# **Evaluation of Family** and Community Social Network **Characteristics Among High-Risk Family Members to Improve** Cancer-Related Health Behaviors

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**OBJECTIVES:** To evaluate the effects of social network characteristics of individuals with a family history of cancer on the use of cancer-related services (e.g., screening, genetic counseling/testing).

SAMPLE & SETTING: 170 family members of individuals with the most common hereditary or familial cancers.

METHODS & VARIABLES: Data collection occurred between March and September 2021 using an online survey.

RESULTS: Having strong within-immediate family relationships and family members who underwent more screening procedures was associated with increased breast cancer screening, and having more family members with cancer was associated with colorectal cancer screening. Having a large family, having family members who underwent screening for more cancers, and having strong social cohesion among families were associated with an increased rate of genetic testing.

IMPLICATIONS FOR NURSING: Nurses working with families affected by cancer should focus on strategies to strengthen relationships among family members to improve knowledge of cancer screening and available genetic services.

KEYWORDS family history of cancer; cancer-related health behaviors; social networks; cancer risk ONF, 50(6), 735-751.

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ancer is the second leading cause of death in the United States after cardiovascular disease, and it is expected to exceed cardiovascular disease as the leading cause of death within the next decade (American Cancer Society [ACS], 2023a). The best strategies in cancer control are the management of known risk factors, protective measures against these factors, and early detection when cancer may have a higher potential for successful treatment (Elmore et al., 2021; Rebbeck et al., 2018). Numerous factors are known to increase cancer risk, including potentially modifiable (e.g., tobacco use, excess body weight) and nonmodifiable (e.g., age, inherited genetic variants) factors. Although an inherited risk is associated with only a small proportion of cancers, a family history of cancer is a significant nonmodifiable risk factor, particularly for breast, ovarian, and colorectal cancers (ACS, 2023a). A family history of cancer is not synonymous with hereditary cancer; however, it may reflect the inheritance of genetic variations that increase risk in concert with similar exposures to behavioral and environmental factors among family members (ACS, 2023a; Bertoni et al., 2019; Bostean et al., 2013).

Screening guidelines for breast or colorectal cancer recommend tailored screening and lifestyle recommendations for high-risk individuals to maximize the reduction of cancer incidence, morbidity, and mortality (Kolb et al., 2020; National Comprehensive Cancer Network [NCCN], 2021, 2023b; Smith et al., 2019). For instance, women at high risk for breast and ovarian cancer have options such as risk-reducing agents (e.g., tamoxifen, raloxifene) and risk-reducing surgery (e.g., mastectomy, oophorectomy) in addition to tailored breast cancer screening (NCCN, 2023b). Based on an individual's family history of cancer, healthcare providers can refer individuals to genetics consultation with a specialist to gather a detailed family history, conduct a risk assessment, educate, counsel, and order genetic testing if needed (American College of Obstetricians and Gynecologists Committee on Practice Bulletins-Gynecology, 2017).

Successful implementation and uptake of cancer screening, such as for breast and colorectal cancer, in the United States has led to a meaningful decline in incidence and mortality for these cancers (ACS, 2023a; Elmore et al., 2021). However, screening uptake in individuals with a family history of breast or colorectal cancer remains suboptimal. Although some studies report a higher (Bronner et al., 2013; Tsai et al., 2015) or similar participation rate (Takeuchi et al., 2020) in cancer screening than the average-risk population, evidence shows the underutilization of cancer screening among high-risk individuals (Erdoğan & Tuzcu, 2020), particularly among racial and ethnic minority groups (Bostean et al., 2013). Some factors may affect the underutilization of cancer screening, including younger age, having limited or no access to care (Wu et al., 2007), a low rate of referral from healthcare providers (Wood et al., 2014), and risk perception of cancer among high-risk individuals (Paalosalo-Harris & Skirton, 2017). Studies on factors affecting the decision to participate in cancer screening and/or genetic counseling among highrisk populations have focused on individual factors (e.g., risk perception, sociodemographic) (Paalosalo-Harris & Skirton, 2017; Seven et al., 2018; Turbitt et al., 2019), risk communication among patients with cancer and their family members, and outcomes among family members without their perspectives (Alegre et al., 2019; Bertoni et al., 2019; Koehly et al., 2003; Ratnayake et al., 2011; Seven et al., 2022). Although compelling evidence suggests a strategic focus on high-risk populations in cancer control (Hemminki et al., 2021; Kolb et al., 2020; Loomans-Kropp & Umar, 2019; Rebbeck et al., 2018), a better understanding of cancer-related health behaviors among individuals with a family history of cancer is needed. Because the small body of relational research has shown mixed results on how friends and family members may influence screening behaviors (Allen et al., 1999; Ashida et al., 2011; Keating et al., 2011), the aim of this study was to evaluate the effects of social network characteristics of individuals with a family history of cancer on the use of cancer-related services (e.g., cancer screening, genetic counseling and testing). Understanding these characteristics can aid in the development of multilevel and targeted interventions to improve risk assessment and the use of screening and genetic services, particularly in high-risk populations.

## Methods

## **Study Design and Participants**

This descriptive, cross-sectional study consisted of 170 family members of individuals with the most common types of hereditary or familial cancer. The inclusion criteria were being aged older than 18 years; having a first- or second-degree family member (e.g., parent, sibling, child, grandparent, uncle, aunt) diagnosed with breast, ovarian, or colorectal cancer; and living in the United States. Individuals with a personal history of cancer were excluded.

#### **Data Collection**

Recruitment was conducted using four main strategies: mailing lists, advertisements on the Facing Our Risk of Cancer Empowered website (www.facingour risk.org), information posted on the website of the College of Nursing at the University of Massachusetts Amherst, and social media. An invitation with the study survey link was sent to potential participants using student and faculty email distribution lists and shared on the College of Nursing website. Facing Our Risk of Cancer Empowered is a group that seeks to improve the lives of individuals with cancer and their families. The Facing Our Risk of Cancer Empowered website has a research and clinical trials page, which shares ongoing studies with its members who may be interested in participating. The research team also shared the survey link multiple times via X, formerly known as Twitter, and Facebook.

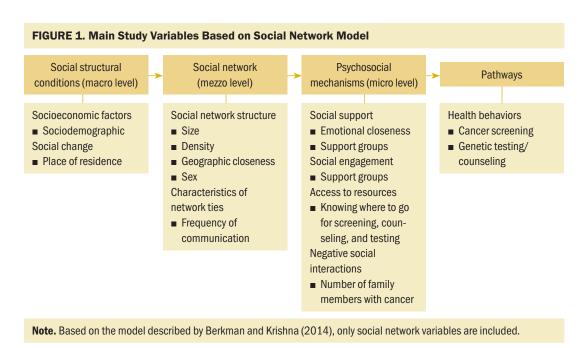
The study was approved by the institutional review board at the University of Massachusetts Amherst. Data collection occurred between March and September 2021 through an online survey. Potential participants were asked to answer screening questions on Qualtrics about their personal and family history of cancer to assess eligibility. Eligible participants provided consent before completing the survey, which took about 35-40 minutes to complete. If participants provided their email address after completing the survey and passed a validity check to rule out automated bots, they were reimbursed \$20 for their time. Because the online data collection relied on self-report of family history and behaviors, the research team took several steps to evaluate valid responses, including omitting those whose email validation code did not match the one provided at the beginning of the survey (n = 269), those who were screened out during initial questions (n = 13), those who skipped through required demographic questions presumably to obtain the participation incentive (n = 6), and those with non-U.S. IP addresses (n = 4). Of note, a small proportion of these participants (n = 15) appeared to have responded to the survey from an IP address already in use by another participant, indicating that they may have shared a residence. A series of analyses where standard errors (SEs) were clustered based on IP address rather than participant ID were not meaningfully different, so analyses were performed with participant ID as the cluster variable. Therefore, responses from 170 participants were included in the analytic study sample.

## Instruments

The researchers developed the study instrument based on a theoretical model of how the existence and characteristics of social networks influence health and health-related behaviors (Berkman & Krishna, 2014), such as cancer screening and genetic counseling. This model describes a cascading causal process from the macrosocial to the psychobiologic mechanisms that are dynamically linked to form social integration, affecting health behaviors (Berkman & Krishna, 2014). In addition to individual attributes, the researchers aimed to understand how the larger

macrosocial context (e.g., place of residence) and the influences of network characteristics (e.g., size, the density of the individual family network, relationships with and among family members) and function (e.g., frequency of communication) affect the use of cancer screening and genetic services among an at-risk population. The focus was on the attributes of the relationships within a family (treated here as an individual's social network), which may shape the risk management behaviors of individuals at higher risk for cancer because of family history. Figure 1 depicts the social network variables investigated in this study based on the social network model described by Berkman and Krishna (2014).

The instrument consisted of 31 questions within five sections to capture the social network and descriptive characteristics of participants. These sections were as follows: (a) sociodemographic characteristics (e.g., age, gender, employment, education level); (b) cancer-related health behaviors (e.g., cancer screening, genetic services); (c) family history of cancer characteristics (e.g., number of family members with cancer, cancer types of family members); (d) family network characteristics (e.g., family size; relationship characteristics, such as emotional closeness, frequency of communication, and geographic closeness); and (e) community-level social network characteristics (e.g., place of residence, use of social support groups, knowing where to go for cancer screening or genetic counseling and testing).



For the family network characteristics, participants were asked to list their 10 closest immediate family members (e.g., spouse, parents, siblings, children, grandparents, aunts, uncles, cousins) and their history of cancer. Various name interpreter questions were also asked to complement these name generator questions, including frequency of contact, type of communication, emotional closeness, and sociodemographic characteristics of each nominated family member. The number of family members nominated was measured as network size, and proxy reports of relationship closeness were used to measure network density, which is a measure of family social cohesion. For an undirected network (i.e., a relationship

between person 1 and family member 2 is assumed if 1 nominates 2 because family members of participants were not enrolled in the study themselves), this measure was calculated as  $T/[(N \times (N-1))/2]$ , in which T = number of identified between-family member ties, and N = number of named family members. The variables measured in the study are presented in Table 1.

## **Data Analysis**

Data were analyzed using IBM SPSS Statistics, version 25.0, and Stata, version 17.0. Before the analyses, data were examined and adequately managed for violation of statistical assumptions, such as missing data, lack of normal distribution, and outliers.

TABLE 1. Main Variables Measured	
Dependent Variable	Measure
Colonoscopy, genetic counseling/testing, and mammography	"Yes" or "no"
Independent Variable	Measure
Community-level network factors	
Attending support groups	"Yes" or "no"
Knowing where to go for cancer screening or genetic counseling/testing	"Yes" or "no"
Place of current residence	Rural, urban, or suburban; U.S. census geographic region
Family-level network factors	
Emotional closeness	Likert-type scale ranging from 1 (least close) to 10 (closest)
Family members' sex	Number of female, male, and nonbinary family members
Family members' screening procedures (Pap test, Pap/HPV test, fecal blood test, colonoscopy, mammogram, and genetic counseling/testing)	Number of procedures
Family members with cancer	Number of family members
Frequency of communication	Number of communications with family members per week
Geographic closeness	Scale ranging from farthest (live 5 hours away or greater) to closest (live together) $$
Network density (social cohesion)	Constructed based on participant responses of how close each named family member is to other named family members
Network size	Number of network members
Sociodemographic information of relatives (gender, education, and employment)	Categorical responses
Individual-level social structure factors	
Sociodemographic information (education, health insurance, and employment)	Categorical responses
HPV—human papillomavirus; Pap—Papanicolaou	

Egocentric social network analysis (Perry et al., 2018) included descriptive characterization and logit modeling with clustered SEs to evaluate the association between network characteristics of multiple members of social and family networks of family members (e.g., network size; network density to measure social cohesion; relationship closeness with family members; frequency of contact with family members; geographic distance from family members; number of previous cancer screening procedures of each family member, including genetic testing of each family member) and measures of the participant's own use of cancer-related services (e.g., screening for breast or colorectal cancer, genetic counseling and testing).

As a normative practice, the researchers first fit single-level models before attempting to fit multilevel models where characteristics of different family members were treated as nested within participants. The multilevel models were ill fitting because of model degeneracy and the relatively small sample size. The next best alternative was to estimate single-level logistic regression models in which multiple responses about each family member were treated as unique but clustered based on participant ID using robust SEs (i.e., data were formatted in "long" format to allow for multiple distinct family member values per participant ID). In this way, the researchers accounted for heterogeneity between the totality of participants' different family members' responses (by the participant), if not the heterogeneity in characteristics between each participant's family members. Therefore, single-level logistic regression modeling was used for each cancer-related outcome (mammography, colonoscopy, and genetic testing) while clustering on participant ID.

# **Results**

## **Descriptive Characteristics of Participants**

The sociodemographic characteristics of the participants are presented in Table 2. Most participants were non-Hispanic (n = 132, 78%), were White (n = 120, 71%), self-identified as female (n = 105, 62%), were employed (n = 102, 60%), and had some college education (n = 69, 41%). Of the participants who self-identified as female, 24% had given birth, and the average number of births was 1.8 (SD = 1, range = 0-4).

Participants' cancer-related health behaviors, including cancer screening, genetic testing and counseling, and other characteristics regarding knowledge of healthcare services, reasons to use genetic services, and communication of cancer risk with their family members, are presented in Table 3.

of Participants (N = 170)	_
Characteristic n	0,

Characteristic		"	/0
Age group (years)			
20-30 31-40 41-50 51 or older Missing data		52 36 28 16 38	31 21 17 9 22
Current region of residency <sup>a</sup>			
Northeast South West Midwest Missing data		52 41 41 22 14	31 24 24 13 8
Education level			
Some high school High school graduate Some college or technical sc or an associate degree College graduate or greater	hool,	18 47 69	11 28 41
Missing data		12	7
Employment status			
Part-time Student and/or working stud Full-time Unemployed Retired or other Homemaker Missing data	ent	84 32 18 13 5 4	49 19 11 8 3 2 8
Ethnicity			
Hispanic or Latinx Non-Hispanic or Latinx Missing data	1	37 132 1	22 78 1
Health insurance status			
Private health insurance <sup>b</sup> State health insurance None Federal insurance or other Missing data		83 45 24 3 15	49 27 14 2 9
Marital status			
Married or in a domestic part Single Divorced, separated, or wido Other		76 68 13 1	45 40 8 1
Missing data	Onational	12	7
	Continued on th	e next p	age

**TABLE 2. Sociodemographic Characteristics** of Participants (N = 170) (Continued)

Characteristic	n	%
Partner's education level (N = 76)		
Some high school High school graduate Some college, technical school, or an associate degree	10 26 26	13 34 34
College graduate or greater Missing data	13 1	17 1
Partner's employment status (N = 76)		
Part-time Full-time Homemaker Unemployed Retired Missing data	56 6 5 5 3	74 8 7 7 4 1
Perceived family income		
Sufficient Insufficient Did not answer or missing data	101 48 21	59 28 12
Race		
American Indian or Alaska Native Asian Black or African American Multiracial Native Hawaiian or Other Pacific Islander White Missing data	1 4 27 10 5 120 3	1 2 16 6 3 71 2
Sex identity		
Female Male Nonbinary Missing data	105 42 5 18	62 25 3 11
<sup>a</sup> Based on U.S. census data <sup>b</sup> With or without state insurance		

The rate of cancer screening was 34% for breast cancer and 49% for cervical cancer among women and 19% for colorectal cancer and 12% for lung cancer among all participants. Of the participants, 51 (30%) had seen a genetic counselor and underwent genetic testing. The most common motivations for deciding to use genetic services were a benefit to the family's future (n = 66, 39%) and an impact on future healthcare decisions (n = 66, 39%). Worry about data privacy/fear of

Note. Because of rounding, percentages may not total 100.

surveillance or breach of confidentiality was reported by eight (5%) participants.

Most participants (n = 124, 73%) had at least one first-degree relative with a history of cancer (see Table 4). A majority (n = 121, 58%) of participants reported having a parent or sibling (n = 39, 23%) diagnosed with breast (n = 59, 35%), ovarian (n = 34, 20%), and colorectal cancer (n = 32, 19%), with other cancers constituting a smaller proportion of participants.

Of all participants, 75 (57%) reported that they knew where to go for cancer screening. Among participants who self-identified as female, knowing where to go for cancer screening was significantly associated with having a Papanicolaou (Pap) test ( $\chi^2 = 106.891$ , p < 0.001); for all participants, it was associated with having a colonoscopy ( $\chi^2 = 125.856$ , p < 0.001). Most women (n = 46, 87%) who had a Pap test knew where to go for cancer screening, and most participants (n = 25, 78%) who had a colonoscopy knew where to go for cancer screening. In addition, having attended any support group was also associated with uptake of mammography ( $\chi^2 = 72.879$ , p < 0.001) and Pap testing for women ( $\chi^2$  = 66.627, p < 0.001) and with colonoscopies for all participants ( $\chi^2 = 112.631$ , p < 0.001). Participants who attended any support group tended to have undergone more cancer screening. However, the relationship between having a mammogram and knowing where to go for cancer screening was not significant ( $\chi^2 = 72.944$ , p > 0.005).

There were statistically significant relationships among attending support groups ( $\chi^2$  = 152.191, p < 0.001), knowing where to go for genetic testing ( $\chi^2$  = 1,230.849, p < 0.001), and undergoing genetic testing among participants. Of participants who had not undergone genetic testing, 68 (88%) did not know where to go if they needed genetic counseling or testing. Among those participants who had not undergone genetic testing or had seen a genetic counselor, 70 (91%) did not attend any support group for patients with cancer and families.

Table 5 shows the network characteristics of participants with 10 nominated immediate family members. The mean family size was 5.91 individuals (SD = 3.65), and the family tie density (weighted by closeness) was 0.31 (SD = 0.34) (range of observed values was 0-0.93, although theoretical network density ranged from 0 to 1). Participants reported an average geographic closeness of 3.67 (SD = 1.15) of 5, an emotional closeness of 7.95 (SD = 1.47) of 10, and communication with family members of 4.02 (SD = 0.99) of 5. Nominated family members were mostly female, with a proportion of 0.56 (SD = 0.25, range = 0-1).

TABLE 3. Participants' Cancer-Related Health Behavior Characteristics (N =	: 170)	
Characteristic	n	%
Cancer screening (N = 105°)		
Papanicolaou and human papillomavirus test  Mammogram  Papanicolaou test	52 36 32	49 34 30
Cancer screening		
Colonoscopy Fecal blood test Low-dose computed tomography scan	32 27 20	19 16 12
Referred to a genetic counselor		
No Yes Missing data	69 63 38	41 37 22
Have seen a genetic counselor		
No Yes Missing data	81 51 38	48 30 22
Have undergone genetic testing		
No Yes Missing data	77 51 42	45 30 25
Genetic testing results (N = 51)		
Positive Negative Variant of unknown significance Do not remember	30 18 2 1	59 35 4 2
Know where to go for cancer screening, if needed (N = 131)		
Yes No	75 56	57 43
Know where to go for genetic counseling, if needed (N = 129)		
No Yes Not sure	51 51 27	40 40 21
Have attended a support group for people affected by cancer (N = 129)		
No Yes	108 21	84 16
Factors affecting decision on whether to undergo genetic services		00
Benefit to family's future Impact on future healthcare decisions Total cost to me My primary healthcare provider's recommendation Whether insurance will cover genetic counseling Whether insurance will cover genetic testing	66 66 45 35 26 25	39 39 27 21 15
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TABLE 3. Participants' Cancer-Related Health Behavior Characteristics (N = 170) (Continued)					
Characteristic	n	%			
Factors affecting decision on whether to undergo genetic services (continued)					
Where the nearest genetics center is located	23	14			
Limited knowledge of genetics	20	12			
Too busy	19	11			
Clinic is too far from home.	18	11			
Ability to obtain genetic counseling by telephone	15	9			
Do not want to worry about having hereditary (familial) cancer	15	9			
No impact on future healthcare decisions	9	5			
Worry about data privacy/fear of surveillance or breach of confidentiality	8	5			
Feelings about talking with family about familial cancer risk					
Нарру	79	47			
Responsible or dutiful	73	43			
Anxious	48	28			
Like a burden	26	15			
Reasons for talking or not talking about familial/genetic cancer risk					
Financial issues	35	21			
Health issues	37	22			
Legalissues	17	10			
Religion	17	10			
Culture	6	4			

<sup>a</sup> Among participants who self-identified as female; n values include only the number of participants who answered "yes." Note. N values may not total 170 because only the number of participants who answered "yes" to each item are reported. Note. Because of rounding, percentages may not total 100.

# **Family Network Characteristics and Participant Cancer-Related Health Behavior Outcomes**

The next set of analyses estimated associations between family network characteristics and participants' cancer-related health behavior outcomes (mammography, colonoscopy, and genetic testing). The odds ratios of three sets of serially estimated regression models adjusted for participants' biologic sex at birth and age are reported in Table 6. The focal independent variable in the first three models in the series related to structural network characteristics (number of family members with cancer, number of nominated close family members, and network density among close family members), and the remaining nine variables related to screening procedures among family members (an aggregate number of all screening procedures by a nominated family member, and then individual mammography, Pap test, Pap/human papillomavirus infection test, colonoscopy, fecal blood test, computed tomography scan, surgery, and genetic testing). As reported in model 1 for breast cancer screening, a one-unit increase in family social

cohesion was associated with a 1.26-times greater likelihood of screening (SE = 0.12, p = 0.02). Model 2 showed likelihood of colonoscopy among participants, and for each family member with cancer reported by the participant, the likelihood of the participant's cancer screening increased by 2.4 (SE = 0.7, p = 0.003). Regarding genetic testing (model 3), there was a positive association between participant genetic testing and the number of family members reported (network size). The odds of genetic testing increased by 1.3 (SE = 0.08, p < 0.001) for each additional family member nominated, suggesting that individuals with comparatively larger family social networks are more likely to seek genetic testing. In addition, the odds of genetic testing increased by 1.3 (SE = 0.1, p = 0.001) for every one-unit increase in social cohesion.

Regarding family member screening behaviors, model 1 suggested that for each additional family member screening procedure, the odds of participant mammography increased by 1.4 (SE = 1.27, p = 0.004); most individual family member screening procedures were positively and significantly associated with the outcome. For model 2 (participant colonoscopy), evidence among all participants largely suggested that family member screening procedures were not associated with participant colonoscopy at conventional levels of significance, except for family member computed tomography scan and surgery being positively associated with the participant's own screening. The most robust and consistent associations were found with participant genetic screening (model 3), in which each additional family member screening procedure was associated with a 1.69-times greater likelihood of genetic screening (SE = 0.18, p < 0.001); most individual family screening procedures were associated with genetic testing, except for family member surgery.

## **Discussion**

This study explored the effects of individual-level, familial-level, and community-level social network

TABLE 4. Family History of Cancer Among First-Degree Relatives and Genetic Testing Status of Participants					
Characteristic		n	%		
Number of family members who had cancer					
At least 1 second-degree family member		46	27		
1 first-degree family member		103	61		
2 first-degree family members		11	6		
3 first-degree family members or more		10	6		
Characteristic	n	$\overline{\mathbf{X}}$	SD		
Average age of family members at the time of diagnosis (years)	112	9.9	9		
Relationship to the family member who had cancer					
Parent (mother or father)	121	0.58	0.47		
Sibling (brother or sister)	121	0.23	0.39		
Other relation	121	0.11	0.3		
Offspring (son or daughter)	121	0.08	0.24		
Cancer types of the family members with cancer					
Breast	121	0.35	0.46		
Ovarian	121	0.2	0.39		
Colorectal	121	0.19	0.37		
Lung	121	0.06	0.22		
Uterine	121	0.05	0.22		
Stomach	121	0.02	0.13		
Brain	121	0.01	0.1		
Pancreatic	121	0.008	0.09		
Thyroid	121	0.007	0.05		
Skin	121	0.004	0.05		
Not specified	121	0.1	0.27		
Participants underwent genetic testing					
No	115	0.52	0.48		
Yes	115	0.48	0.48		
Genetic testing results of the participants					
Proportion positive	115	0.32	0.45		
Proportion negative	115	0.08	0.25		
Proportion of variants of uncertain significance	115	0.04	0.19		
Proportion who did not know	115	0.1	0.3		

 $\textbf{Note.} \ \text{Among the family members of the } 121\ \text{participants who provided valid relationship information}, 9\ \text{observations were}$ missing valid age of diagnosis, and 6 observations were missing valid information on the genetic testing history and results.

characteristics on cancer-related health behaviors (e.g., cancer screening, genetic testing) among individuals with a family history of breast, ovarian, or colorectal cancer. Using a social network-focused framework for individuals nested in a family network provided more in-depth insight into why some at-risk individuals undergo genetic testing and counseling and participate in cancer screening and others do not.

Cancer screening reduces cancer mortality through the early detection and prevention of some cancers (e.g., breast, colorectal, cervical) by identifying removable precancerous lesions (ACS, 2023a; Gorina & Elgaddal, 2021). Data show that up-to-date screening rates are 59% for colorectal cancer among adults aged older than 45 years, 57% for breast cancer among women aged 50-74 years, and 84% for cervical cancer among women aged 21-65 years (ACS, 2023b). Although the general trend shows an increased cancer screening rate in the average-risk population (ACS, 2023b; Gorina & Elgaddal, 2021), studies on those at high risk for cancer because of a family history of cancer are limited. In the current study, cancer screening rates among women were 34% for breast cancer, 49% for cervical cancer, and 19% for colorectal cancer among all participants with a family history of cancer. In a study by Almario et al. (2015), 60% of adults with a family history of colorectal cancer received a colonoscopy within the past five years. Bertoni et al. (2019) reported rates of 60.6% for mammography

and 68.7% for Pap testing among women with a family history of breast cancer. When comparing screening behaviors of individuals with and without a family history of cancer, Bertoni et al. (2019) reported that having a family history of cancer influenced individuals' breast cancer screening behavior. In the current study, screening rates for breast, cervical, and colorectal cancer were lower than the current data on cancer screening (ACS, 2023b) and Healthy People 2030 (n.d.) targets, which are 72.8%, 84.3%, and 74.4% for breast, cervical, and colorectal cancer, respectively. These findings show the need for a strategic focus on high-risk populations to increase cancer screening and early detection. Previous studies have reported that tailored interventions, such as sending invitation letters (Bauer et al., 2018) or providing nurse-led counseling (Ingrand et al., 2016), can promote cancer screening among first-degree relatives of individuals with a personal history of colorectal cancer.

Although access to health care is important for cancer screening, research on barriers to cancer screening shows that multiple factors, including at individual, clinician, system, and community levels, influence cancer screening uptake (ACS, 2023b). Previous studies have primarily focused on social determinants of health, such as race and ethnicity, socioeconomic status, and place of residence, as causes for low uptake of cancer screening (Almario et al., 2015; Gorina & Elgaddal, 2021; Islami et al.,

TABLE 5. Relationship Characteristics of Probands With All Nominated Family Members						
Characteristic	n	%	$\overline{\mathbf{X}}$	SD	Range	
Family network						
Average family network size Family tie density (unweighted) Family tie density (weighted by closeness)	107 101 101	63 59 59	5.91 0.44 0.31	3.65 0.44 0.34	1-10 0-1 0-0.93	
Relationship	101	00	0.01	0.04	0 0.50	
Emotional closeness Frequency of communication Geographic closeness	101 102 101	59 60 59	7.95 4.02 3.67	1.47 0.99 1.15	0-10 0-5 0-5	
Sex of family members						
Proportion family network female Proportion family network male Proportion family network nonbinary Proportion family network nonresponse	107 107 107 107	63 63 63 63	0.56 0.43 0.002 0.006	0.25 0.25 0.01 0.05	0-1 0-1 0-0.2 0-0.6	

Note. Emotional closeness was rated on a scale ranging from 0 (no closeness) to 10 (very close), frequency of communication was rated on a scale ranging from 0 (never) to 5 (3 times per week or more), and geographic closeness was rated on a scale ranging from 0 (5 hours away or greater) to 5 (live together).

Note. 63 (37%) participants did not provide information on first-degree family members or their characteristics.

TABLE 6. Social Network Associations With Screening Outcomes					
Variable	n	OR	Rob SE	р	Pseudo-R <sup>2</sup>
Model 1 (mammography <sup>a</sup> )					
Number of family member screenings	81	1.4	0.16	0.004	0.1
Number of family members with cancer	81	1.32	0.3	0.23	0.06
Family member colonoscopy	75	2.94	1.28	0.01	0.13
Family member mammography	75	2.8	1.27	0.02	0.12
Family member Pap test	75	2.62	1.22	0.04	0.11
Family member Pap and HPV test	71	3.44	1.87	0.02	0.11
Family member genetic testing	70	5.73	3.71	0.007	0.15
Number of network members	69	1.14	0.09	0.09	0.06
Family member fecal blood test	67	3.77	2.33	0.03	0.16
Social cohesion (network density)	64	1.26	0.12	0.02	0.1
Family member computed tomography	63	6.55	4.1	0.003	0.16
Family member surgery	62	2.57	1.5	0.11	0.15
Model 2 (colonoscopy)					
Number of family member screenings	118	1.18	0.1	0.07	0.15
Number of family members with cancer	118	2.41	0.7	0.003	0.2
Family member mammography	112	1.54	0.59	0.26	0.13
Family member Pap test	112	1.43	0.56	0.36	0.12
Family member colonoscopy	111	1.92	0.76	0.1	0.12
Family member Pap and HPV test	108	1.69	0.67	0.18	0.13
Family member genetic testing	106	1.59	0.78	0.34	0.16
Family member fecal blood test	98	1.89	0.92	0.19	0.11
Number of network members	98	1.06	0.07	0.37	0.16
Family member computed tomography	94	3	1.28	0.01	0.1
Social cohesion (network density)	94	1.12	0.11	0.21	0.17
Family member surgery	91	2.99	1.39	0.02	0.1
Model 3 (genetic testing)					
Number of family member screenings	128	1.69	0.18	< 0.001	0.09
Number of family members with cancer	128	1.3	0.27	0.23	0.01
Family member mammography	121	5.3	2.01	< 0.001	0.1
Family member Pap test	121	6.8	2.64	< 0.001	0.12
Family member colonoscopy	120	6.48	2.41	< 0.001	0.12
				Continued on	the next page

TABLE 6. Social Network Associations With Screening Outcomes (Continued)					
Variable	n	OR	Rob SE	р	Pseudo-R <sup>2</sup>
Model 3 (genetic testing) (continued)					
Family member Pap and HPV test	117	8.09	3.42	< 0.001	0.13
Family member genetic testing	115	21.4	11.19	< 0.001	0.26
Family member fecal blood test	107	6.05	3.02	< 0.001	0.08
Number of network members	107	1.34	0.08	< 0.001	0.17
Family member computed tomography	103	5.6	2.47	< 0.001	0.08
Social cohesion (network density)	101	1.3	0.1	0.001	0.1
Family member surgery	100	2.59	1.27	0.052	0.05

<sup>&</sup>lt;sup>a</sup> Among participants who self-identified as female

HPV-human papillomavirus; OR-odds ratio; Pap-Papanicolaou; rob-robust; SE-standard error

Note. Models 1-3 represent 12 serially estimated logistic regression models, and each model adjusts for age and sex at birth. Data are formatted in ego-alter (dyadic) "long" format, such that each respondent has 10 possible distinct alter values for key independent variables. Models cluster on participant ID.

2022; Perencevich et al., 2013). These factors shared by family members and support from family members and friends may affect an individual's decision to participate in cancer screening. Family is formed through sets of activities within a shared system of meaning (Dimond et al., 2022). Attitudes toward cancer screening for family members, family history of cancer, and gender of family members all may affect cancer screening (Manjer et al., 2015) and uptake of health behaviors to reduce cancer risk. Families with a history of cancer may reflect the shared behavioral risk and lack of knowledge and awareness of how lifestyle behaviors affect cancer risk (Bostean et al., 2013). In the current study, a strong relationship among immediate family members increased breast cancer screening rates, and as the number of family members with cancer increased, the number of family members who underwent colorectal cancer screening also increased. Family relationships are built by giving meaning to family members' actions to do "family things" (Dimond et al., 2022). This may increase the opportunity to communicate, share, and reflect on the cancer experience of one family member among other family members. Studies have reported that family composition and social integration are associated with cancer screening. Research has shown that being married or having children (Manjer et al., 2015; Ye et al., 2009) increases uptake of breast or colorectal cancer screening, and having friends or family members talk about health and community

organization membership increases cancer screening uptake (Ye et al., 2009) among the average-risk population. However, one study reported that social participation (attending any formal or informal groups), social anchorage (feeling a sense of belonging to any formal or informal groups), and instrumental support (ability to get help from people) were not associated with nonadherence to mammography among women aged older than 45 years (Manjer et al., 2015). In the current study, 43% of participants reported not knowing where to go for cancer screening, which was associated with low rates of cervical and colorectal cancer screening. However, knowing where to go was not associated with breast cancer screening rates. These findings show that each cancer diagnosis and cancer experience in a family may bring different challenges; engaging individuals with a personal cancer history would be an opportunity to identify and address barriers to access and awareness of cancer screening services among high-risk family members.

Cascade genetic testing refers to providing genetic counseling and testing to those who are blood relatives of individuals with a specific genetic variant (American College of Obstetricians and Gynecologists Committee on Gynecologic Practice, 2018). It is cost-effective because starting the testing process with an affected individual is less expensive than whole-gene sequencing for those not affected (American College of Obstetricians and Gynecologists Committee on Gynecologic Practice, 2018). Cascade testing relies on the proband, the first individual in a family to receive genetic counseling and/or testing for suspected genetic risk (National Cancer Institute, n.d.). Studies have shown that most individuals who test positive for cancer susceptibility genes disclose and communicate their test results with first-degree family members (Conley et al., 2020; Seven et al., 2022), yet communication with secondand third-degree relatives occurs less often (Stoffel et al., 2008). In addition, after communication, genetic testing rates among eligible first-degree relatives are low (Seven et al., 2022), generally less than 30% (Baroutsou et al., 2021; Whitaker et al., 2021). However, these studies mostly focused on individuals who underwent testing for personal cancer history. In the current study, participants had a family history of cancer, with 37% being referred to a genetic counselor and 30% having seen a genetic counselor or undergone genetic testing. Of those who had seen a genetic counselor, 59% had a positive test result for a genetic variant. One study reported that communication of cancer genetic testing with healthcare providers was about 11% in a population-based sample, and 62.6% of individuals tested had a family history of cancer, showing the significant effect of having a personal history of cancer on testing (Makhnoon et al., 2021). Although not every individual with a family history of cancer is eligible for genetic testing, having a family history of some cancers is significant for further assessments and considerations (NCCN, 2023a). Recognition of at-risk individuals requires better collection and use of family history information to inform genetic counseling and testing decisions (Smith et al., 2019), as well as well-informed probands who initiate communication of test results and their implications for family members.

There are socioeconomic and racial and ethnic disparities in access to specialized care, such as risk assessment, counseling, and genetic testing (Underhill et al., 2016). A lack of understanding of the risk and limited access to genetic counseling and testing in disparate populations have a detrimental cascade effect (Underhill et al., 2016). Because cascade testing relies on the individual who tested positive initiating communication of genetic risk, previous studies have focused on family dynamics to improve risk communication from the proband to family members. The education level of probands, the emotional closeness between probands and their family members, and the age of relatives affected the communication between probands and their

#### **KNOWLEDGE TRANSLATION**

- The use of cancer-related services among high-risk individuals with a family history of cancer was moderately low.
- Family members of individuals affected by cancer must be identified to improve cancer-related health behaviors.
- Community-based interventions may be useful to reach high-risk individuals to improve the use of cancer screening and genetic

first-degree relatives (Seven et al., 2022). However, studies on risk communication and its subsequent outcomes among family members mostly included perspectives from individuals who tested positive and had a history of cancer (Koehly et al., 2003; Schmidlen et al., 2022; Seven et al., 2022). In this study, having a large family, having a strong network of relationships among family members (social cohesion), and having family members who underwent screening for more cancer types were associated with an increased rate of genetic testing among those with a family history of cancer. When an individual tests positive for a cancer susceptibility gene, all first-degree relatives are eligible for testing; having more family members means having more family members to test. In addition, a strong family relationship among larger families appears to increase decision-making or acceptability of testing (Seven et al., 2022). In the process of constituting family practice, an individual's actions are conveyed and understood by other members (Dimond et al., 2022). Similarly, this study found that the number of family members screened was associated with an increased odds ratio of mammography, colonoscopy, and genetic testing. Individuals who do not have a personal history of cancer but are at risk because of family history may rely only on the information given to them by probands. This shared information is a significant factor in how family members use it to inform their decisions (Himes et al., 2019). For example, informing family members where to get genetic testing can be effective to have eligible individuals consider genetic counseling. Similarly, in this study, most immediate family members of individuals with cancer who did not undergo genetic testing or counseling also reported that they did not know where to go if they needed these services. Interventions aimed to improve risk communication from probands to family members, which ultimately inform decision-making among family members with or without a cancer history, suggest that more family-focused approaches are needed (Baroutsou et al., 2021). Considering that many individuals who undergo testing tend to share their genetic test results with family members, it is important to focus on how this communication occurs, what information is conveyed, and how to improve this process to increase informed decisions on subsequent cascade genetic testing for eligible family members.

### Limitations

This is one of the few studies focused on family members of individuals with a personal history of common hereditary cancers. However, the study has some limitations. The first limitation is a relatively small study sample size derived from an online survey that was interrupted during the COVID-19 pandemic. Another potential limitation may be the lack of diversity in participant characteristics regarding sex identity and race and ethnicity. Although family network size and characteristics were collected from family members, participants were limited to nominating only 10 of their closest immediate family members to increase recall and reliability of data. Network surveys of this type that ask participants to name socially connected contacts and provide information on characteristics relating to each person can be onerous for participants and lead to fatigue. The authors attempted to mitigate this limitation by having relatively few follow-ups and using varying question types and styles.

# **Implications for Nursing**

The use of cancer-related services among family members of individuals affected by breast, ovarian, or colorectal cancer was moderately low. Initiation of communication of test results and their implications for family members relies on probands (Seven et al., 2022); therefore, probands who undergo testing for hereditary cancer need to be well informed and encouraged to communicate their test results with family members during the testing process (NCCN, 2023a). Nurses working with people affected by cancer can focus on strategies to strengthen family members' relationships to improve communication about familial cancer risk, cancer screening, and available genetic services. Oncology nurses can be proactive in supporting people affected by hereditary cancers by disclosing test results and optimizing genetic services for family members.

It is also important to identify unaffected at-risk individuals through risk assessment to improve cancer-related health behaviors. Risk assessment involves evaluating an individual's family history, personal history, and risk factors that may indicate an increased risk of developing cancer. Because cancer risk assessment can occur in different settings, all nurses need to be competent in risk assessment and refer those who may benefit from genetic services to appropriate providers (Forman & Schwartz, 2019). Nurses can collaborate with community-based organizations and centers to target high-risk individuals with a family history of cancer to improve the use of cancer screening and genetic counseling when needed. In community settings, nurses can organize educational activities in collaboration with cancer support and advocacy groups to create awareness about the importance of family history and cancer screening for early detection.

## Conclusion

Despite the small sample size that comes from diverse geographic areas and multicultural families in the United States, this study has the potential to inform future research and practices in cancer screening and cascade genetic testing among individuals with a family history of cancer. Moderately low cancer screening uptake and use of genetic counseling or testing among high-risk populations require future studies focused on strategies to improve cancerrelated health behaviors among individuals with a family history of cancer. Family networks and familyfocused approaches supporting family dynamics and relationships may have the potential to inform community-based practice to engage high-risk individuals who are not in contact with the healthcare system.

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