research performed by the individual.

Study Limitations

This study was limited by the number of participants as well as the demographic location of the participants interviewed. The participants were all practicing genetic counselors in the Southern California region. This is a limitation that warrants a wider outreach to determine if other genetic counselors working in the cancer specialty share the same views about the importance of nutrition and its impact on cancer risks in all geographic locations. Eight participants were interviewed and the findings of the study are limited by the number of interviewees. Therefore, the main limitation of the study is the small-scale nature of the research. In expanding the cohort to genetic counselors working across the country in the cancer specialty, a more enriched sample would provide data on whether the views of this cohort match the views of the majority of genetic counselors.

Future Research

The interviews and subsequent analysis from this small, location-limited cohort highlights the need for a more formal and uniform approach to incorporating nutrition into training for cancer genetic counseling. With this in mind, a great next step would be to produce a survey utilizing the themes identified in the current study to determine if the same values and concerns hold true for a large number of genetic counselors in various geographic locations. This information could provide evidence opposing or in favor of the inclusion of nutritional discussion in cancer genetic counseling sessions. Genetic counseling graduate programs could benefit from such research in that they may implement changes in curriculums based on this information to prepare students with the knowledge they need to provide their future patients with the best, wholistic care possible.

Conclusion

Using the definition of nutrition to mean diet as it contributes to body fatness, as well as specific foods a person consumes, evidence on the link between diet and cancer risk is undeniable. Without formal training on the subject, genetic counselors in this study drew from their own experiences and beliefs in order to address questions about nutrition. Their personal experience with food and nutrition framed the way they received the questions. Some participants (2/8) discussed weight after the interviewer asked about how nutrition impacts cancer risk, while others talked about specific foods and nutrients like red meats and turmeric. Based on this cohort, it is important to give these counselors a basic framework from which they can utilize resources to provide patients with information when they seek it. Participants differed in their choice to include nutrition in sessions which shows that within this study, there is discrepancy in patient care even though all counselors stated that they valued nutrition in the cancer setting. This population while small, was united in their need for formal training to address nutrition. It is the researcher's opinion that a larger scaled study including genetic counselors across the nation, should be pursued in order to determine if there is in fact a gap in knowledge that is shared by genetic counselors in the cancer field, or if this finding is limited to the cohort interviewed in this exploratory study.

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Appendix A

Salutations _____,

My name is Bre Reinsch and I am a current genetic counseling graduate student at Keck Graduate Institute. I received your contact information from _____. For my thesis project, I am hoping to understand genetic counselors' attitudes toward dietary recommendations in cancer genetic counseling sessions. I would like to ask if you are interested in participating in a brief interview (approximately 30 minutes), in person or over the phone, to discuss your current practices in cancer genetic counseling sessions.

I would provide questions ahead of time, in case you would like to think about your current practices and whether any discussions of nutrition are included in your sessions. If you are interested in participating, please email me for more information and/or to set up a preferred date/time/place for the interview at: BREINSCH18@students.KGI.edu

Thank you for your time and I hope to hear from you soon!

**Best,
Bre Reinsch**

MS in Human Genetics and Genetic Counseling (MSGC), 2020

602.509.0852



This email may contain confidential and/or private information.
If you received this email in error, please delete and notify sender.

Appendix B

Interview Date:

GC Code:

Graduation Year:

Graduation State:

Years Practicing in Cancer Genetic Counseling:

Questions:

1. How much do you feel nutrition affects cancer risk?
2. What is your current stance on incorporating nutritional recommendations into genetic counseling sessions for cancer risk?
3. How do you feel about genetic counselors giving nutritional recommendations as cancer risk-reduction options during genetic counseling sessions?
4. How do you currently incorporate nutritional recommendations into your cancer genetic counseling sessions?
 - a. What resources do you use for nutrition recommendations specifically associated with cancer risk reduction?
 - b. If you do not incorporate these recommendations, why don't you?
5. What type of exposure have you had with nutritional causes or risk reduction in cancer?
(ex. Taught in graduate school, learned through research, other)
6. Do you feel your exposure to nutrition (either high or low) affects whether you choose to offer it as a risk reduction technique?
7. What would you say your confidence level when making nutritional recommendations in cancer genetic counseling sessions is?

Appendix C

**AGREEMENT TO PARTICIPATE IN IDENTIFYING GENETIC COUNSELORS ATTITUDES TOWARD NUTRITIONAL SUGGESTIONS IN CANCER GENETIC COUNSELING SESSIONS**

You are invited to participate in a research project. While volunteering will probably not benefit you directly, you will be helping to the investigators to learn more about genetic counselors' attitudes toward nutritional recommendations. If you decide to volunteer, you will have an in person or phone interview which would require about fifteen to forty-five minutes of your time. Volunteering for this study does not involve risk beyond what a typical person would experience on an ordinary day. Since your involvement is entirely voluntary, you may withdraw at any time for any reason. Please continue reading for more information about the study.

STUDY LEADERSHIP: This research project is led by Breann Reinsch, a Masters of Human Genetics and Genetic Counseling student at Keck Graduate Institute and Emily Quinn, MS, LCGC, the associate program director for the Human Genetics and Genetic Counseling program at Keck Graduate Institute, and Danielle Sharaga, the genetic counseling program manager at Ridley-Tree Cancer Center.

PURPOSE: The purpose of this study is to learn how genetic counselors are incorporating nutritional suggestions into cancer genetic counseling sessions and to identify any limits in training or resources.

ELIGIBILITY: To be in this study, you must be a genetic counselor currently working in the field of cancer.

PARTICIPATION: During the study, you will be asked to discuss your current practice methods in an informal interview with genetic counseling student Breann Reinsch. This interview will take 15-45 minutes, involving questions about current practices, educational background, and other factors that may related to your current thoughts on cancer and nutrition. You will be provided an outline of the questions/topics during the recorded interview.

RISKS OF PARTICIPATION: The risks associated with taking part in this study are minimal. The risks do not exceed those experienced on an ordinary day.

BENEFITS OF PARTICIPATION: There are no personal benefits of participation. While the study may not benefit you directly, it will help researchers learn genetic counselors' attitudes toward incorporating nutrition recommendations into clinical cancer genetic counseling sessions.

COMPENSATION: There is no direct compensation to for participating in this study.

VOLUNTARY PARTICIPATION: Your participation in this study is completely voluntary. You may stop or withdraw from the study at any time or refuse to answer any particular question for any reason, without it being held against you. Your decision whether or not to participate will have no effect on your current or future connection with anyone at KGI.

CONFIDENTIALITY: Your individual privacy will be protected in all papers, books, talks, posts, or stories resulting from this study. We may share the data we collect with other researchers, but we will not reveal your identity with it. In order to protect the privacy of your responses, interviews will be transcribed and each interviewee assigned a generic title such as "Genetic Counselor 1". The written copies of the

interviews will be saved on secure servers during the study. The recordings will be erased after they are transcribed and no names will be published in the study.

FURTHER INFORMATION: If you have any questions or would like additional information about this study, please contact the study investigators:

Breann Reinsch
602-509-0852
BREINSCH18@students.kgi.edu

Emily Quinn
909.607.6474
Emily_Quinn@kgi.edu

The Claremont Graduate University (CGU) Institutional Review Board has approved this project. You may contact the CGU Board with any questions or issues at (909) 607-9406 or at irb@cgu.edu. A copy of this form will be given to you if you wish to keep it.

CONSENT. Your signature below means that you understand the information on this form, that someone has answered any and all questions you may have about this study, and you voluntarily agree to participate in it.

Signature of Participant _____ Date _____

Printed Name of Participant _____
