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Exploring Patient Perceptions and Misconceptions: Beliefs Regarding Hereditary Cancer

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Exploring Patient Perceptions and Misconceptions: Beliefs Regarding
Hereditary Cancer

by

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ABSTRACT

Many patients who enter a genetic counseling session have preconceived notions about why they or their family members developed a genetic condition. Often these perceptions are deeply rooted in personal, familial, and/ or cultural beliefs; individuals typically have a personal framework, or schema, into which they incorporate new information. There is limited research on what information patients are retaining during a genetic counseling session and how they are assimilating that knowledge into their existing views. We attempted to characterize these patient perceptions with respect to hereditary cancer, in order to assess how patients are adopting the information presented in a genetic counseling session into their current schemas. We conducted semi-structured interviews along with a true/false assessment with 18 female participants who have had genetic counseling due to a personal or family history of breast cancer. From these interviews, eight major themes emerged: 1) Those who have already had cancer thought their odds of developing the disease were low prior to their diagnosis, 2) Those who have not had cancer think their odds of developing the disease are very high, 3) Participants believe that lifestyle modifications are the best way to prevent cancer, 4) Participants, even those with known mutations, believe that their cancer was caused by lifestyle/ life events, 5) Patients put emphasis on information about risk estimate, 6) A main takeaway from genetic counseling is how a mutation can cause more than one type of cancer, 7) The majority of participants said that genetic counseling changed their perception of cancer, and 8) The change in perception was connected to gaining more information. Analysis of the True/False

assessment showed that participants most frequently erroneously believed that hereditary cancer genes can “skip” a generation and that everyone has a different set of genes. Incorporating these themes into a genetic counseling session can provide support and understanding about patient perceptions and facilitate a more effective genetic counseling experience.

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CHAPTER 1

BACKGROUND

Origin of cancer myths and learning theories

Patients often hold personal beliefs about why they get cancer, have a child with a birth defect, or experience a medical condition. Some experts call these “personal myths,” others, such as Clara Gaff, call them “personal theories of inheritance.” These personal theories, while often erroneous, can reveal underlying truths about a patient’s culture, attitudes, and beliefs and therefore should not be dismissed by healthcare professionals. There have been many studies investigating these personal myths, and the reasons behind them, but there is not much research on how these theories change and grow as the patient becomes more educated about their condition. This gap in knowledge is something that we seek to address, as it holds implications for the practice of genetic counseling.

Significant research exists about how people categorize information and incorporate new knowledge into their current view of the world, which should be considered when investigating how people alter their personal beliefs. Individuals dislike uncertainty, and thus seek explanations for disease. The process of explaining and rationalizing frightening or uncertain situations is a protection mechanism for individuals who are not ready to feel a loss of control (Fisher & Roccotagliata 2017). This uncertainty shapes how people develop beliefs about their genetic condition. Fisher and colleagues

explain in their 2017 paper that people fear uncertainty and feel compelled to attribute a condition, such as cancer, to a specific event or phenomenon. Women with a family history of cancer face a great deal of uncertainty. They face uncertainty when deciding to undergo genetic testing or not. Additionally, they face the uncertainty as to whether, or when, they will develop cancer. These women also face the uncertainty over how to manage their cancer, unsure of whether or not to undergo risk-reducing surgery or additional surveillance. Most individuals who enter a genetic counseling session have already addressed this uncertainty and formulated an explanation, often rooted in cultural or familial dogmas, for why they have cancer. This can create an ideological barrier between the genetic information presented by the counselor and the understanding of the patient. It will also be the lens through which patients process and learn new information pertaining to their diagnosis.

The notion of ‘illusion of control’ has been demonstrated as beneficial to patients who are suffering from disease. This is the concept that an individual is in control of a situation, despite the reality of an inflexible predicament. For example, several of the women in Kenen and colleagues’ 2003 study on breast cancer patients believed that they could greatly reduce, or eliminate their risk of developing cancer due to a genetic mutation through changes in lifestyle and diet, even though there was no evidence for this. Studies have shown that patients who possess the illusion of control have better physical and mental outcomes. Individuals who can attribute their disease to a tangible event or action feel as though they have more control over their situation. This is a very common coping mechanism in cancer genetics, especially given the knowledge that a genetic risk is a predisposition rather than a diagnosis. Individuals may desire control over the situation as

a way of coping. Thus, these personal explanations should not be entirely disregarded by the healthcare professional, rather, they should be taken for what they are: tools used by the patient to cope with the fear surrounding the uncertainty of a diagnosis (Yarritu, Matute, Vadillo 2016).

A key concept in understanding how cancer myths arise is the idea of a schema. This is the way that an individual categorizes the world around him or her, making it easier to interpret. Psychologist Jean Piaget has conducted extensive research on how humans make sense of the surrounding world. According to Piaget, a schema includes knowledge as well as the process of obtaining that knowledge; both the information itself and the way that it was learned. Both these factors heavily influence how a patient will incorporate new information into their schemas. This suggests that the manner in which a genetic counselor educates a patient is equally as important as the information they are giving. A good example of how a schema evolves is such: a child first encounters a dog that is furry, small, and four-legged. This child will then believe that all dogs are furry, small, and four-legged. After the child encounters a large dog, the child will incorporate this information to modify his schema. This is the basis for how we incorporate new knowledge into our worldview (Piaget, 1957). The reality of cancer genetics, of course, is far more complex, but the basic principle still stands: patients will have an existing schema regarding the cancer in their family; the information a genetic counselor provides will simply be incorporated into the patient's existing view of cancer.

One theory of how we modify our existing schemas is the cognitive load theory. This theory emphasizes the limitations of working memory, which can only hold 5-9 information elements at a time, and loses information within about twenty seconds.

However, working memory limitations apply to only novel information; they do not pertain when utilizing the long-term memories in our cognitive schemas. These loads on our cognition can be categorized into intrinsic load, extrinsic load, and germane load, which deals with memory resources that lead to learning. This theory postulates that learners create schemas that incorporate intrinsic cognitive load by categorizing elements and then abstracting from them by identifying key structural features and surface qualities. This process is known as “mindful abstraction.” Learners also construct schemas when they connect new information elements to things they already know, incorporating these ideas into existing schemas in their long-term memory in a process of elaboration. Because people use existing knowledge to anchor and frame new knowledge, each new knowledge acquisition is framed by the information that a patient already knows. Thus, the information given in a genetic counseling session will be perceived by the patient relative to their prior knowledge and existing schemas (Van Merriënboer & Sweller, 2010).

Patient perception and beliefs about cancer

Because individuals use past experiences to anchor new information in their schemas, it is important to recognize the general perception regarding cancer. Each individual’s perception of cancer is the lens through which they interpret new information from a genetic counselor. A 2009 investigation by Giraldo-Mora utilized semi-structured interviews to understand social representation of breast cancer and how it has influenced personal prevention measures amongst women. They found that the phrase “breast cancer” was associated with inevitable death, suffering, terror, incurability, devastation, pain, and powerlessness amongst patients. The researchers deduced that cancer’s strong social representation is due to its effects on female self-image and perceived attractiveness. The

women they interviewed listed eating an unhealthy diet, daily bad habits, and emotional issues as the leading causes of breast cancer. Factors that can be easily controlled are often over-cited as reasons for one's cancer, as it makes the situation easier to rationalize. Additionally, the authors assert that these cancer myths are rooted in the fact that breast cancer affects the outward appearance of the body. Giraldo-Mora characterized the overarching theme of these theories as the "life-style myth," due to the fact that many women blamed breast cancer solely on lifestyle factors. Giraldo-Mora warns that this mentality causes people to blame the patient for breast cancer, rather than the disease. This negative perception of breast cancer influences the way that women perceive new information on cancer, and also reveals that cancer perceptions can deeply affect self-image and self-worth.

Just as understanding how people form personal beliefs and learn is important, it is crucial to understand what the most common cancer myths are, and how they can affect a genetic counseling session. Daher conducted a review of the cultural myths and taboos surrounding a cancer diagnosis in his 2012 paper. This review emphasizes that cancer myths and stigmas vary from culture to culture. Daher also states the necessity of addressing these beliefs. He explained that many patients feel uninformed about cancer, and that the perpetuation of erroneous beliefs is a barrier to early detection and treatment of cancer. This is one reason that it is important to recognize a patient's personal beliefs and educate them on cancer risks and inheritance. Daher found that celebrities and media are an important channel for dissemination of knowledge about cancer and treatment. Many people in the study cited media as a channel where they receive news about medicine, including cancer. This paper also revealed that people have a desire to be educated about

cancer and its origins, but many individuals feel uninformed on the topic. This research suggests that patients desire the education that genetic counselors can provide, and are receptive to information about their condition, even if it conflicts with their personal myths. Many patients seek education and have a desire to be better-informed.

In their 2018 paper, Elangovan and colleagues examine beliefs about cancer perception amongst a population in India, with a focus on awareness and myths regarding cancer. They found that several common myths were shared amongst this population, many of them rooted in Indian culture. One myth shared by approximately 20% of the population was that only the poor can get cancer. Another 50% believed that getting a biopsy or surgery to treat cancer will cause the disease to spread to other parts of the body. This is a potential barrier between some women of Indian ancestry and getting screened for cancer. This misconception may be rooted in a distrust of medicine, as patients believe that surgical treatment can exacerbate their cancer. Patients also had misconceptions about treatment, believing that cancer treatment involves electric shocks to destroy cancer cells. This fear of painful or cruel treatment is another reason that women of this population avoid seeking medical care related to cancer. About 30% of respondents believed that cancer can spread from one person to another. The concept that cancer is contagious may prevent women from recognizing the true risk factors for cancer. Other myths amongst this population included the notion that cancer tumors are painful, and that cancer cannot be hereditary. Cultural beliefs deeply influence how patients view cancer and its treatment, and it is important to consider a patient's cultural background during a session (Griffith, 2012).

A paper published in 2012 by Griffith and colleagues examined myths pertaining to African American males and their beliefs about colorectal cancer. The findings revealed that many African Americans' personal myths about cancer stem from a larger distrust in the medical community, which is a common sentiment amongst the African American population. The researchers found that many African Americans, particularly males, feel ostracized by the healthcare system and believe that providers do not have patients' best interests at heart. The majority of these men believed that colorectal cancer can only affect men, which may cause fewer African American women to undergo screening, as they believe colon cancer cannot affect them. A large proportion of these males also believed that colorectal cancer was due to the ingestion of a virus, which is a common misconception about cancer and its origins. The participants also held the belief that a healthy lifestyle, particularly abstaining from drugs and alcohol, can protect an individual from getting cancer. While these lifestyle factors certainly play a role, it is important for individuals to be fully educated on cancer risk factors such as family history as well. This is another example of people placing heavier emphasis on factors that are external and controllable. Finally, a majority of patients stated that they were unaware that colorectal cancer could be inherited from a parent; many individuals may not realize that they are at higher risk due to having affected family members. Griffith and colleagues asserted that many of these misconceptions are barriers to cancer screening and care amongst the African American community. This demonstrates the importance of recognizing and addressing personal cancer myths.

Another recent paper, published by Lee-Lin and colleagues in 2018, explored the cancer beliefs of Asian-American women. Asian women in particular seem to share

several common myths about the origin of their cancer. Superstitions that attribute cancer to punishment or divine retribution were common amongst the women surveyed. A large barrier to communication about cancer amongst these women involves modesty and shame. Asian American women often reported that it is embarrassing and immodest to discuss disease of the breast. There is also an aspect of shame; women do not want to tell friends and family about their cancer. This population tends to view cancer as their “burden” to bear, not wanting to weigh down friends and family with the shameful news. The article emphasizes the utility of understanding these beliefs in order to create an open dialogue around cancer.

A 2003 study by Wong-Kim and colleagues showed similar themes regarding cancer beliefs in Asian- American women, specifically Chinese immigrants. The authors conducted a phone interview of nearly 800 Chinese immigrants to establish their beliefs regarding cancer. They identified key themes regarding community stigma toward cancer. One major theme was the fatalistic view that cancer is God’s punishment, God’s plan, or “bad karma.” Some of the respondents replied that cancer was retribution for a crime committed in a past life. Others said that cancer was due to risky behaviors and bad habits. Immoral behavior and the mistakes of one’s ancestors were common beliefs on the origin of cancer. Respondents also cited a polluted environment, excessive technology use, and bad luck as reasons they or their family members developed cancer. Over 25% of the respondents stated that they believed cancer to be contagious. Overall, diet and immoral behaviors emerged as the top two cancer myths, with lifestyle risks and punishments for ancestors’ misconduct following closely.

Cancer myths and the genetic counseling session

Another crucial part of this study is learning what patients recall and learn from a genetic counseling session. We are particularly interested in understanding what information patients are retaining and recalling. A 2013 paper by Aspinwall and colleagues studied the long-term impact of genetic test reporting and counseling on melanoma patients. The researchers found that unaffected patients who had undergone genetic testing and counseling were more likely to adhere to screening guidelines, and received more cancer surveillance pertaining to melanoma. One month after genetic counseling, families with a melanoma predisposition showed overall improvement in self-skin examination adherence, number of body sites examined, and intentions to obtain annual total body skin examinations. This shows that patients are affected by what they learn during a genetic counseling session and will take action based on genetic counseling. Thus, it is important for us to ascertain what parts of a genetic counseling session patients are understanding and absorbing, because it may affect how they manage their health in the future.

A 2018 paper by Hamilton and colleagues investigated maternal perceptions of BRCA gene counseling regarding a novel genetic counselor-patient communication model. The authors sought to address a gap in current knowledge by characterizing whether patients or providers typically initiate a discussion about familial hereditary breast and ovarian cancer (HBOC) testing. They used a newly developed “GCCP measure,” which assesses discussion initiation in a genetic counseling session. There were two factors that remained consistent in this communication process: patient-led communication, and provider-led communication. The authors analyzed patient and provider communication to see how cancer risks were most typically disclosed amongst family members. Most

participants reported that healthcare providers, such as a genetic counselor, typically lead the discussion in their family about their genetic test results as opposed to the patients leading the discussion. Providers were more likely to facilitate the discussion process when the mother had a strong family history of cancer. Interestingly, mothers were more likely to begin the discussion when they held positive attitudes towards genetic testing. The most important factors in these communications were cancer family history, child age, and maternal attitudes. The authors concluded that communication style should be fluid and that genetic counselors should be mindful of patient attitudes and experiences when facilitating complex family discussions.

In their 2007 essay on healthcare rhetoric, Mebust and Katz review certain assumptions underlying genetic counseling communication styles in order to promote the efficacy of rhetoric between a genetic counselor and client. The article outlines several communication styles and ways of encoding and decoding information. As the authors point out, a common theme in genetic counseling is the importance of communication. A large part of what people process and understand comes from the way that the information is communicated. The authors explore the role of both the genetic counselor and the client in different communication models. Two models of communication, the information processing model and the affective-values model, are outlined in the essay. The information processing model is aimed at providing accurate risk information to a patient, allowing them to feel informed and empowered to make decisions. The language utilized in this model is targeted to provide education and resources to patients. The affective-values model uses language that reflects the goal of providing support and guidance to patients, allowing them to cope with and interpret their genetic information. This style of

communication is more rhetorical and focuses on communication that can empower a patient psychosocially. It is important to recognize the different methods of communication in order to understand how information is being conveyed and received in a genetic counseling session. We cannot conclude that one communication model is the best, but we can observe the benefits and drawbacks of each style, and how they will affect patient understanding.

Similar to how patients receive knowledge into an existing framework, the way that healthcare providers such as genetic counselors deliver this information is framed by their existing knowledge. Studies have suggested that the prior knowledge and personal attitudes of health care professionals will influence their style of patient communication. This, in turn, will affect the patient's medical decision. A 2003 survey investigated healthcare professionals' attitudes towards genetic screening. One group studied was genetic counseling students, although the study also surveyed medical students and residents. Most of the providers reported that they felt comfortable facilitating discussion about disability and genetics decision-making. The providers were also surveyed on their personal beliefs regarding genetic disabilities. The majority reported that they believe disability causes "significant suffering" for the person affected as well as their family. Additionally, the majority expressed a belief that medical research should target ways to prevent genetic disability. This attitude affected how the providers discussed the topic of genetics and disability with their patients.

Genetic counseling students included in the survey reported a different attitude towards genetic disability than the other cohorts. The group of genetic counseling trainees

placed a heavier emphasis on social issues versus medical issues. The other cohorts, residents and medical students, placed more weight on the medical implications of disability. This, too, affected the way the participants interacted with patients. The genetic counseling students were more likely to offer social and support resources, whereas the medical student and resident cohorts were less likely to address these social issues and provide resources. Thus, the way that the healthcare providers viewed genetic disability framed medical communication with their patients. This research demonstrates the importance of recognizing the beliefs and attitudes of healthcare providers as well as the patients, as these beliefs will inevitably frame patient communication, and even decision-making (Ormond, 2003).

Clara Gaff, in her 2010 book Family Communication about Genetics, synthesizes personal myths and learning. A chapter dedicated to attributions and personal theories explains that

People are unlikely to come to a clinic as blank slates, waiting for their health-care practitioner to explain to them why a disease or condition has occurred in their family. Often they will come to a clinic with ideas of their own about why they, their children, or other relatives have been so afflicted and hope that their practitioner can help them. (page 52)

Gaff (2010) explains that people find comfort in causal attributions when unexpected or distressing things occur. The locus of these attributions refers to where people lay the blame: internally or externally. A man may believe his lung cancer is due to his smoking (internal) or due to living in a polluted city (external). Controllability is a

large dimension of personal attributions as well. Since genetic makeup is low in terms of controllability, *i.e.*, one cannot change or alter their genes, some people prefer environmental factors which they believe are within their control. Stability is the final dimension of personal attributions, according to Gaff. This describes how changeable the cause is over time. Since genetic makeup rarely changes over time, this is considered largely unchangeable, as opposed to lifestyle factors, which can be altered. Gaff found that these attributions lead to personal theories of inheritance, or PTIs. Patients often use PTIs to explain the pattern of cancer in their family and to predict who will get cancer next. This may influence who is perceived at highest risk in the family, despite contrary genetic evidence. These person beliefs are a crucial framework for how individuals acquire information about cancer during a genetic counseling session.

As we have reviewed, there are many studies that identify personal beliefs about cancer and their reasoning. There also exists significant research on how individuals process and incorporate new information, as well as how information is communicated during a genetic counseling session. However, there are no studies that have investigated how a person's beliefs towards cancer are impacted by genetic counseling. This disconnect between understanding how a person enters a genetic counseling session with beliefs about cancer and not understanding how these ideas are influenced or affected post-genetic counseling, is what we seek to address. We predict that the genetic counseling process influences patient perceptions of cancer.

CHAPTER 2

PATIENT PERCEPTIONS AND MISCONCEPTIONS ABOUT CANCER

INTRODUCTION

It has been well-documented that patients often enter a genetic counseling session with preconceived ideas and theories about why they have cancer (Gaff, 2010). A myth is a widely-held erroneous belief that explains a natural or social phenomenon, whereas a theory is a supposition or a system of ideas intended to explain something. Patient myths are often grounded in misinformation and fear, whereas theories are typically attributions based on observations and reasoning. Both myths and theories are widely held amongst cancer patients. These explanations arise as a mechanism to exert control over a frightening situation (Yarritu et al. 2016), and are often deeply immersed in cultural and familial beliefs (Daher, 2012). Personal myths influence the way that patients view new information about cancer (Giraldo-Mora, 2009). Thus, it is imperative that healthcare providers address and understand these personal myths, as they can give insight into a person's beliefs, feelings, and culture. Some common beliefs are that cancer is contagious (Elangovan, 2018), that cancer is due to an act of divine retribution (Lee-Lin, 2018), and that cancer is due solely to lifestyle factors (Griffith, 2012). It is not known which myths are most common amongst patients in a cancer genetic counseling session.

People learn in complex ways. Individuals form schemas, which are cognitive structures used to organize information. People incorporate new information into their existing schemas by modifying their previous views to accommodate new knowledge

(Piaget, 1957). There are several theories on how people incorporate new knowledge into their existing schemas. Thus, we know that personal myths will not be entirely re-written after genetic counseling, rather, the patients will modify their beliefs by incorporating the scientific information from the counseling session. Understanding how patients learn will provide valuable insight about what information is most accessible to patients during a cancer genetic counseling session.

No previous study, to our knowledge, has addressed how patients incorporate the information they learn during a genetic counseling session into their personal cancer theories. This gap between patient myths and the information given in a genetic counseling session is what we seek to address. This study will be exploratory as well as quantitative, identifying themes about personal myths, how people learn, and what genetic information is beneficial to patients. This research will bolster our understanding of patient perception and learning, as well as characterize the myths surrounding cancer. Our objectives are:

1. To elucidate common cancer beliefs
2. To understand what information patients are retaining from genetic counseling
3. To assess if genetic counseling influences patient beliefs about cancer

Understanding a patient's personal myths about cancer can help genetic counselors address these beliefs. Previous studies have shown that these personal myths, while often erroneous, can provide insight into how a patient is coping and about their attitude towards cancer. A patient's beliefs about cancer are the lens through which he/she comprehends the genetic counseling session. Appreciating how these myths affect a patient's perception of the cancer session will be useful for the genetic counselor. Additionally, the process of

identifying and categorizing these myths can give more insight into the patient perspective in a cancer setting.

It will benefit genetic counselors to learn what information patients are retaining and recalling from a genetic counseling session; this will provide insight on what education is most valuable and accessible to patients. Finally, the knowledge of how patients modify their personal beliefs will elucidate how patient perception of cancer changes after genetic counseling.

METHODS

Materials/Measures

Semi- structured interviews were conducted over the telephone with women who have a personal or family history of breast cancer and have had genetic counseling. Our exclusionary criteria were as follows:

1. The participant must be biologically female
2. She is over age 18
3. She has a personal or family history of breast cancer
4. She has received genetic counseling
5. She speaks English

We included only females to maintain continuity in our results, as males are under-represented in the realm of breast cancer and it would be difficult to draw conclusions from this minority group. The participants must also be legal adults to consent to participate. We targeted women with a personal or family history of breast cancer to ensure that

patients have experience and opinions on cancer. The participants must receive genetic counseling in order for us to assess if genetic counseling changed their perceptions of cancer. Due to limited resources available for interpretation, only English-speaking participants were included in the study. The University of South Carolina Institutional Review Board performed a review of the study protocol and deemed it as exempt.

Procedure

The principal investigator reached out to participants through online support groups, specifically, FORCE: Facing Our Risk of Cancer Empowered, (<http://www.facingourrisk.org/index.php>), which has over 44,000 members on its Facebook group, and BRCA Genetic Sisters Support Group (<https://www.facebook.com/groups/BRCAGeneticSistersGroup/>), which has around 2,000 members, all of whom are diagnosed with a HBOC-associated genetic mutation.

Participants received a recruitment notice via email. Participation in this study was voluntary. Participants did not receive compensation for their participation. Participants were permitted to withdraw from the study at any time and were not required to answer questions they did not want to answer. Demographic information was collected either during recruitment or the telephone interview.

The principal investigator conducted semi-structured interviews using the questions included in Appendix B. The primary investigator also asked each participant an identical series of ten true/false questions about cancer. These were scored for correctness. Each interview was recorded by the primary investigator. After the information was gathered, the primary investigator deleted identifying information, such as age and names, to protect

the identity of participants.

The principal investigator transcribed each interview verbatim. The resulting transcripts were thematically analyzed using grounded theory. The result is a summary of themes identified. Identifying information was not used while analyzing qualitative data.

The series of true/ false questions was scored quantitatively for correctness. The final score is the number of correct responses over ten. The mean, median, and mode of correct responses amongst the cohort were calculated. The researchers then identified which questions had the lowest correct response rate. The number of questions correct by age was also analyzed.

RESULTS

Participants

Eighteen individuals recruited through online support groups completed a semi-structured interview. The majority (15/18) of participants were Caucasian. Education status amongst participants ranged from an associate's degree to doctorate. Participants ranged in age from 26 to 69 years, with a mean age of 48 years. Twelve states of residence were represented.

Thematic Analysis

Several themes emerged from our analysis of the interview transcripts. These themes are illustrated by quotes from the transcripts.

Theme 1: Those who have already had cancer thought their odds of developing the disease were low prior to their diagnosis

Participants who have had cancer report that they did not consider themselves at high risk for developing cancer before it occurred. Many even reported that cancer was not something they had considered before they were diagnosed. Patients who got cancer prior to their genetic counseling seemed more blindsided by the diagnosis, even if they had a family history of cancer already.

I thought the likelihood was pretty low since I hadn't considered myself as a person who would get cancer. *Participant 5*

I really hadn't considered it...probably wasn't something that was going to affect me. *Participant 1*

Before receiving a diagnosis, participants reported a strong belief that lifestyle factors would protect them from getting cancer. Most participants did not view themselves as high risk prior to their diagnosis.

I thought that due to lifestyle I was very unlikely to get [cancer] because I nursed or was pregnant from the time that I was 18 to 33. I had six kids, and from what's released to the public generally, at least in the past, I did everything I could. I did that and that was supposed to lower your risk. I didn't drink alcohol for 30 years, I stayed in great shape and exercised and ate healthy. I did all the things I thought was supposed to keep me from getting cancer. *Participant 4*

Theme 2: Those who have not had cancer think their odds of developing the disease are very high

In an interesting contrast, participants who have not been diagnosed tended to perceive their risk to develop the disease as high. These participants are women who had

genetic counseling but have not developed cancer. They have a very different concept of their risk compared to those participants who were diagnosed before receiving genetic counseling.

I think [the risk of getting cancer is] very high, even after I have the mastectomy.

Based on my family history and the little bit of knowledge about my specific mutation, it would be fairly high for sure. *Participant 10*

Theme 3: Participants believe that lifestyle modifications are the best way to prevent cancer

A strong theme amongst participants was an emphasis on lifestyle factors as a method of preventing cancer or lowering the risk of cancer. The most commonly reported lifestyle modifications involve diet and exercise. Many patients could recall specific diet modifications that they had heard of or personally tried in an attempt to reduce cancer risk.

I do have a strong belief in diet, and exercise, and environmental factors, so I watch my food and limit processed foods and exercise regularly and take supplements and keep inflammation reduced. All of those things, I do believe, have an effect. Limiting plastics in my cooking materials... *Participant 15*

Participants named several “fad diets” that they heard reduce cancer risk. Several responses also conveyed confusion over hearing unclear or mixed messages about dietary and lifestyle modifications associated with cancer risk.

They’re saying the keto diet... [to reduce risk] you should eat fat, but no carbs and you can’t eat sugar. They debate about whether not eggs are good for you, and debate over whether immunizations are good for you or not. *Participant 10*

Most participants felt that living a healthy lifestyle would help prevent cancer, even if they could not articulate why this would decrease cancer risk.

Certain diets lower your chances [of developing cancer], and living a healthy lifestyle and being fit. *Participant 11*

Theme 4: Participants, even those with known mutations, believe that their cancer was caused by lifestyle/ life events

Nearly all of our participants had a known familial mutation (this is likely due to the fact they were recruited from certain support groups which are targeted towards women with known mutations). Despite this knowledge, many of the participants cited lifestyle factors or environmental triggers as a reason that they or their family members developed cancer. Several different environmental causes emerged as reasons, but they most commonly related to food/ diet, chemicals in foods or personal products, or a stressful lifestyle. Having a traumatic life event was a reason that several participants named as an impetus for their cancer.

I think I got cancer because of stress. My family was under a tremendous amount of stress for a period of time. *Participant 1*

I had breast cancer again in 2005... At that time in 2005 my daughter had a critical illness. She was with this [man] who was very abusive. They had a boy together and they weren't married and he was very abusive to her... She was so stressed out and at her wits end...right after that she was diagnosed with breast cancer.

Participant 12

Others named specific products or items they believed contributed to the cancer in themselves or their family.

[My family members] got [cancer] from using a specific deodorant. *Participant 6*

...plastics in my cooking materials and all of the things that have been shown to be associated with risk factors [contributed to cancer]. *Participant 15*

Participants also felt that the environment in which they were raised contributed to their cancer, citing the influence of chemicals and other environmental hazards.

We just thought it was a localized thing because we grew up on Long Island in New York, which has high rates of cancer... a lot of pesticides were used on golf courses and along railroad tracks, so there was a lot of incidence of cancer. I lived in Maryland at one point and it's very high there too. *Participant 13*

Theme 5: Patients put emphasis on information about risk estimate

When asked what information about cancer they recalled from the genetic counseling session, participants most frequently stated that they recalled risk estimates. Many of the participants recall hearing numerical values for their percent chance of getting cancer, even if they were not able to recall the number correctly. Some interviewees did well in their approximation of risk numbers.

[The genetic counselor] laid out a 40 to 85% risk of breast cancer and at 20 to 40% risk of ovarian cancer. *Participant 14*

Other participants were erroneous in their recollection of the numbers themselves, tending to overestimate the risks quoted by their genetic counselor. Although the values were incorrect, patients seemed to latch onto risk numbers.

...What the next steps were, the percentages of risk with BRCA1 versus after surgeries. So knowing with BRCA1 that I had a 70 or 80 percent chance of ovarian cancer... *Participant 15*

[The genetic counselor] said I have an 87% chance of getting ovarian cancer.
Participant 12

Theme 6: A main takeaway from genetic counseling is how a mutation can cause more than one type of cancer

When asked to recall what information about cancer they recalled from the genetic counseling session, many participants also remembered learning about how different cancers can fall under a single gene mutation. Many patients were previously unaware that they were at risk for several different cancer types.

[I remember learning about] looking for things like the pancreatic cancer, the colon cancer, and the things that could be genetically linked. *Participant 3*

For genes like *BRCA1/2*, participants were already aware that there was a risk for breast and ovarian cancer, but they learned from the genetic counselor about other risks, such as the increased chance for melanoma or cancer of the peritoneal tissue.

...specifically, increased risk of melanoma as well, not just breast cancer and ovarian cancer and things like that. *Participant 8*

The kinds of cancer I could get because of my increased risk. They know that peritoneal cancer, even if you've had your ovaries removed, you're at risk for peritoneal cancer. *Participant 10*

Theme 7: The majority of participants said that genetic counseling changed their perception of cancer

When asked if genetic counseling changed their perception of cancer, 9/17 participants who responded to this question responded yes. One of the 18 participants did not give a clear answer to this question, and thus was excluded from the analysis. For those who responded in the affirmative, they were asked to clarify how genetic counseling impacted their view of cancer.

Theme 8: The change in perception was connected to gaining information

When asked how their views on cancer were altered by genetic counseling, most of the participants cited that they felt more informed and educated on the topic. Most specifically, participants revealed that they had a new understanding of how a single mutation can cause multiple types of cancers and how the risk is inherited.

I didn't know how it would affect my life in such a broad way. It's not just that I could get breast cancer. It affects my life in many other ways, like I could get melanoma. *Participant 13*

Some participants simply felt more informed about the cause of their cancer and how cancer develops on the cellular level.

It helped me understand the genetic side of it. How everyone has genes and they get

corrupted and they get passed down. *Participant 15*

Simply taking the time to become educated allowed patients to feel more informed and empowered about their cancer.

I think there's a lot more information that the oncologist doesn't have the time to sit and explain to you that the genetic counselors do have. *Participant 4*

True/False Statement Analysis

The true/false statements were scored for correctness. Table 2.1 summarizes the responses. The average amount of correct responses was 7.67/10. Of the ten statements, numbers 8, 9, and 10 were answered incorrectly most frequently. Statement 8, "Genes are carried in the blood" and statement 9, "Everyone has the same genes," were answered correctly by only 9/18 (50%) of respondents. Similarly, statement 10, "The breast cancer can skip a generation" was answered correctly by 9/18 respondents (50%). All of the respondents gave the correct answer for questions 4 and 6, which were "Not every person with a breast cancer- associated gene will get breast cancer" and "stress, exercise, and eating well can change your genes", respectively.

Additional findings emerged when the responses were sorted by age and education level. Eight of the participants were age 45 or under, and half were older than 45. Amongst these two cohorts, the older group had more formal education than the younger group, with more of the older cohort attending 4-year university and achieving doctorate-level degrees. When the true/false responses were sorted by age, the younger group got slightly more answers correct, despite having less formal education, as demonstrated in Table 2.2. The older group had a higher educational level but got a slightly lower score.

Table 2.1: True/False Statements by Number Correct

Statement	1	2	3	4	5	6	7	8	9	10
Correct	17	17	10	18	14	18	17	9	9	9
Percentage	94%	94%	56%	100%	78%	100%	94%	50%	50%	50%

Table 2.2: Percentage of T/F Correct by Age

Age group	Average out of 10	Percentage correct
45 and under	7.8	78%
Over 45	7.4	74%

DISCUSSION

This qualitative study assessed patient perceptions and beliefs about hereditary cancer as well as how these perceptions evolved as a result of genetic counseling. The results suggest that genetic counseling does affect cancer risk perception. Theme 1 demonstrates that individuals who developed cancer before having genetic counseling perceived their risk as low; however, the second theme suggests that unaffected individuals who have received genetic counseling feel that their risk of getting cancer is high. This change in risk perception may be due to gaining greater awareness and more education about hereditary cancer, although most participants suggested that they had already done research on cancer prior to their genetic counseling session. The process of genetic

counseling may introduce patients to the concepts of hereditary cancer and screening, perhaps making the idea of getting cancer seem more likely.

Another major theme was patient emphasis on lifestyle factors and the perceived importance of lifestyle factors in developing cancer. When asked how to prevent getting cancer, participants were more likely to cite lifestyle changes than risk-reducing surgeries, which have been shown to reduce cancer risks by upwards of 90 percent. Specifically, diet and exercise were emphasized by participants as ways to prevent cancer. While we certainly know that a healthy lifestyle can aid in preventing cancer, the effects of lifestyle are not fully understood in terms of cancer risk. Furthermore, most genetic counselors would emphasize screening tools, such as mammograms, or risk-reducing surgeries, such as a bilateral salpingo-oophorectomy, more heavily than diet and exercise, leading us to wonder where this fixation on lifestyle factors arose from. Many people seek control and would prefer to believe that they have an influence on life events, such as developing cancer. This may help explain why participants feel so strongly about the role of diet and exercise in preventing cancer-- this is something they can control.

Similarly, when asked why they or their family members developed cancer, the most frequent responses from participants related to lifestyle factors or life events. This was more surprising, as all of our participants were recruited from support groups for women with known mutations; for this reason, nearly all the participants have a known familial mutation. Despite this knowledge, lifestyle factors were reported more commonly than the mutation as a reason for developing cancer. Several participants named traumatic events, such as an abusive relationship or an illness in the family, as the reason for their cancer developing. Others named factors such as chemicals or other environmental

hazards. This, again, may stem from a desire to point to something more external, rather than something like a mutation which is intrinsic and present from birth. As genetic counselors, we tend to address lifestyle information briefly during the session. Knowing that patients focus so heavily on this aspect of cancer, perhaps we should set aside more time to discuss lifestyle and environmental risk factors.

When asked what information about cancer they recalled from the session, the most common response was risk estimate information. Participants seemed to recall receiving this information most frequently, even if they did not retain it correctly. Several of the interviewees remembered the risk information incorrectly, with a tendency to overinflate the actual number. This tendency to overestimate the true risk may be due to interviewees' feelings of anxiety around developing cancer. As genetic counselors, we should be aware that patients place value on risk estimates. It is also worth noting that patients often recall a higher risk estimate than what was quoted to them. The other topic that patients most frequently remembered from a session that one gene change can cause multiple types of cancer. Participants seemed to recall this because they were surprised to learn it.

For the majority of patients, genetic counseling did change their perception of cancer. This change in perception most frequently related to gaining a deeper understanding of hereditary cancer. Patients simply felt more educated and better equipped to understand their personal or family history of cancer.

This study helped elucidate patient beliefs about hereditary cancer, and how patients react and change their views based on genetic counseling. As indicated by the thematic results, genetic counseling has an impact on patient perceptions of hereditary

cancer. The goal of this study was to identify patient perceptions and how they evolve in order to understand how patients are incorporating the information presented during genetic counseling. We hope that this study will be valuable to patients and genetic counselors, promoting a greater understanding about patient beliefs and facilitating a more effective genetic counseling session.

There were several limitations to our study. The study participants were recruited from support groups; our cohort was possibly representing a more active and information-seeking minority of the hereditary breast cancer community. In addition, these support groups are aimed at women with a known familial mutation, so the opinions of women who had genetic testing and did not come back positive are underrepresented. The majority of our participants were Caucasian and well-educated.

Future research pertaining to this topic may incorporate a larger, more diverse group of individuals. Additionally, further research may include more representation from women who had genetic testing and were negative. Our study mainly included women whose genetic testing results were positive; the opinions and perceptions of individuals who tested negative were under-represented, especially considering that the majority of cancer genetic counseling patients get a negative result. Finally, this study did not investigate perceptions amongst patients with other types of hereditary cancer, whose experiences and beliefs may differ from the themes identified amongst those surveyed with breast cancer.

CHAPTER 3

CONCLUSIONS

Patients already have preconceived ideas and perceptions about cancer and genetics before they enter a genetic counseling session. Previous research suggests that these beliefs are rooted in a myriad of personal, familial and cultural factors.

This study found that patients have several misconceptions about hereditary cancer, most notably, the belief that diet and exercise is a large factor for developing cancer in those with a known mutation. Participants are recalling information from cancer genetic counseling sessions; they most frequently recalled risk estimates. The majority of participants stated that genetic counseling influenced their perception of cancer.

Healthcare providers, including genetic counselors, should be aware of patient perceptions of cancer prior to an appointment, in order to better connect and communicate with patients. This will facilitate a more effective and productive experience for the patient and provider.

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APPENDIX A: RECRUITMENT LETTER

Dear Madam:

Thank you for your interest in this study. You are invited to participate in a graduate research study focusing on how women feel about a diagnosis of breast cancer and the effect of genetic counseling on these thoughts and feelings. We are looking for women who are at least 18 years of age, who have a personal or family history of cancer, and who have received genetic counseling. The study involves a telephone interview, which will last for 20 to 30 minutes, and a series of ten true/false questions.

All responses gathered from the interviews will be kept confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified. Your participation in this research is voluntary and you may choose not to answer all questions. You may withdraw from the study at any time.

Thank you for your time and consideration to participate in this research. Your responses may help further genetic counselors' understanding of patient thoughts and feelings about cancer. If you have any questions regarding this research, you may contact either myself, Margaret Masterson, or my faculty adviser, Crystal Hill-Chapman, PhD, using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803)777-7095.

Please provide the following information about yourself:

1. Are you over age 18?
2. What is your sex? Male/ Female
3. Have you or a first degree relative (parent, sibling, or child) had breast cancer?
4. Have you received genetic counseling services?
5. Do you speak English fluently?

Please provide your phone number and email if you are willing to participate in the interview. I will contact you to set up a date and time.

APPENDIX B: INTERVIEW QUESTIONS

Consent Statement

You are agreeing to participate in a telephone interview as a part of a genetic counseling graduate school research project. This interview will last approximately 30 minutes. Your participation in this project is voluntary. You may withdraw from the study at any time. If at any time there is a question you are not comfortable answering, please let me know and we can proceed to the next question. This study may provide benefit to participants who desire to speak openly about cancer, and to healthcare professionals who will gain a greater understanding about patient perception of cancer. The risk for participating in this study is minimal.

With your consent, this conversation will be recorded and transcribed. All responses gathered from the interviews will be kept confidential. If a quotation is used from this interview, all identifying information will be removed and you will be assigned an alternative name.

Do you consent to this research study?

Date: _____ Time: _____

Demographic Information

1. What is your age?
2. What is your highest level of education?
 - a. Some high school, High school diploma/GED, technical/vocational school, some college, associate's degree, bachelor's degree, master's degree, professional degree
3. What is your race?

- a. Alaska Native, American Indian, Asian, African American, Caucasian, Hispanic, Native American, Native Hawaiian/Pacific Islander, Unknown, Other, do not wish to specify
4. What state do you live in?
5. What is your relationship status?
 - a. Single, committed relationship, married/domestic partnership, separated, widowed, divorced

Interview Questions

1. How was cancer discussed in your family?
2. Where have you gotten most of your information about cancer?
 - a. What information did you get?
3. What (did) do you think the likelihood of you getting cancer is?
4. How can you prevent getting cancer?
5. What are the reasons that you or your family members became ill with cancer?
6. Describe your experience with genetic counseling
7. What information about cancer do you recall from the session?
8. Did genetic counseling change your perception of cancer?
 - a. If so, how?

True/ False Questions

1. Males can carry the breast cancer gene.
2. The breast cancer gene can come from the paternal side, but only the women carry it.

3. In the general population, one out of three women will eventually die of breast cancer.
4. Not every person with a breast cancer- associated gene will get breast cancer.
5. As you move down generations, the chance of someone carrying the mutated breast cancer gene gets less and less.
6. Stress reduction, eating well and exercise can change your genes.
7. Males can have breast cancer.
8. Genes are carried in the blood.
9. Everyone has the same genes.
10. The breast cancer gene can skip a generation.

I would like to thank you for your time and participation. I've really enjoyed hearing your thoughts and this information will be beneficial for genetic counselors.