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Ethnic Differences in the Frequency of Cancer Reported from Family Pedigrees in the Prenatal Genetic Counseling Setting

THESIS

submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

Alex Palacios

Thesis Committee:
Professor Moyra Smith, Chair
Adjunct Professor Pamela Flodman
Health Sciences Clinical Professor Kathryn Steinhaus French

2021

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DEDICATION

To

My family, especially my parents. Thank you for all the sacrifices you made to allow me to be where I am now. I love you with all my heart.

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ABSTRACT OF THE THESIS

Ethnic Differences in the Frequency of Cancer Reported from Family Pedigrees in the Prenatal Genetic Counseling Setting

by

Alex Palacios

Master of Science in Genetic Counseling

University of California, Irvine, 2021

Professor Moyra Smith, Chair

This study analyzed if differences in cancer reporting exist between different ethnic groups when collecting family pedigrees in a prenatal genetic counseling setting. Data was collected from 446 prenatal charts at University of California, Irvine from January 1, 2015 – August 31, 2020. A total of 795 pedigrees meeting inclusion criteria (409 maternal pedigrees and 386 paternal pedigrees) were analyzed from four ethnic groups: non-Hispanic White, Hispanic/Latino(a), Asian, and African American/Black. The total number of first- and second-degree relatives and number of these relatives affected with cancer were calculated for each pedigree and analyzed using contingency tables, non-parametric tests, and Poisson regression. Cancer reporting in first- and second-degree relatives was the highest among the non-Hispanic White group. Reporting of a family history of cancer was lower in Hispanics, Asians, and African Americans. Ethnicity was a significant factor in predicting the number of relatives reported to have cancer in a Poisson regression model (controlling for the total number of relatives in the pedigree). The incidence of cancer reported in the pedigrees for Hispanics,

African Americans, and Asians was 36.3%, 50.2%, and 65.5% (respectively) of the incidence seen in the non-Hispanic White pedigrees. The cancer reporting differences observed in the Asian pedigrees are similar to differences in population incidence as reported by the CDC, but the reporting in the Hispanic and African American pedigrees is less than would be expected based on population incidence. This suggests that cancer histories in some minority populations may be truncated. Genetic counselors should recognize that certain patient populations may be at risk for limited knowledge of a family cancer history. The study also identified that cancer reporting in the paternal family history was significantly increased when the father was present, and that a family history of cancer was under-reported in questionnaires completed prior to clinic. In order to provide appropriate risk assessment, staff should encourage patients to obtain family cancer and health history ahead of their appointment, since the prenatal clinic may be the only time a comprehensive family health history is obtained.

INTRODUCTION

Previous studies have revealed that differences in cancer reporting exist between different ethnic groups. While there have been many studies that have explored family communication about cancer in Caucasian families, there are fewer studies about the communication of cancer histories in other ethnic groups (Etchegary et al., 2013). According to a previous study, cancer among relatives is reported less frequently when individuals and their families are of Hispanic or Asian ethnicity (Maves et al., 2020); this study analyzed pedigree data provided by individuals who had been referred for genetic counseling in the cancer genetics clinic. It should be noted that the cancer incidence rate is also lower in these ethnicities (CDC.gov); however, this alone may not explain the reporting disparity observed. Therefore, it is possible that family cancer histories in minority populations may be truncated. Nevertheless, the data analyzed by Maves et al. were collected in a cancer genetics clinic, and it is not clear whether these findings can be generalized to other settings.

The current study explores the frequency of cancers reported from family pedigrees in a prenatal genetic counseling setting. The patient population in a prenatal clinic is not referred based on individuals who have a primary indication or are thinking about cancer. Thus, a study exploring the reporting of a cancer family history outside the cancer genetics clinic could better determine if there are cancer reporting disparities in ethnic minorities.

Classification of Cancer

All cancers have a genetic basis; however, not all cancers are hereditary. Cancer can be classified into one of three groups: sporadic, familial, and hereditary. Approximately 75-80% of

all cancer cases are sporadic, roughly 15-20% of cancers are familial, and between 5-10% of all cancers are hereditary (Nagy et al., 2004). However, the proportion of cancers attributable to any of these three groups can be different depending on the type of cancer being considered. Approximately 23% of all ovarian cancers, for example, are due to a hereditary cancer syndrome (Toss et al., 2015). On the other hand, only about 5-8% of all diagnosed kidney cancers are hereditary (Ball and Shuch, 2019).

Hereditary cancer syndromes are inherited conditions where there is an increased risk to develop cancer due to pathogenic mutations in a highly penetrant gene or a combination of multiple genes with variants that each provide different additive effects (Rahner and Steinke, 2008; Zhang et al., 2020). Features that could suggest a hereditary cancer syndrome include having multiple individuals in various generations within a family diagnosed with the same type of cancer or related cancers, having a cancer diagnosed at an age younger than the average (ex: cancer diagnosed before age 50), and presence of a rare cancer such as male breast cancer. An example of an inherited cancer syndrome with the previously mentioned features is Hereditary Breast and Ovarian Cancer syndrome (HBOC), where women can develop breast and/or ovarian cancer before the age of 50 and men are at an increased risk to develop male breast cancer (Rahner and Steinke, 2008). On the other hand, familial cancers are cancers that can cluster in families and occur more frequently than would otherwise be expected. These cancers are thought to result from the combination of several low penetrant mutations in different genes, with or without interaction of environmental influences that may result in a relatively increased risk to develop cancer (Nagy et al., 2004). It is worth noting that familial clustering of cancers may be polygenic and, in rare circumstances, related to joint exposures to carcinogens experienced by family members (Zhang et al., 2020). Finally, sporadic cancers account for the

vast majority of all cancer cases (Nagy et al, 2004). These are the cancers that are usually not seen in multiple generations within a family, are diagnosed at later ages, and are generally due to factors such as exposures or certain lifestyle choices (Kenemans et al., 2004).

Genetic counselors can interpret the cancers observed in a family pedigree to try to determine which of these three classifications is most consistent with the cancer family history. This allows the formation of a personalized risk assessment for the patient that can guide medical management, screening recommendations, and eligibility for genetic testing. In the prenatal clinic, a family history of cancer that is suggestive of a hereditary cancer syndrome would prompt a referral to see a cancer genetic counselor and warrant additional follow up. Thus, the family pedigree can be useful in providing an initial risk assessment for cancer risk, including hereditary cancer.

The Family Pedigree

The family pedigree is a visual representation of a family's health history depicted through different standardized symbols and lines (Bennett et al., 2008). A pedigree typically documents multiple generations within a family and can reflect both the physical and mental health of each family member. Genetic counselors can utilize a pedigree to identify inheritance patterns and determine the risk for certain conditions, including cancer (Bennett et al., 2008). A more precise cancer risk assessment based on a family pedigree can be provided if the patient is aware of individuals in the family who have or had a cancer diagnosis.

Unlike written documentation of a family's cancer history, using a pedigree provides certain advantages in cancer risk assessment. These include facilitating recognition of

inheritance patterns, keeping track of the different cancers that arise by using different shading as the pedigree is drawn, and identification of the most informative person to offer genetic testing (Bennett, 2019). In addition, eliciting a pedigree provides the opportunity for the healthcare professional to identify the patient's motivations or concerns and build rapport with the patient, which can be extremely valuable in certain racial or ethnic groups (Bennett, 2012). Certain patterns of affected family members documented in a pedigree may make a genetic counselor suspicious for an increased risk for cancer or a hereditary cancer syndrome in an individual. These include having two or more relatives with the same type of cancer or related cancers (ex: colon and uterine cancer), earlier age of onset for a cancer diagnosis, and clustering of cancers over multiple generations within a family (Nagy et al., 2004). A pedigree is able to provide all of this information at a glance compared to a written family cancer history. Hence, the family pedigree is an important tool that healthcare professionals, including genetic counselors, can use to help identify which patients have an increased risk to develop cancer.

Incidence of Cancer Across Different Ethnic Groups

The incidence of cancer varies for different ethnic groups in the United States. According to data from the Centers for Disease Control and Prevention (CDC), Hispanics, Asians, and Blacks have lower cancer incidence rates compared to non-Hispanic Whites when including both sexes (CDC.gov). Specifically, cancer incidence rates based on CDC data obtained in 2017 were 438.8, 333.0, 284.2, and 429.1 per 100,000 non-Hispanic Whites, Hispanics, Asians, and Blacks, respectively. This data can be further classified for each individual sex. In males, cancer incidence rates from the 2017 CDC data were 470.8, 350.4, 285.4, and 497.1 per 100,000 non-Hispanic Whites, Hispanics, Asians, and Blacks, respectively.

In contrast, female incidence rates of cancer were 418.3, 326.9, 287.4, and 383.2 per 100,000 non-Hispanic Whites, Hispanics, Asians, and Blacks, respectively. If a difference in the reporting of a family history of cancer is observed between these four ethnic groups, it could be explained to some extent by differences in cancer incidence rates. If there is a disparity in reporting of a cancer family history that is bigger than the differences in cancer incidence rates across all groups, other causes should be considered. Reasons that may explain disparities in cancer reporting could include stigma or privacy associated with cancer, low health literacy, lost or unknown family history, and medical mistrust of the healthcare system.

Cancer Reporting in Ethnic Minorities

Several different studies indicate that cancer may be reported less frequently in ethnic minorities. For example, one study focused on attitudes and beliefs about cancer in the Latino community found stigma, fear, and secrecy associated with a cancer diagnosis (Kinney et al., 2010). Latino participants in this study also reported fatalistic views and not wanting other family members to know they have cancer, which could prevent Latinos from being aware of their family cancer history. Lower health literacy, which includes not being conscious of what health information might be relevant to share with other relatives, might be another impediment in awareness of a family history of cancer in Hispanics. Lower health literacy affects adults of all racial and ethnic groups in the United States, but Hispanic adults account for the largest proportion with basic or below basic levels of health literacy (National Center for Education Statistics, 2006). This, together with some misunderstandings about what can cause cancer including having a breast lump that is pressed or touched too often, may impede Hispanics from

recognizing the value of a family history with regards to cancer risk management (Rauscher et al., 2010).

Research aimed at understanding factors that influence colorectal cancer screening in Chinese and Korean Americans identified fear and stigma related to cancer as barriers that hinder open conversations about colorectal cancer (Jung et al., 2018). Specifically regarding stigma surrounding cancer, Simon et al. (2017) noted how certain cultural beliefs grounded in superstition, such as hiding one's illness to prevent bad luck and punishment, could make Chinese Americans present themselves as healthy to other individuals. Similarly, a study comparing attitudes about cancer among Asian ethnic subgroups found that Vietnamese subjects were more likely to associate a cancer diagnosis with inevitable death and appeared less receptive to colorectal cancer screening relative to Chinese and Korean individuals in the absence of a family history of cancer (Le et al., 2013). Furthermore, studies have also identified geographical location and loss of contact with family members as barriers to communication of cancer risk information in Caucasian families (MacDonald et al., 2007). With this in mind, these barriers may be particularly significant in Asian and other minority populations, including Hispanics, who often immigrate more regularly into the United States (Department of Homeland Security, 2020).

In African Americans, similar themes about cancer as well as medical mistrust have been reported. A paper exploring perceptions of prostate cancer in African American men described how these individuals associate cancer as a "death sentence" and how some Black individuals do not talk about cancer openly (Allen et al., 2007). Greiner et al. (2005) also reported similar findings when examining attitudes about colorectal cancer screening in African Americans. Participants in this research expressed that there was usually a tendency of silence and avoidance

around discussion of cancer, as well as misconceptions including cancer spreading from surgical procedures (Greiner et al., 2005). Furthermore, medical mistrust is a recurrent theme in many studies assessing engagement of African Americans with cancer prevention efforts and genetic testing. A literature review from Orji et al. (2020) suggests that Black women may have lower mammography uptake compared to White women due to fear of being taken advantage of in medical settings. This is of concern because Black women have the highest incidence of triple-negative breast cancer, which is an aggressive breast cancer subtype distinguished by lack of expression of receptors for estrogen and progesterone as well as low levels of human epidermal growth factor receptor 2 protein (Dietze et al., 2015). Similarly, medical mistrust and concerns about genetic discrimination have also been described as two sociocultural determinants that lead to lower use of genetic counseling and testing for the *BRCA* genes in Black women (Sheppard et al., 2013). Medical mistrust of the healthcare system in the Black community likely stems from historical events such as the Tuskegee syphilis study, lack of informed consent in use of Henrietta Lacks' tumor cells, and other forms of perceived discrimination that could result in under-reporting of cancer in Black individuals (Scharff et al., 2010).

Gender Differences in Health-Seeking Behaviors

The role of women as health information gatherers and disseminators in most racial and ethnic groups has been well established in the literature. In Latino families, women often adopt the role of looking after the health of their family and this may lead to women having more knowledge as well as a stronger desire to immerse in health-protective behaviors compared to men (Peak et al., 2017). With respect to African Americans, men are less likely to engage in health-seeking behaviors compared to women; it has been suggested that this may be due to

masculine gender norms and bias against using healthcare services (Eley et al., 2019). These cultural gender norms in the Black community may make men less likely to openly discuss health concerns and rely heavily on women to utilize preventive health behaviors. On the other hand, these behaviors could be different in some Asian cultures. In Asian Americans, factors including religion may shape the role of health-seeking behaviors between men and women, where women might not actively seek health information since this role is intended to be embraced by men (Tung, 2010). Patriarchal beliefs and familism have also been suggested to make Asian men perceive health-seeking behaviors as a sign of weakness and consequently hinder communication about health information between Asian men and healthcare providers (Tung, 2010).

Most research also supports the notion that women tend to have more health-seeking behaviors compared to men for diseases including cancer. A paper by Finney Rutten et al. (2007) that assessed characteristics of cancer information seekers and non-seekers in the American public found that men had lower odds to be information seekers about cancer-related information compared to women. Similarly, a recent study analyzing family cancer history knowledge and communication among U.S. adults found that women were more likely to have knowledge and discussion with at least one biological relative as well as a healthcare provider about their family cancer history relative to men (Krakow et al., 2020). Participants in this same study also reported that mothers were the biological relative with whom individuals discussed their family cancer history most regularly. It is worth mentioning that the subjects in both of the previously mentioned studies were primarily non-Hispanic White. Nevertheless, it is evident that despite cultural differences in terms of gender roles about health-seeking behaviors, women generally are more involved with their family's health history in comparison to men.

Communication Through Medical Interpreters

The use of medical interpreters in healthcare services have become more important as the number of non-native English speakers in the United States has grown. The 2015 U.S. Census reported that there are more than 350 different languages spoken in households throughout the country and about 25 million people report speaking English "less than well" (Ault et al., 2019). Under Title IV of the Civil Rights Act, interpreter services are mandated for all patients with limited English proficiency (LEP) who are receiving federal financial assistance (Ku and Flores, 2005). Use of professionally trained medical interpreters can be important to reduce the number of medical errors and prevent adverse health outcomes for LEP patients.

In genetic counseling, medical interpreters can help bridge the gap imposed by a language barrier in order to effectively communicate with LEP patients. This is important since a primary emphasis in genetic counseling is to empower patients with information to help them make well-informed decisions about their health. While the impact of medical interpreters on interactive communication in genetic counseling sessions has previously been explored, errors in interpretation for genetic counseling sessions has not been well studied (Ault et al., 2019). Flores et al. (2012) have shown that trained medical interpreters significantly reduce the likelihood of errors of clinical consequence compared to non-trained interpreters in medical encounters. However, even trained interpreters can average about six errors of clinical consequence in one single visit, with the most common being omission of information spoken by the patient (Flores et al., 2012). Therefore, even though trained medical interpreters can reduce the number of clinically significant errors in communication, the possibility of information being lost in the process of communication between LEP patients and healthcare providers still exists.

Hypothesis

The hypothesis that was investigated in this study is that ethnic minorities including Hispanics, Asians, and African Americans report cancer less frequently in family pedigrees compared to non-Hispanic Whites in the prenatal genetic counseling setting. The primary aim was to identify if there was a disparity in cancer family history reporting between these ethnic groups by looking at significant differences in the frequency of cancers reported in first- and second-degree relatives.

Secondary aims of this study included assessing how often patients reported cancer on the questionnaire provided prior to their genetic counseling appointment and how often they reported cancer only when the genetic counselor obtained the pedigree during the appointment. Another question investigated was comparing the reporting of cancer in the pedigree from the prospective mother versus the prospective father, especially when taking into account the presence of the father when the pedigree was elicited. Other secondary aims of the study included whether the use of an interpreter affected the reporting of cancer in the family pedigree for non-English speaking patients compared to English-speaking patients. Finally, comparing cancer reported in pedigrees collected during the COVID-19 pandemic when genetic counseling transitioned into telemedicine, versus cancer reported when genetic counseling was provided in-person, was attempted.

It was hypothesized that some patients who did not report cancer on the questionnaire would subsequently inform the genetic counselor of at least one first- or second-degree relative with cancer when providing information about their family history at the time the pedigree was

elicited. It was also speculated that more cancer would be reported in maternal pedigrees in comparison to paternal pedigrees across all ethnic groups, when taking into account the presence of the prospective father in the appointment. In addition, it was predicted that the use of an interpreter may result in less cancer being documented in the family pedigree, due to time constraints or lost communication that could occur when information is communicated between the genetic counselor and the patient via an interpreter. Lastly, with respect to the effect of genetic counseling in a telemedicine setting versus in-person, it was hypothesized that there would be a higher frequency of cancers reported in family pedigrees in telemedicine compared to in-person visits across all ethnic groups.

RESEARCH METHODS AND DESIGN

Pedigree Collection

This study obtained University of California, Irvine (UCI) institutional review board approval of application HS#2020-6158. A total of 446 prenatal charts, each including a maternal and/or paternal pedigree, were reviewed from patients seen at the UCI Center for Fetal Evaluation. Prenatal charts that were analyzed for this study included those collected between January 1, 2015 – August 31, 2020 and uploaded into a secure electronic database (FileMaker). During this time period, there were three prenatal genetic counselors collecting family pedigrees from patients and drawing the pedigrees along with genetic counseling graduate students under their direct supervision. A total of 795 pedigrees, which consisted of 409 maternal pedigrees and 386 paternal pedigrees, were analyzed from the 446 prenatal charts that were reviewed in the study. The pedigrees were eligible for the study if more than half of the countries of origin or reported ethnicity in the prospective mother and/or prospective father's pedigree included one of the four ethnic groups of interest for this study: non-Hispanic White, Hispanic/Latino(a), Asian, and African American/Black. In order to classify a country of origin to a specific ethnicity, classification from professional databases such as the World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC) were utilized. The non-Hispanic White group was further divided by those who reported Ashkenazi Jewish ancestry, which was considered separately.

Additional inclusion criteria for pedigrees included that the prospective mother and/or prospective father be eighteen years of age or older at the time of the prenatal genetic

counseling appointment. Pedigrees were excluded if the majority ethnicity could not be determined due to mixed ethnicity or adoption, if the prospective mother and/or prospective father were less than eighteen years of age at the time of their appointment, and if the patient was seen more than once during the time period of the study. For the latter case, the pedigree from the mother's initial consultation was included in the data collection. Due to the small numbers, all identified African American prenatal charts with their corresponding pedigrees that satisfied the inclusion criteria during the time period of the study were collected, while stratified random sampling was used to obtain the prenatal charts from the other three ethnic groups. Prenatal charts for these groups were randomly selected using a random number generator until 390 prenatal charts that included pedigrees meeting inclusion criteria had been reviewed.

Variables Collected

There were a number of variables collected for this study. These included the ethnicity in the prospective mother and prospective father of the pregnancy based on the reported countries of origin in the pedigree. The number of first- and second-degree relatives were totaled in the pedigree for each prospective parent. First-degree relatives included biological children, biological parents, and full siblings. Second-degree relatives included half-siblings, nieces, nephews, aunts, uncles, and grandparents. See Figure 1 for an example of first and second-degree relatives to the prospective mother. In all pedigrees analyzed, each shorthand "n" inside a diamond was counted as one individual. This notation is typically used to denote an unknown or unstated number of relatives. From these first- and second-degree relatives, those who were affected or diagnosed with cancer as well as the total number of these relatives

were computed. In this study, cancer was defined as a malignant tumor. Therefore, individuals with a tumor that was denoted as benign, such as a brain tumor that was not otherwise reported as malignant, were considered unaffected with cancer. The type of cancer in each affected first- and second-degree relative as well as the type of cancer history reported (i.e. all known or some unknown cancer versus all unknown cancer) was also collected for each pedigree.

Other variables of interest that were gathered included whether cancer was reported in the questionnaire provided prior to the appointment. This was documented for those pedigrees obtained during an in-person visit since a questionnaire was not given to patients seen through telemedicine. The prospective mother and father's age at the time of the prenatal visit was another variable that was collected. Specifically, age was dichotomized into two age groups for each ethnic group studied: individuals who were between 18-34.9 years of age and those who were 35 years and older. Another variable of interest that was compiled was whether there was the use of an interpreter or not during the prenatal genetic counseling appointment. With regards to the appointment itself, it was also noted whether the prospective father was present when the pedigree was obtained during the genetic counseling session. Lastly, it was documented whether the mode of counseling for the appointment was performed in-person or via telemedicine.

Statistical Analysis

Data was compiled in a coded data collection spreadsheet that contained information matching each individual's data to their corresponding chart and pedigree. After all data of

interest was collected, the coded information was deleted and the spreadsheet was manipulated accordingly in order to import the data into IBM SPSS version 25 statistical software.

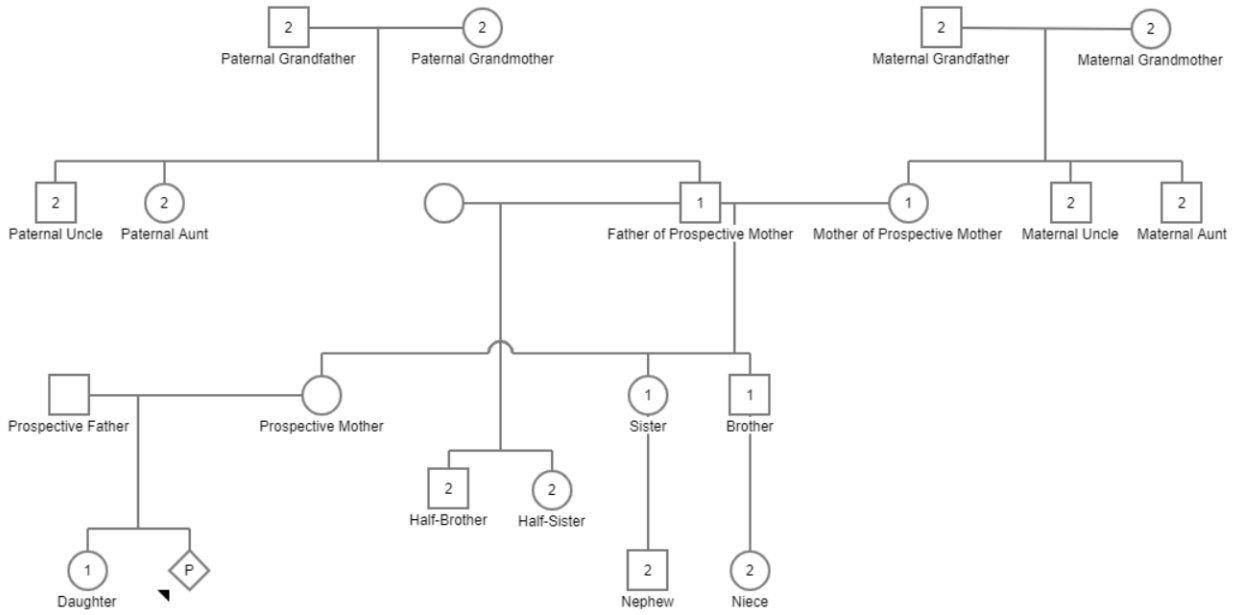


Figure 1: Example of first- and second-degree relatives to the prospective mother. The number inside each shape represents the degree of relationship the family member has to the prospective mother. 1: First-degree relative (children, full siblings, and parents). 2: Second-degree relative (half-siblings, nieces, nephews, aunts, uncles, and grandparents). P: Pregnancy

A total of 446 prenatal charts, resulting in 795 pedigrees that consisted of 409 maternal pedigrees and 386 paternal pedigrees, were reviewed. Descriptive analysis was used to present the information collected such as demographics, presence or absence of the prospective father in the appointment, and mode of counseling, among other data. Non-parametric tests, including a chi-square test, were applied to analyze factors including, but not limited to, differences in cancer reporting for maternal and paternal pedigrees as well as the type of cancer history reported across all ethnic groups of interest. A Poisson regression was also

used to model the effect of ethnicity and other predictors in determining the number of relatives reported with cancer when considering differences in family size. Nominal p-values are reported with no correction for multiple comparisons.

RESULTS

A total of 795 pedigrees were analyzed. The ethnicities reported in the pedigrees were categorized as 205 non-Hispanic White, 242 Hispanic/Latino(a), 237 Asian, 92 African American/Black, and 20 Ashkenazi Jewish. Of the total 795 pedigrees, there were 409 maternal pedigrees in which 96 represented non-Hispanic Whites, 124 Hispanic/Latinas, 127 Asians, 50African Americans/Blacks, and 12 Ashkenazi Jewish. There were 386 paternal pedigrees analyzed in which 108 represented non-Hispanic Whites, 118Hispanic/Latinos, 110 Asians, 42 African Americans/Blacks, and 8 Ashkenazi Jewish. Table 1 on the next page provides a summary of the descriptive data collected for all pedigrees analyzed. Table 2 and Table 3 provide a summary of the descriptive data collected for only maternal and paternal pedigrees, respectively. Figure 2 summarizes the total number of pedigrees analyzed by reported ethnicity and for each prospective parent.

The pedigrees in which Ashkenazi Jewish ancestry was reported were separated from the non-Hispanic White group due to the recognition that this particular group of individuals could have more awareness of the *BRCA* genes, which could further enable family communication and hence reporting of cancer in their pedigrees. However, given the low number of Ashkenazi Jewish pedigrees, these were excluded from further descriptive statistics and data analysis in the study.

Table 1:

Demographic and descriptive data collected from 795 pedigrees analyzed

Data 1/1/2015 - 8/31/2020	Non-Hispanic White	Hispanic/ Latino(a)	Asian	African American/ Black	Ashkenazi Jewish
Total Pedigrees	204 (25.7%)	242 (30.4%)	237 (29.8%)	92 (11.6%)	20 (2.5%)
Age (years)					
Mean	34.9	34.0	36.7	34.2	32.3
Median	35.3	35.5	36.6	35.0	32.5
Minimum	22.6	18.5	22.1	19.3	20.0
Maximum	56.4	60.5	61.8	54.0	50.0
Number of Pedigrees by Age Group (years)					
18-34.9	97 (47.5%)	113 (46.7%)	81 (34.2%)	45 (48.9%)	15 (75.0%)
35.0 and older	107 (52.5%)	129 (53.3%)	156 (65.8%)	47 (51.1%)	5 (25.0%)
Total number of First- and Second-Degree Relatives					
Mean	13.33	18.41	15.08	16.09	13.00
Median	12.50	17.00	14.00	14.00	12.00
Number of Pedigrees with Cancer					
Yes	111 (54.4%)	66 (27.3%)	92 (38.8%)	28 (30.4%)	14 (70.0%)
No	93 (45.6%)	176 (72.7%)	145 (61.2%)	64 (69.6%)	6 (30.0%)
Number of Pedigrees with Interpreter Use					
Yes	4 (2.0%)	50 (20.7%)	30 (12.7%)	2 (2.2%)	0 (0.0%)
No	200 (98.0%)	192 (79.3%)	207 (87.3%)	90 (97.8%)	20 (100.0%)
Mode of Counseling					
In Person	197 (96.6%)	229 (94.6%)	223 (94.1)	86 (93.5%)	19 (95.0%)
Telemedicine	7 (3.4%)	13 (5.4%)	14 (5.9%)	6 (6.5%)	1 (5.0%)

Table 2:

Demographic and descriptive data collected from maternal pedigrees

Data 1/1/2015 - 8/31/2020	Non-Hispanic White	Hispanic/ Latina	Asian	African American/ Black	Ashkenazi Jewish
Total Pedigrees	96 (23.5%)	124 (30.3%)	127 (31.1%)	50 (12.2%)	12 (2.9%)
Age (years)					
Mean	33.9	33.0	35.8	32.8	30.3
Median	35.4	35.4	36.3	34.0	30.9
Minimum	22.3	18.8	22.6	19.3	22.2
Maximum	46.9	42.6	46.4	41.5	37.4
Total number of First- and Second-Degree Relatives					
Mean	13.94	20.98	15.64	17.54	13.67
Median	13.00	20.00	15.00	15.50	11.50
Number of Pedigrees in Prospective Mother with Cancer					
Yes	66 (68.8%)	40 (32.3%)	60 (47.2%)	19 (38.0%)	9 (75.0%)
No	30 (31.2%)	84 (67.7%)	67 (52.8%)	31 (62.0%)	3 (25.0%)
Number of Pedigrees with Interpreter Use					
Yes	2 (2.1%)	25 (20.2%)	15 (11.8%)	1 (2.0%)	0 (0.0%)
No	94 (97.9%)	99 (79.8%)	112 (88.2%)	49 (98%)	12 (100.0%)
Mode of Counseling					
In Person	92 (95.8%)	118 (95.2%)	120 (94.5%)	46 (92.0%)	12 (100.0%)
Telemedicine	4 (4.2%)	6 (4.8%)	7 (5.5%)	4 (8.0%)	0 (0.0%)

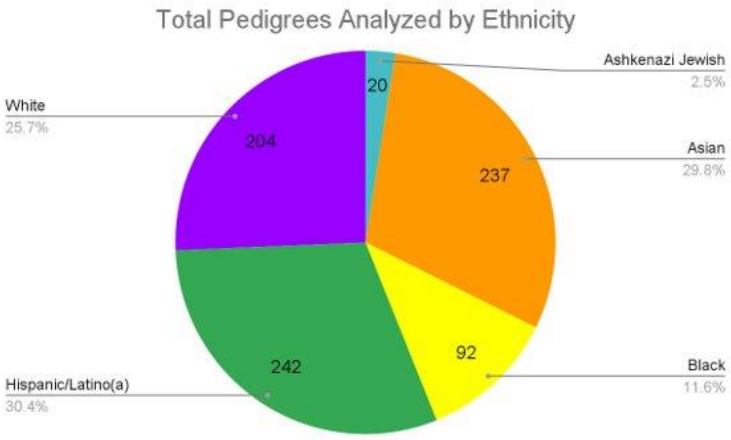
Table 3:

Demographic and descriptive data collected from paternal pedigrees

Data 1/1/2015 - 8/31/2020	Non-Hispanic White	Hispanic/ Latino	Asian	African American/ Black	Ashkenazi Jewish
Total Pedigrees	108 (28.0%)	118 (30.6%)	110 (28.5%)	42 (10.9%)	8 (2.1%)
Presence or Absence of FOP in Paternal Pedigrees					
FOP Present	48 (44.4%)	37 (31.4%)	57 (51.8%)	15 (35.7%)	6 (75.0%)
FOP Absent	60 (55.6%)	81 (68.6%)	53 (48.2%)	27 (64.3%)	2 (25.0%)
Age (years)					
Mean	35.5	35.1	37.7	35.1	34.6
Median	35.1	35.6	37.1	35.6	32.7
Minimum	23.0	18.5	22.1	19.8	20.0
Maximum	59.3	60.5	61.8	54.0	50.0
Total number of First- and Second-Degree Relatives					
Mean	12.80	15.70	14.44	14.36	12.00
Median	12.00	15.00	13.00	13.00	12.00
Number of Pedigrees in Prospective Father with Cancer					
Yes	45 (41.7%)	26 (22.0%)	32 (29.1%)	9 (21.4%)	5 (62.5%)
No	63 (58.3%)	92 (78.0%)	78 (70.9%)	33 (78.6%)	3 (37.5%)
Number of Pedigrees with Interpreter Use					.
Yes	2 (1.9%)	25 (21.2%)	15 (13.6%)	1 (2.4%)	0 (0.0%)
No	106 (98.1%)	93 (78.8%)	95 (86.4)	41 (97.6%)	8 (100.0%)
Mode of Counseling					
In Person	105 (97.2%)	111 (94.1%)	103 (93.6%)	40 (95.2%)	7 (87.5%)
Telemedicine	3 (2.8%)	7 (5.9%)	7 (6.4%)	2 (4.8%)	1 (12.5%)

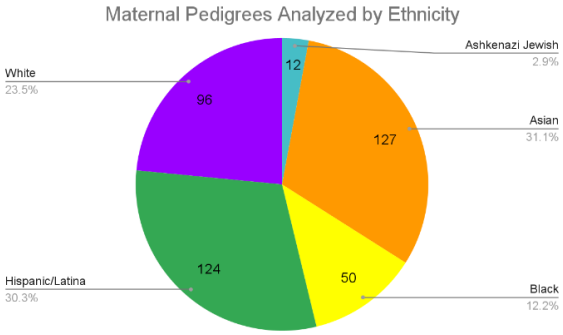
FOP = Father of the pregnancy

A



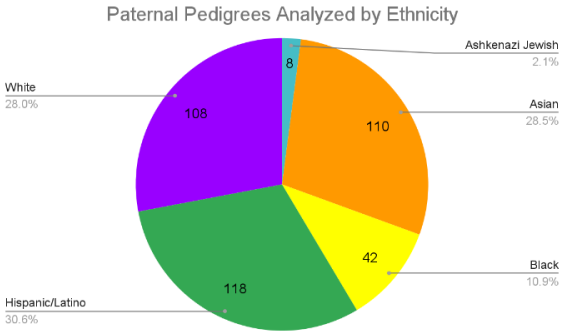
Total number of pedigrees
N = 795

B



Total number of maternal pedigrees
N = 409

C



Total number of paternal pedigrees
N = 386

Figure 2: Total number of pedigrees analyzed (including for each prospective parent) by ethnicity. All the pedigrees analyzed by ethnicity are shown in Figure 2A, while only maternal pedigrees analyzed by ethnicity is shown in Figure 2B and only paternal pedigrees analyzed by ethnicity is shown in Figure 2C.

Descriptive Data

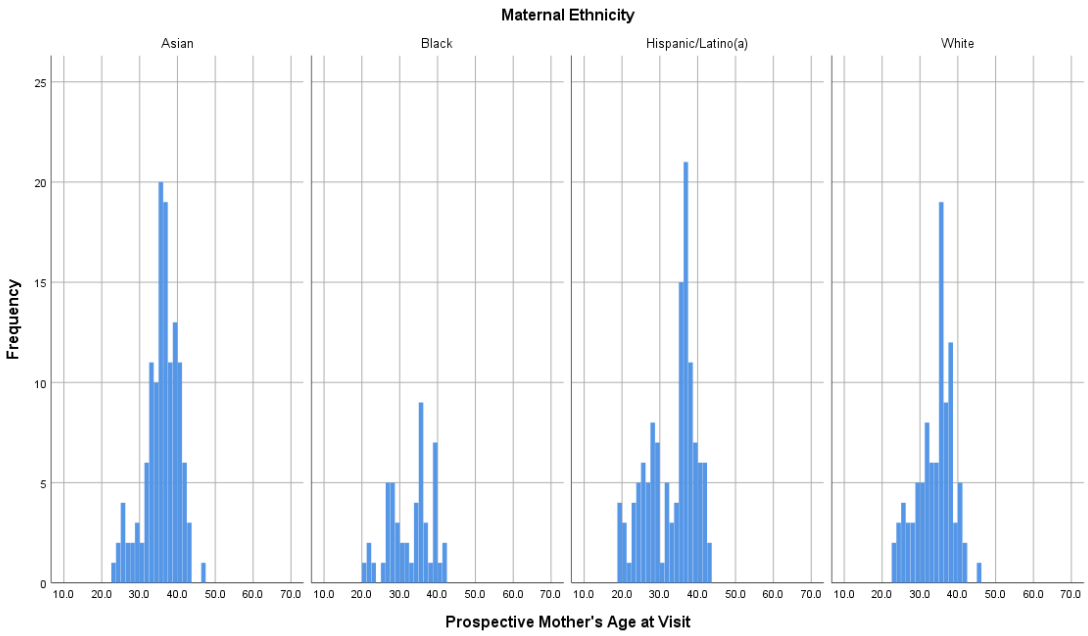
Age

Figure 3 illustrates the age distribution for the prospective mother and prospective father by ethnicity. Overall, age was normally distributed for each group. The median age for the prospective mothers were 35.4, 35.4, 36.3, and 34.0 in the non-Hispanic White, Hispanic/Latina, Asian, and African American group, respectively. The median age of the prospective fathers were 35.1, 35.6, 37.1, and 35.6 in the non-Hispanic White, Hispanic/Latino, Asian, and African American group, respectively. The age distribution was dichotomized into individuals between 18-34.9 years of age and those who were 35 years and older (Figure 4). It was noted that for the Asian group, there were a greater number of prospective mothers and fathers who were 35 years and older at the time of the prenatal visit in comparison to the other groups studied. However, the age group differences between prospective parents by ethnicity was not statistically significant (see Figure 4).

Total Number of Relatives

The total number of first- and second-degree relatives varied between the different ethnic groups (Figure 5). The median number of relatives for the prospective mothers were 13, 20, 15, and 15.50 in the non-Hispanic White, Hispanic/Latina, Asian, and African American group, respectively. The median number of relatives in the prospective fathers were 12, 15, 13, and 13 in the non-Hispanic White, Hispanic/Latino, Asian, and African American group, respectively. It is apparent that Hispanics/Latinos(as) reported greater number of first- and second-degree relatives for both the maternal and paternal pedigrees compared to the other three groups.

A



B

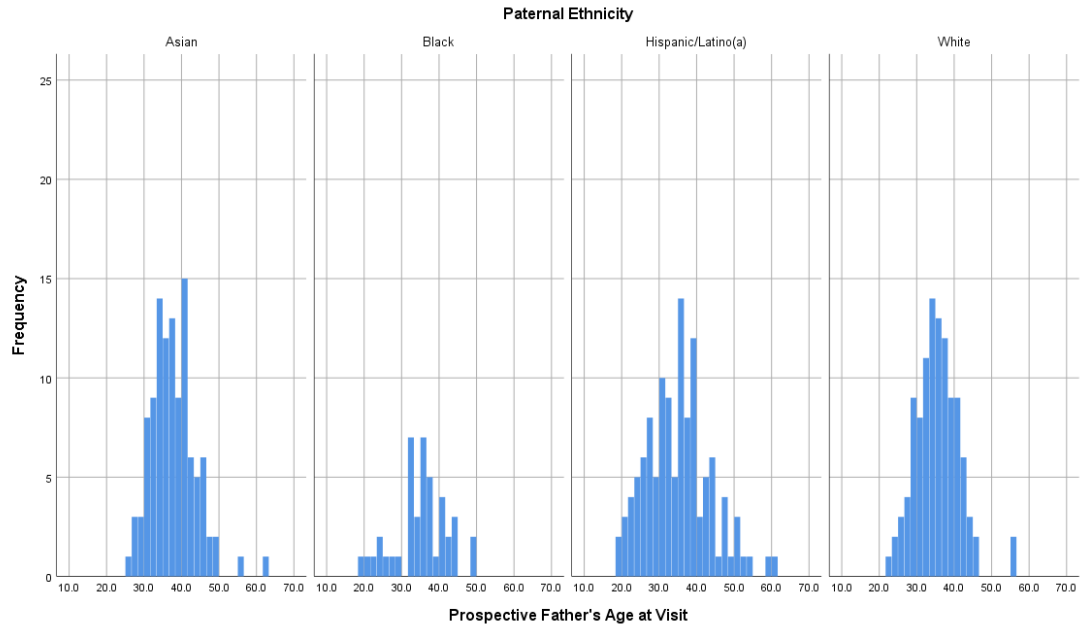
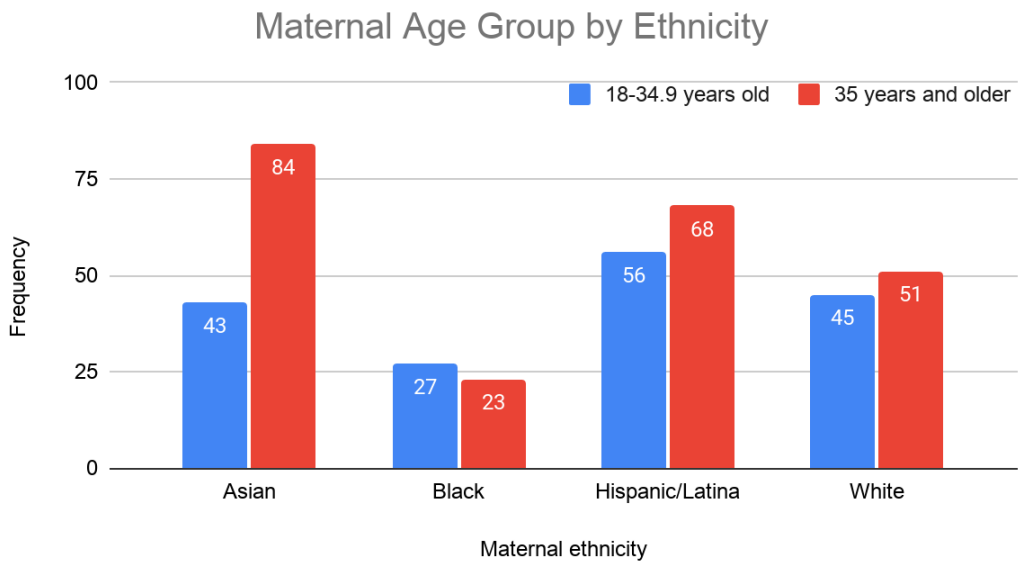


Figure 3: Age distribution of prospective parents by ethnicity. The age distribution for prospective mothers by ethnicity is shown in Figure 3A, while the age distribution for prospective fathers by ethnicity is shown in Figure 3B.

A



B

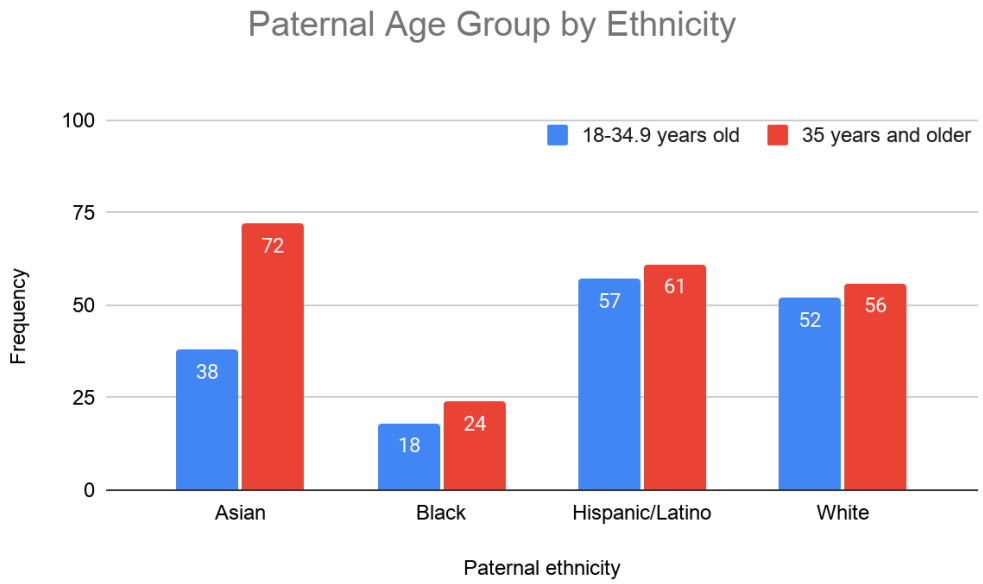
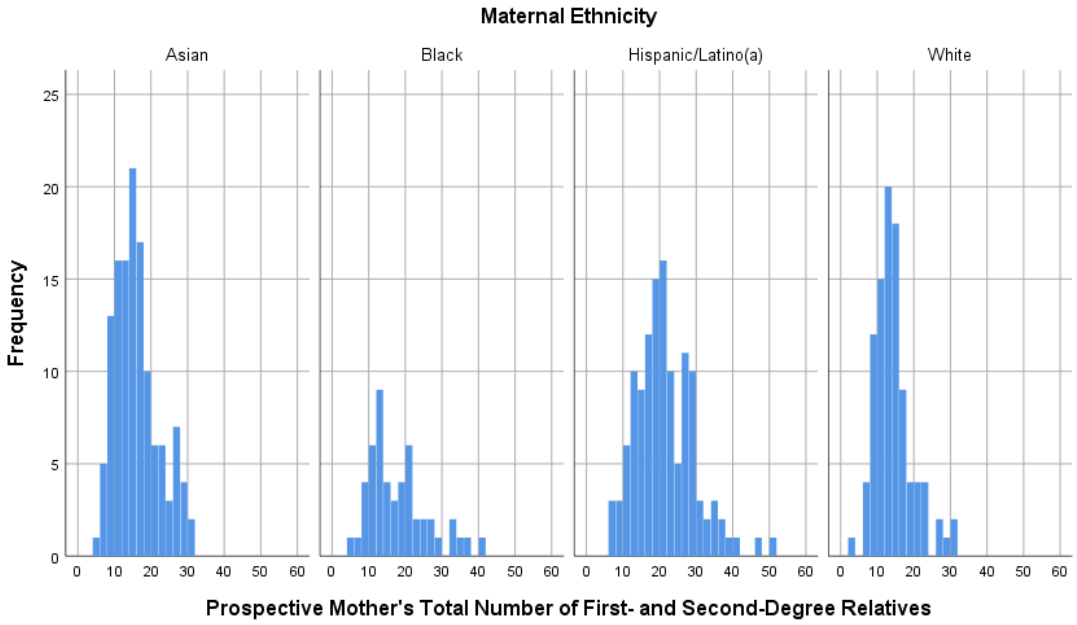


Figure 4: Age group of prospective parents by ethnicity. The age group of prospective mothers by ethnicity is shown in Figure 4A. Comparison of prospective mothers by ethnicity did not show a significant difference in age group distribution (chi-square = 7.619, degrees of freedom = 3, p = 0.055). The age group of prospective fathers by ethnicity is shown in Figure 4B. Comparison of prospective fathers by ethnicity did not show a significant difference in age group distribution (chi-square = 5.646, degrees of freedom = 3, p = 0.130).

A



B

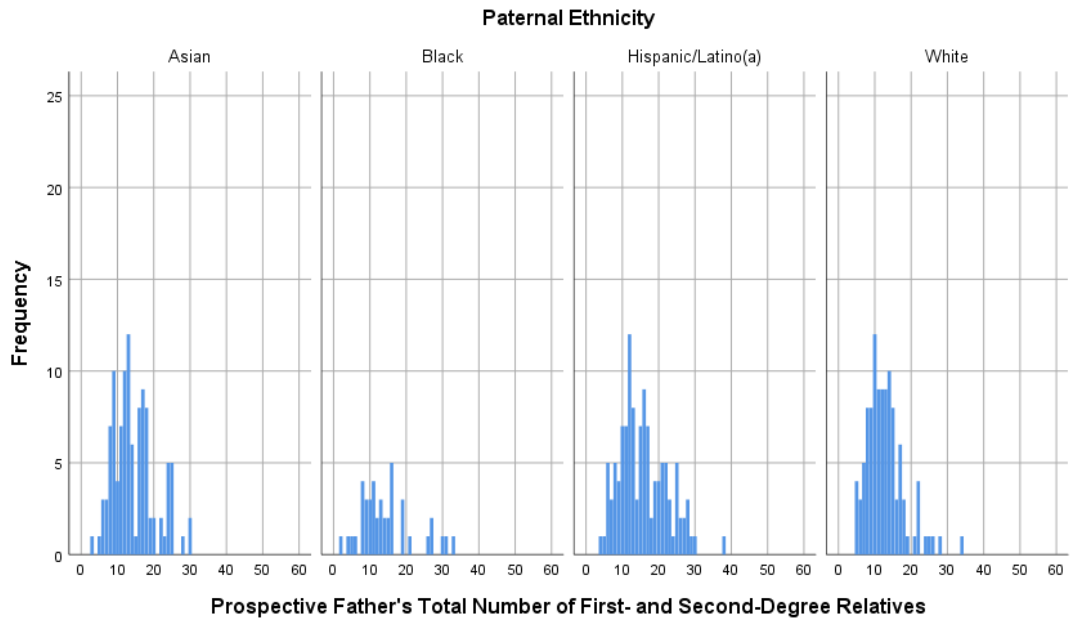


Figure 5: Distribution of total number of first- and second-degree relatives in prospective parents by ethnicity. The distribution of total number of relatives in prospective mothers is shown in Figure 5A, while the distribution of total number of relatives in prospective fathers by ethnicity is shown in Figure 5B.

Presence of Prospective Father

The presence of the prospective father in the prenatal genetic counseling appointment was also analyzed. Figure 6 below depicts the proportion of paternal pedigrees where the prospective father was present or absent for each ethnic group. The prospective father was proportionally more present in the Asian (51.8%) and non-Hispanic White group (44.4%). Proportions of paternal pedigrees where the prospective father was present for the Black (35.7%) and Hispanic group (31.4%) were relatively similar. Use of a chi-squared test found statistically significant differences of paternal pedigrees in which the prospective father was present by ethnicity ($p = 0.013$).

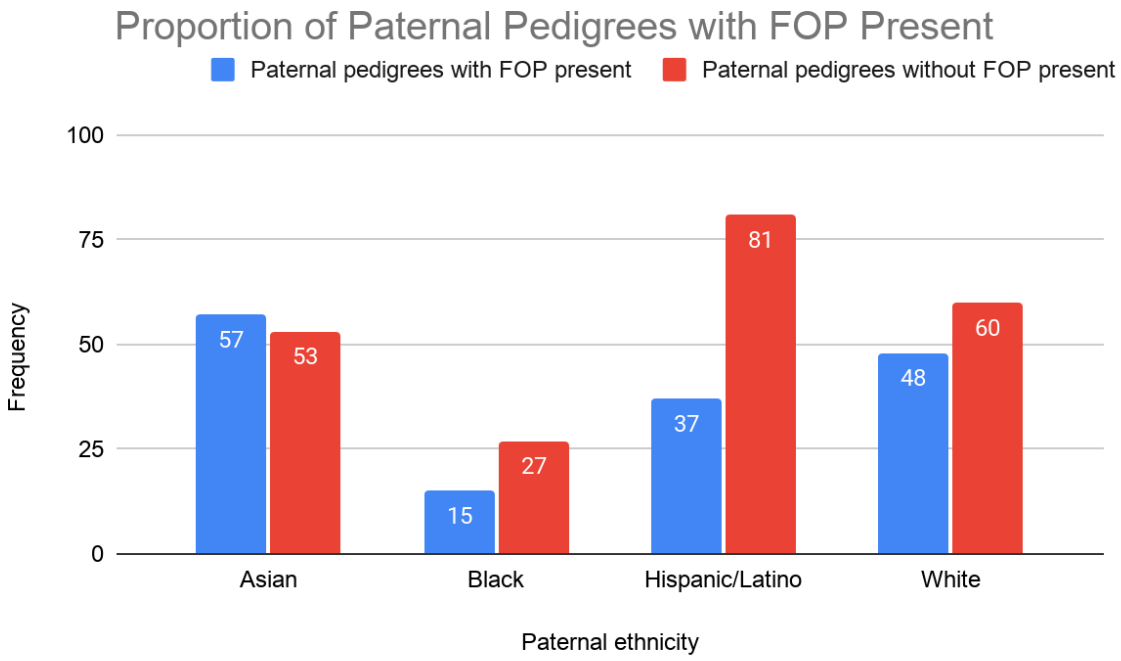


Figure 6: Proportion of paternal pedigrees with father of the pregnancy (FOP) present by ethnicity. There was a significant difference in the number of paternal pedigrees with presence of FOP by ethnicity (chi-square = 10.787, degrees of freedom = 3, p = 0.013).

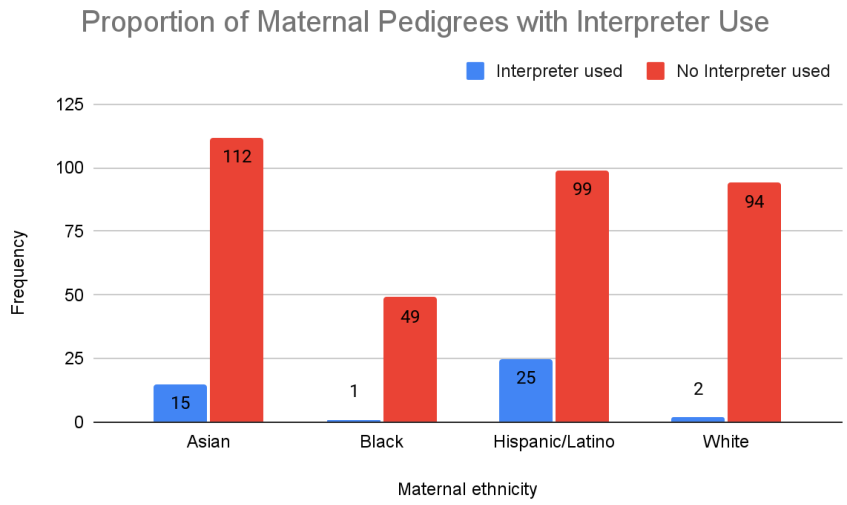
Interpreter Use

Figure 7 on the next page shows the number of maternal and paternal pedigrees that were elicited with the use of an interpreter. For maternal pedigrees, an interpreter was used more frequently for Hispanics/Latinas (20.2%) and Asians (11.8%) relative to non-Hispanic Whites (2.1%) and African Americans (2.0%). These differences were found to be statistically significant when analyzed using a chi-squared test ($p < 0.001$). Similarly, in paternal pedigrees Hispanics/Latinos (21.2%) and Asians (13.6%) had a greater interpreter use than African Americans (2.4%) and non-Hispanic Whites (1.9%). These differences were also statistically significant when analyzed with a chi-squared test ($p < 0.001$). Hispanic/Latinos(as) and Asians required the use of an interpreter more frequently compared to non-Hispanic Whites and African American for both maternal as well as paternal pedigrees.

Cancer Reporting in Prospective Parents' Pedigrees

Reporting of cancer in the pedigrees of each prospective parent were analyzed by ethnicity (Figure 8). More maternal pedigrees had cancer reported in non-Hispanic Whites (68.8%) followed by Asians (47.2%), African Americans (38.0%), and Hispanic/Latinas (32.3%). Use of a chi-squared test found these differences to be statistically significant ($p < 0.001$). Likewise, more paternal pedigrees had cancer reported in non-Hispanic Whites (41.7%) followed by Asians (29.1%), Hispanic/Latinos (22.0%), and African Americans (21.4%). Analysis using a chi-squared test found these differences to be statistically significant ($p = 0.007$). Cancer was reported more frequently in non-Hispanic Whites compared to the other three ethnic groups in both maternal and paternal pedigrees.

A



B

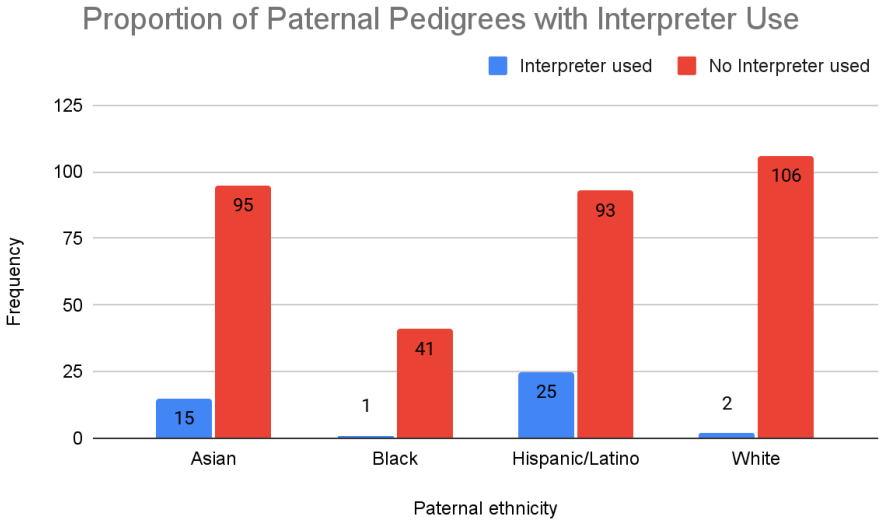
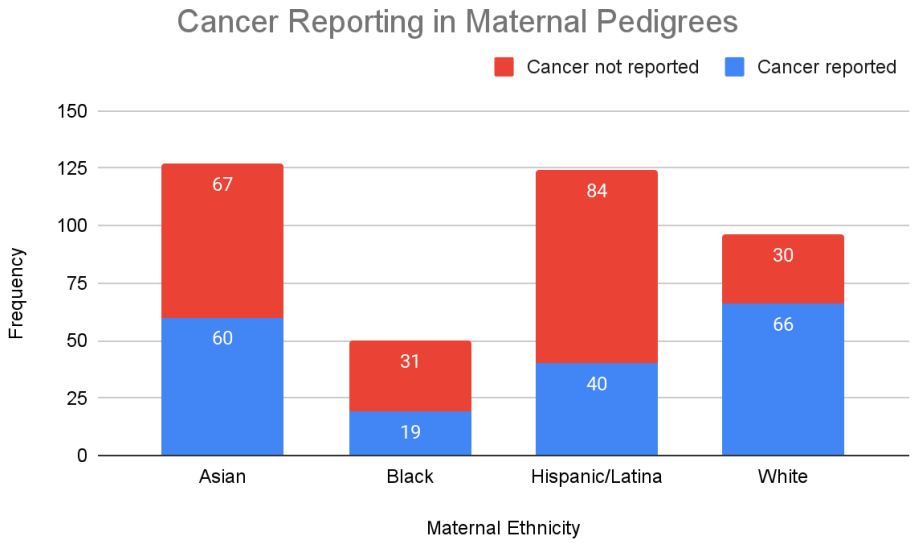


Figure 7: Proportion of prospective parents' pedigrees with interpreter use by ethnicity. The number of maternal pedigrees elicited with an interpreter by ethnicity is shown in Figure 7A. The comparison of maternal pedigrees obtained using an interpreter showed a significant difference by ethnicity (chi-square = 22.947, degrees of freedom = 3, $p < 0.001$). The number of paternal pedigrees elicited with an interpreter by ethnicity is shown in Figure 7B. The comparison of paternal pedigrees obtained using an interpreter showed a significant difference by ethnicity (chi-square = 24.910, degrees of freedom = 3, $p < 0.001$).

A



B

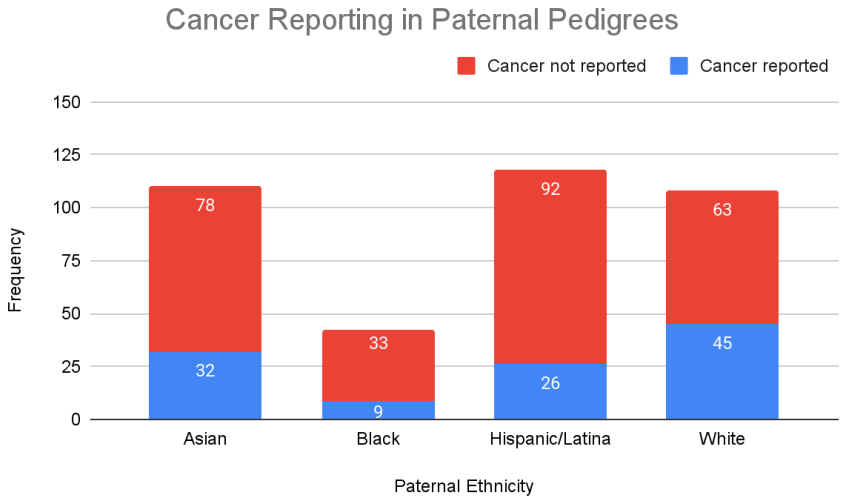


Figure 8: Cancer reporting in pedigrees of prospective parents by ethnicity. Cancer reporting in maternal pedigrees by ethnicity is shown in Figure 8A. The comparison of prospective mothers reporting cancer in their pedigree showed a significant difference by ethnicity (chi-square = 30.684, degrees of freedom = 3, $p < 0.001$). Cancer reporting in paternal pedigrees by ethnicity is shown in Figure 8B. The comparison of prospective fathers reporting cancer in their pedigree showed a significant difference by ethnicity (chi-square = 12.140, degrees of freedom = 3, $p = 0.007$).

Type of Cancer History Reported

Maternal or paternal pedigrees in which cancer was reported were further classified based on the type of cancer history reported by ethnicity (Table 4). Specifically, pedigrees with cancer were dichotomized into two groups: those who reported knowing all or some of the types of cancer in affected relatives, and those who reported not knowing any of the types of cancer in affected family members. It is notable that in maternal pedigrees with cancer, Black women were less likely to know the types of cancer in their affected relatives (26.3%) in comparison to the other ethnic groups and this was statistically significant when analyzed with a chi-squared test ($p = 0.026$). For paternal pedigrees, Hispanic (23.1%) and Black men (22.2%) were less likely to know what types of cancer were present in their family history. However, this was not found to be statistically significant when analyzed using a chi-squared test ($p = 0.081$). It is important to emphasize that for paternal pedigrees, these percentages could have been lower if we would have taken into account the presence of the prospective father when the pedigree was elicited. Nevertheless, this data suggests that not only might certain ethnic groups be at risk for under-reporting cancer, but they may also not be fully aware of what types of cancers their family members had.

Mode of Counseling

The mode of counseling utilized for each of the maternal and paternal pedigrees obtained was collected (Figure 9). The vast majority of pedigrees were acquired during an in-person appointment rather than through telemedicine. Therefore, given the low number of maternal and

paternal pedigrees obtained through telemedicine, no analysis of cancer reporting for in-person pedigrees versus those obtained through telemedicine was performed.

Table 4: Type of cancer history in prospective parents' pedigrees with cancer by ethnicity

A

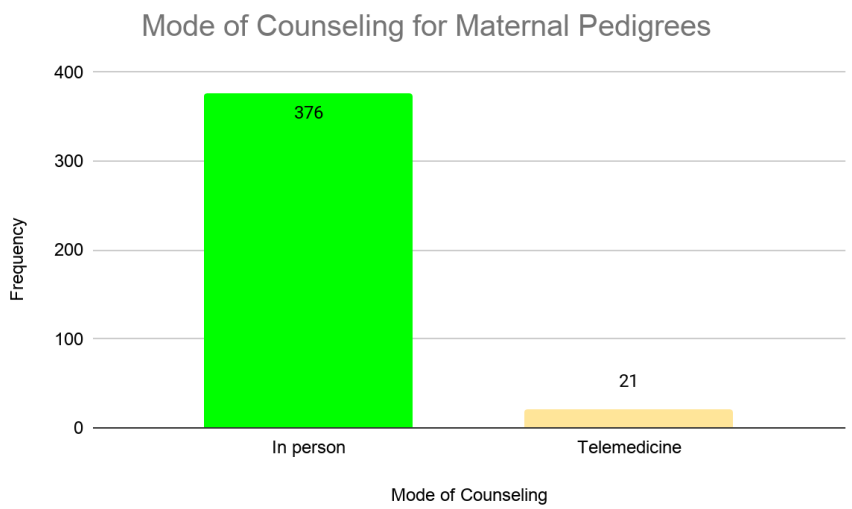
	Type of Maternal Cancer History Reported		
	All Known or Some Unknown Cancer	All Unknown Cancer	Total
Asian	57 (95.0%)	3 (5.0%)	60
Black	14 (73.7%)	5 (26.3%)	19
Hispanic/Latina	35 (87.5%)	5 (12.5%)	40
Non-Hispanic White	62 (93.9%)	4 (6.1%)	66

B

	Type of Paternal Cancer History Reported		
	All Known or Some Unknown Cancer	All Unknown Cancer	Total
Asian	29 (90.6%)	3 (9.4%)	32
Black	7 (77.8%)	2 (22.2%)	9
Hispanic/Latino	20 (76.9%)	6 (23.1%)	26
Non-Hispanic White	43 (95.6%)	2 (4.4%)	45

Table 4A: Type of cancer history reported for maternal pedigrees with cancer by ethnicity. The comparison of the type of cancer history reported in maternal pedigrees with cancer showed a significant difference by ethnicity (chi-square = 9.240, degrees of freedom = 3, p = 0.026).
Table 4B: Type of cancer history reported for maternal pedigrees with cancer by ethnicity. The comparison of the type of cancer history reported in paternal pedigrees with cancer did not show a significant difference by ethnicity (chi-square = 6.728, degrees of freedom = 3, p = 0.081).

A



B

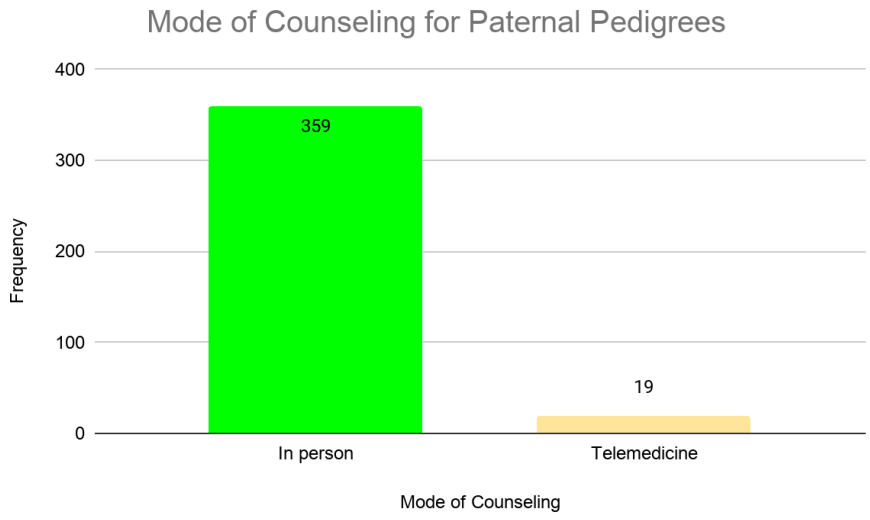


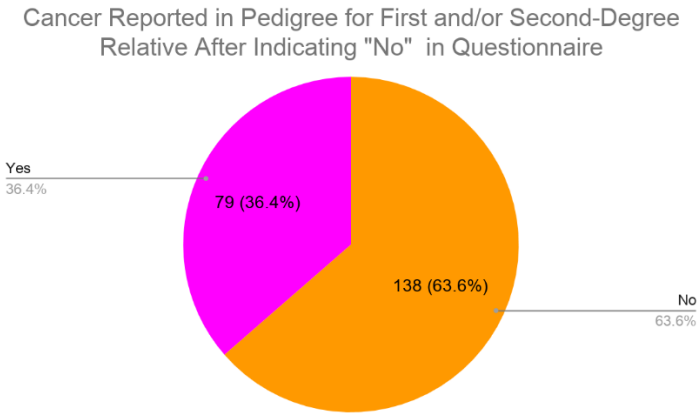
Figure 9: Mode of counseling for prospective parents' pedigrees. The number of pedigrees taken during an in-person visit versus those obtained during a telemedicine visit is shown for both maternal pedigrees (Figure 9A) and paternal pedigrees (Figure 9B).

Reporting of Cancer in Questionnaire

The responses recorded for each of the questionnaires in the prenatal charts reviewed are shown in Figure 10. Of note, the prenatal charts in which the mode of counseling was through telemedicine did not have a questionnaire provided to the prospective parents prior to their appointment. Furthermore, those questionnaires where "unknown" was indicated for whether there was a relative on the prospective mother or prospective father's side of the family with cancer are not part of the data reflected in Figure 10.

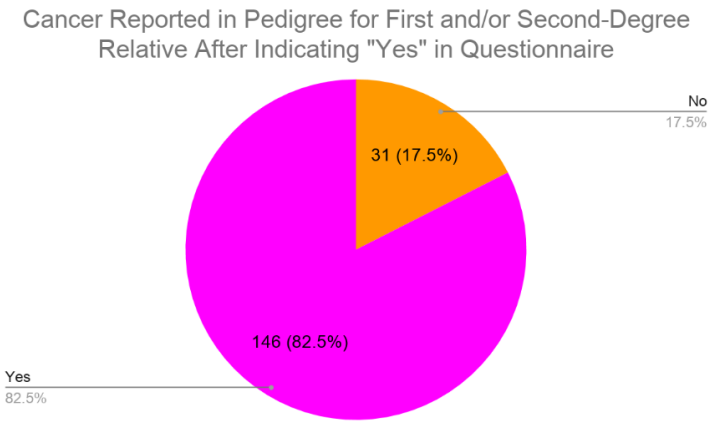
Based on the data collected, the responses noted in the questionnaire did not always correspond to what was reported on the pedigree. Specifically, from the 217 questionnaires in which cancer was not recorded to be present in a relative from either prospective parent, 79 of the individuals (36.4%) actually reported there to be a first- and/or second-degree relative affected with cancer when the pedigree was elicited. Conversely, in 177 questionnaires in which cancer was recorded to be present in a family member from any of the prospective parents, 31 of the individuals (17.5%) did not report cancer in a first- and/or second-degree relative in the pedigree.

A



Total number of questionnaires with “No”
N= 217

B



Total number of questionnaires with “Yes”
N = 177

Figure 10: Comparison of cancer reporting for first- and/or second-degree relative in pedigrees to responses recorded in questionnaires. Figure 10A shows the comparison of cancer reporting for first-and/or second-degree relative in pedigrees to questionnaires in which no cancer was indicated. Figure 10B shows the comparison of cancer reporting for first-and/or second-degree relative in pedigrees to questionnaires in which cancer was indicated.

Data Analysis

A Poisson regression was utilized to model whether ethnicity and other predictors were significant factors in determining how many relatives were reported to be affected with cancer. One of the reasons why the Poisson regression was considered relevant to use is because it can take into account differences in family size between each ethnic group.

For maternal pedigrees, the independent variables entered included ethnicity, age group, use of an interpreter, and the total number of first- and second-degree relatives reported. The dependent variable was total number of relatives affected with cancer. Ethnicity and use of an interpreter were significant predictors in determining the total number of relatives affected with cancer (see Table 5 on the next page). For ethnicity, coefficients from the Poisson regression established that non-Hispanic Whites had the highest percentage of cancer reported for first- and second-degree relatives followed by Asians and African Americans. Hispanics/Latinas were modeled to report cancer the least in first- and second-degree relatives compared to the other three ethnic groups. Regarding interpreter use, the model determined that use of an interpreter resulted in less cancer being reported in first- and second-degree relatives. When an interpreter was not used, there was about 91% more cancer reported in relatives of maternal pedigrees compared to maternal pedigrees where an interpreter was used. Age group was not found to be a significant predictor in determining how many relatives in maternal pedigrees were reported to be affected with cancer in the model.

Table 5: Poisson regression output for maternal pedigrees

Poisson Regression (Maternal Pedigrees)							
Parameter	**B**	**Standard Error**	**DF**	**Significance**	**Exp (B)**	**Lower**	**Upper**
(Intercept)	-0.562	0.3078	1	0.068	0.570	0.312	1.042
[Mat ethnicity=Asian]	-0.446	0.1358	1	0.001	0.640	0.491	0.836
[Mat ethnicity=Black]	-0.549	0.1875	1	0.003	0.578	0.400	0.834
[Mat ethnicity=Hispanic/Latina]	-1.059	0.1765	1	< 0.001	0.347	0.246	0.490
[Mat ethnicity=White]	0[a]				1		
[Mat age group=18-34.9]	-0.068	0.1153	1	0.555	0.934	0.745	1.171
[Mat age group=35 and older]	0[a]				1		
[Use of an interpreter (Y/N)=N]	0.648	0.2697	1	0.016	1.912	1.127	3.244
[Use of an interpreter (Y/N)=Y]	0[a]			.	1		
Mother's total # of 1st and 2nd degree relatives	0.014	0.0084	1	0.087	1.015	0.998	1.031
(Scale)	1[b]						
Dependent Variable: Mother's total number of first- and second-degree relatives affected with cancer							
Independent Variables: Maternal ethnicity, Maternal age group, Use of an interpreter							
Model Offset: Mother's total number of first- and second-degree relatives							

Mat = Maternal DF= Degrees of Freedom Y = Yes N = No
Lower = Lower bound of 95% Confidence Interval for Exp (B)
Upper= Upper bound of 95% Confidence Interval for Exp (B)
a: Set to zero because this is the reference group
b: Fixed at the displayed value

A similar approach was used for the paternal pedigrees. The independent variables entered included ethnicity, presence or absence of prospective father during the appointment, age group, use of an interpreter, and the total number of first- and second-degree relatives reported.

The dependent variable was total number of relatives affected with cancer. Ethnicity and presence or absence of the prospective father were significant predictors in determining the total number of relatives affected with cancer (Table 6). Similar to the model for the maternal pedigrees, coefficients from the Poisson regression determined that non-Hispanic Whites had the highest percentage of cancer reported for first- and second-degree relatives. Asians and Hispanics followed, while African Americans were modeled to report cancer the least in first-

and second-degree relatives compared to the other three ethnic groups. In addition, when the prospective father was not present in the visit, the model determined that cancer was reported in relatives about 55% less frequently in comparison to when the father was present in the visit. The model did not find age group and use of an interpreter to be significant predictors in determining how many relatives in paternal pedigrees were reported to be affected with cancer.

Table 6: Poisson regression output for paternal pedigrees

Poisson Regression (Paternal Pedigrees)							
Parameter	**B**	**Standard Error**	**DF**	**Significance**	**Exp (B)**	**Lower**	**Upper**
(Intercept)	-0.544	0.3730	1	0.145	0.580	0.279	1.206
[FOP ethnicity=Asian]	-0.410	0.1750	1	0.019	0.664	0.471	0.935
[FOP ethnicity=Black]	-1.045	0.3253	1	0.001	0.352	0.186	0.665
[FOP ethnicity=Hispanic/Latino]	-0.872	0.2157	1	< 0.001	0.418	0.274	0.638
[FOP ethnicity=White]	0[a]				1		
[FOP present in appointment (Y/N)=N]	-0.795	0.1663	1	< 0.001	0.452	0.326	0.626
[FOP present in appointment (Y/N)=Y]	0[a]				1		
[FOP age group=18-34.9]	-0.169	0.1569	1	0.283	0.845	0.621	1.149
[FOP age group=35 and older]	0[a]				1		
[Use of an interpreter (Y/N)=N]	0.178	0.2999	1	0.552	1.195	0.664	2.152
[Use of an interpreter (Y/N)=Y]	0[a]				1		
FOP's total # of 1st and 2nd degree relatives	0.036	0.0117	1	0.002	1.037	1.014	1.061
(Scale)	1[b]						
Dependent Variable: Father's total number of first- and second-degree relatives affected with cancer							
Independent Variables: FOP ethnicity, FOP present in appointment, FOP age group, Use of an interpreter							
Model Offset: Father's total number of first- and second-degree relatives							

FOP = Father of the pregnancy DF= Degrees of Freedom Y = Yes N = No
Lower = Lower bound of 95% Confidence Interval for Exp (B)
Upper= Upper bound of 95% Confidence Interval for Exp (B)
a: Set to zero because this is the reference group
b: Fixed at the displayed value

Lastly, a Poisson regression was used to model whether ethnicity and other predictors were significant factors in determining how many relatives were reported to be affected with cancer when analyzing each ethnic group as a whole (i.e. including both maternal and paternal

pedigrees). The independent variables entered included ethnicity, whether the pedigree was maternal or paternal, presence or absence of prospective father during the appointment, use of an interpreter, and total number of first- and second-degree relatives reported The dependent variable was total number of relatives affected with cancer. Ethnicity, presence or absence of the prospective father, and use of an interpreter were significant predictors in determining the total number of relatives affected with cancer (refer to Table 7 on the next page). Coefficients from the Poisson regression determined that the non-Hispanic White group as a whole had the highest percentage of cancer reported for first- and second-degree relatives followed by Asians and African Americans. Hispanics/Latinos(as) were modeled to report cancer the least in these relatives compared to the other three ethnic groups. Furthermore, when the prospective father was not present in the appointment, cancer was reported in relatives approximately 58% less compared to when the father was present in the appointment. In terms of interpreter use, there was approximately 55% more cancer reported in pedigrees when an interpreter was not used compared to pedigrees elicited when an interpreter was used during the visit. The model did not find significant differences in cancer reporting between maternal and paternal pedigrees when taking into account the presence of the prospective father in the appointment.

Table 7: Poisson regression output for all pedigrees analyzed

Poisson Regression (All Pedigrees)							
Parameter	**B**	**Standard Error**	**DF**	**Significance**	**Exp (B)**	**Lower**	**Upper**
(Intercept)	-0.595	0.2437	1	0.015	0.552	0.342	0.889
[MatorPat=Mat]	0.079	0.1059	1	0.458	1.082	0.879	1.331
[MatorPat=Pat]	0[a]				1		
[Parent ethnicity=Asian]	-0.423	0.1069	1	< 0.001	0.655	0.531	0.808
[Parent ethnicity=Black]	-0.688	0.1605	1	< 0.001	0.502	0.367	0.688
[Parent ethnicity=Hispanic/Latino(a)]	-1.013	0.1367	1	< 0.001	0.363	0.278	0.475
[Parent ethnicity = White]	0[a]				1		
[FOP present in appointment(Y/N)=N]	-0.860	0.1604	1	< 0.001	0.423	0.309	0.580
[FOP present in appointment(Y/N)=Y]	0[a]				1		
[Use of an interpreter (Y/N)=N]	0.440	0.1990	1	0.027	1.553	1.051	2.293
[Use of an interpreter (Y/N)=Y]	0[a]				1		
Parent's total # of 1st and 2nd degree relatives	0.022	0.0067	1	0.001	1.022	1.009	1.035
(Scale)	1[b]						
Dependent Variable: Parent's total number of first- and second-degree relatives affected with cancer							
Independent Variables: Parent ethnicity, FOP present in appointment, Use of an interpreter							
Model Offset: Parent's total number of first- and second-degree relatives							

Mat = Maternal Paternal = Paternal
FOP = Father of the pregnancy DF= Degrees of Freedom Y = Yes N = No
Lower = Lower bound of 95% Confidence Interval for Exp (B)
Upper= Upper bound of 95% Confidence Interval for Exp (B)
a: Set to zero because this is the reference group
b: Fixed at the displayed value

DISCUSSION

Ethnic Differences in Cancer Reporting

Based on the results of this study, it is evident that there are significant differences in cancer reporting for first- and second-degree relatives between different ethnicities. Hispanics/Latinos(as), Asians, and African Americans reported cancer in first- and second-degree relatives less often than non-Hispanic Whites. It is important to emphasize that despite this finding, there are subgroups within these ethnicities that differ from each other and this study did not analyze differences in cancer reporting within these subgroups. Therefore, caution should be exercised if attempting to generalize these results to subgroups within these particular ethnic groups.

It is worth mentioning that this study was not designed to infer whether differences in cancer reporting for relatives exist due to a reduction in cancer incidence. However, further comparisons were performed to investigate whether the degree of differences in cancer reporting by families is greater than the differences in cancer incidence rates for the different ethnic groups as determined by the CDC. Cancer incidence data from the CDC was averaged for men and women, and cancer incidence rate ratios were obtained by comparing cancer incidence in non-Hispanic Whites relative to Hispanics, Asians, and Blacks (CDC.gov). The incidence rate ratios of cancer in Hispanics, Asians, and Blacks are 75.9%, 64.8%, and 97.8% that of non-Hispanic Whites, respectively.

Estimated cancer incidence rate ratios from the Poisson regression analyzing all pedigrees by ethnicity (Table 7) were used to compare incidence rate ratios in the study to

incidence rate ratios from the CDC data. The cancer incidence rate ratios obtained in the study were assessed using 95% confidence intervals. When looking at the minority groups, the incidence rate ratios in Hispanics and Blacks differed significantly from the incidence rate ratios obtained using CDC data (Table 8). Specifically, in Hispanics the incidence rate ratio in the study was estimated to be 36.3%, which was distinct from the 75.9% incidence rate ratio based on the CDC data. Similarly, the incidence rate ratio for Blacks in the study was estimated to be 50.2%, which was different from the 97.8% incidence rate ratio as determined by the CDC. In Asians, the incidence rate ratio was estimated to be 65.5% in the study, which is not different from the 64.8% incidence rate ratio derived from the CDC data. Of note, it is possible that the incidence rate ratio for cancer reporting in pedigrees appears higher for Asians in this study since the effect of age was not taken into account in the Poisson regression model used. Asians had a higher proportion of individuals who were 35 years and older. Nevertheless, it is striking that even though CDC cancer incidence rate ratios are lower in Hispanics and Blacks compared to non-Hispanic Whites, the rate that individuals from these ethnicities report cancer in their families based on data in this study are significantly lower.

Table 8: CDC cancer incidence rate ratios compared to study cancer incidence rate ratios

	CDC Data		Current Study Data
	*Average male and female incidence rate per 100,000	Cancer incidence rate ratio to non-Hispanic Whites	Cancer incidence rate ratio to non-Hispanic Whites *(95% Confidence Intervals)*
Non-Hispanic White	438.8	1.000	1.000
Hispanic	333.0	0.759	0.363 *(0.278, 0.475)*
Asian	**284.2	0.648	0.655 *(0.531, 0.808)*
Black	429.1	0.978	0.502 *(0.367, 0.688)*

Current study data incidence rate ratios are estimates based on Poisson Regression output
*Incidence rates per CDC.gov data for 2017
**Asian: Asian and Pacific Islander for CDC data

Overall, it seems that population differences in cancer incidence cannot fully explain the reduced cancer reporting of relatives in Hispanic and Black populations. Ideally, age should have been taken into account in the Poisson regression used to obtain cancer incidence rate ratios for all ethnic groups in the study. If that was the case, it is possible that reduced cancer reporting in Asians could have also not been explained by differences in population cancer incidence rates. Furthermore, it is worth mentioning that Ashkenazi Jewish individuals were not separated from the non-Hispanic White group in the CDC data as it was in this study. Regardless, there are some possible causes that should be considered to interpret the differences in cancer reporting observed. Reasons such as stigma or privacy associated with cancer, low health literacy, lost or unknown family history, and medical mistrust of the healthcare system may contribute to the reduction in cancer reporting in some minority populations.

The results obtained in this study align to some extent with what has been observed in former studies. When analyzing differences in reporting a family history of cancer in a cancer genetic counseling clinic, cancer among relatives was reported less frequently when patients and their families are of Hispanic or Asian ethnicity (Maves et al., 2020). Ponce et al. (2012) also noted significant differences in the degree that Latinos and Asians reported a family history of breast and colorectal cancer compared to non-Hispanic Whites. Another study also found that the frequency that individuals reported a parent to be affected with cancer was significantly lower in Hispanics, Asians, and African Americans relative to non-Hispanic Whites (Pagán et al., 2009). Therefore, the findings from this study together with those from previous studies ultimately bring to attention reduced cancer reporting in some minority populations.

There are different approaches that can be implemented if genetic counselors and other healthcare professionals are aware that cancer may be under-reported in some ethnic minorities.

Staff can encourage patients to obtain family cancer and health history ahead of their appointment in order for the genetic counselor to provide an accurate risk assessment. This is particularly important in a prenatal genetic counseling setting, since the prenatal clinic may be the only time a comprehensive family health history for the purpose of risk assessment is obtained for a patient. Facilitating ways to identify families at an increased risk for cancer in a prenatal clinic could be valuable in order to provide for referral to a cancer clinic. Furthermore, the prenatal genetic counselor can also discuss with the patient the importance and benefits of knowing one's family history of cancer in terms of screening recommendations and medical management. This could also include educating patients of the importance of learning about the specific types of cancer in affected family members, since our study found that Black women were less likely to know the types of cancers present in their family history (see Table 2). If genetic counselors and other healthcare professionals recognize that certain patient populations may report cancer less frequently, then specific strategies can be utilized to improve health outcomes in the presence of possible truncated family histories.

Cancer Reporting in Questionnaires

Another relevant finding from our study was under-reporting of a family history of cancer in questionnaires completed prior to clinic. In approximately 18% of questionnaires where prospective parents indicated they had at least one family member affected with cancer, cancer was not reported in a first- and/or second-degree relative in the pedigree. However, for this particular case, it is possible that there were more distant relatives affected with cancer in the pedigree. On the other hand, it is noteworthy that in about 36% of questionnaires where prospective parents indicated that no family member had cancer, cancer was reported in at least

one first- and/or second-degree relative when eliciting the family pedigree during the appointment. This highlights the importance of genetic counselors using a pedigree during a genetic counseling visit. A questionnaire can be useful in helping patients start thinking about their family health history and enhance their ability to recall family members with significant health concerns, including cancer, before their visit. However, the family pedigree is able accomplish this and has other associated benefits.

There are many possible reasons that could explain the under-reporting of cancers in questionnaires completed prior to a genetic counseling visit. The time allocated in obtaining a pedigree during a genetic counseling appointment may allow patients an additional opportunity to recall more information about their family's health history in comparison to what was marked on the questionnaire. Similarly, it is possible that having the genetic counselor dedicate time to elicit a pedigree might help patients better understand the importance of family health history and consequently reveal more than what they indicated when filling out the questionnaire. Another likelihood worth considering is that patients might have simply wanted to avoid delays in starting their genetic counseling visit and thus not dedicate too much time in filling out the questionnaire as accurately as possible. Due to its utility in identifying affected family members, a family pedigree should continue being a fundamental tool that genetic counselors and other healthcare professionals should utilize to identify families at an increased risk for cancer.

Gender Differences in Cancer Family History Reporting

Our study also found no significant differences in cancer reporting in relatives between females and males when taking into account the presence of the male partner in the prenatal

appointment. It is interesting that when not considering the presence or absence of the prospective father into the Poisson regression, the model determined that more cancer was reported in maternal pedigrees compared to paternal pedigrees. It is possible that even though the prospective father was present in the appointment, the prospective mother might have known more about the father's cancer family history than the father himself. Nevertheless, this finding is different from what has been mostly reported in the literature, where women tend to have more knowledge about their cancer family history compared to men (Krakow et al., 2020).

This finding raises implications for the prenatal genetic counseling clinic. Since cancer reporting in maternal and paternal pedigrees was similar when the prospective father was present, but was significantly reduced when the prospective father was absent, then women should be encouraged to come with their partner to a prenatal genetic counseling appointment to allow for the most accurate risk assessment. This may also assist with the risk assessment for other conditions as well besides cancer. In families of a lower socioeconomic status, it is not always possible for the prospective father to be present in the prenatal appointment because of the inability to take time off from work. Also, depending upon the relationship, it may be more uncomfortable for the prospective mother to have the father of the pregnancy present or he may not want to be in the prenatal visit. Therefore, mechanisms should be employed that would facilitate the ability to obtain more comprehensive and accurate family health information from the prospective father. These can include acquisition of the prospective father's family cancer and health history ahead of the prenatal appointment, obtaining information from the prospective father in a remote fashion during the session, and having other paternal or maternal family members attend the appointment either in person or remotely who are aware of the father's family health history. Providing the option for the prospective father's or mother's relatives to

attend the appointment remotely would be especially relevant in addressing potential barriers such as geographical location. These are some methods that can be used to help identify prospective fathers and their family members who may be at an increased risk for cancer, thereby allowing them to obtain further counseling as needed.

Effect of Interpreter Use in Cancer Reporting

Based on our study, the use of an interpreter during the prenatal genetic counseling appointment resulted in less cancer being reported in pedigrees. While medical interpreters can be a valuable member of the healthcare team for individuals with limited English proficiency, there are certain issues that can occur when using an interpreter during a genetic counseling visit. These can include errors or information being lost in interpretation when the genetic counselor and patient are communicating via an interpreter to elicit the family pedigree. In addition, sometimes there are time constraints associated with appointments performed with the help of an interpreter. Using an interpreter typically adds time to the session, since information has to be repeated. If the session is complex, this would add even more time to the session. Furthermore, there can be a waiting time in getting an interpreter on the visit. These issues could possibly explain why less cancer was reported in pedigrees elicited via an interpreter.

Some strategies to streamline sessions with an interpreter could be to attempt to obtain a family pedigree ahead of time using telemedicine. In addition, providing patients with resources including brochures or videos in their native language emphasizing the importance of being aware of one's family history prior to their appointment could help patients start thinking if they have relatives affected with cancer or other heritable conditions. Examples of these resources

include tailored family health history tools created for the community by organizations such as Genetic Alliance, who provide brochures in different languages including Spanish and Tagalog to promote conversations about health within the family (Edelson et al., 2010). During the prenatal appointment itself, the genetic counselor can verify the cancers reported in the pedigree and provide an opportunity for the patient to report any additional relatives affected with cancer. This is an area worth investigating further since cancer reporting disparities in minorities might be widened if communication barriers exist.

Limitations

One limitation to the study was that all the information compiled was from a single prenatal clinic in southern California. In terms of the pedigrees that were analyzed, all referral indications were considered and this, together with the use of a random number generator, was an attempt to prevent an ascertainment bias that could have influenced the results obtained. However, there may be other systematic differences between the patients of different ethnic groups that were not identified, which may have affected the results of this study. Furthermore, in instances where more than one country of origin was reported in the pedigree, there was a level of assumption in designating ethnicity to that particular pedigree (refer to Methods section).

Other limitations to the study included the consideration of each shorthand "n" inside a diamond to be counted as one individual in all pedigrees. This approach could have led to an underestimate of the total number of relatives in each pedigree. Given that the study involved a retrospective chart review, it was not practical or possible to define the actual number of relatives for each of the pedigrees with this notation. If pedigrees for certain ethnic groups had a higher

number of this shorthand notation, this could have led to an overestimate of the cancer family history reporting for those particular groups. A future study could include the incidence of the shorthand notation when analyzing differences in cancer reporting between different ethnicities.

Future Directions

Areas that would be relevant to investigate in future studies regarding cancer reporting in pedigrees include length of residency in the United States or level of education. Although the occupation of both the prospective mother and father were indicated in most of the questionnaires from the prenatal charts reviewed, information about length of residency in the United States and level of education were not available in this study. These might have been included in the analysis to assess if these factors are also predictors in determining the number of relatives reported with cancer in a family pedigree. Other areas of research could involve studying cancer reporting in other major ethnic groups, including Middle Eastern, or within subgroups in the ethnicities that were part of this study.

In addition, more research focused on family communication about cancer in minority populations is warranted to better understand facilitators and barriers in communication regarding health-related issues among family members. This is especially crucial given the findings from this study and previous studies that indicate cancer being under-reported in ethnic minorities. Lastly, there were very few pedigrees collected via telemedicine. Thus, there was not enough power to detect significant differences in cancer reporting for pedigrees obtained during in-person visits versus those obtained during the COVID-19 pandemic. A future study

could be designed to analyze if cancer reporting differences exist depending on the mode of counseling used to elicit the pedigree.

Conclusion

Cancer among relatives is reported less frequently in family pedigrees when individuals and their families are Hispanic, Asian, and African American. Differences in cancer reporting could not be fully explained by population differences in cancer incidence based on CDC data for Hispanics and Blacks. Therefore, differences in cancer reporting suggest that cancer histories in some minority populations may be truncated. Some reasons that could explain reduced cancer reporting in relatives of these ethnicities include stigma or privacy associated with cancer, low health literacy, lost or unknown family history, and medical mistrust of the healthcare system. This is important in a prenatal genetic counseling setting since the prenatal clinic may be the only time a comprehensive family health history is obtained. Knowing one's cancer family history can help genetic counselors provide an appropriate risk assessment, guide cancer screening recommendations, and refer families at increased risk for cancer to a cancer genetics clinic if warranted.

This study highlights the need for more efforts to educate ethnic minorities of the importance and benefits in sharing cancer history within their families. Recognition of patient populations who may be at risk for limited knowledge of a cancer family history is critical so that healthcare professionals can use effective strategies to address the possibility of truncated family pedigrees. Increasing awareness of the value of family cancer history can ultimately help reduce some of the cancer health disparities that are prevalent in some of these racial and ethnic groups in the United States.

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