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Information Seeking and Intentions to Have Genetic Testing for Hereditary Cancers in Rural and Appalachian Kentuckians

Kimberly M. Kelly, PhD;¹ James Andrews, PhD;² Donald O. Case, PhD;³ Suzanne L. Allard, PhD;⁴ and J. David Johnson, PhD³

ABSTRACT: *Context:* Research is limited regarding the potential of genetic testing for cancer risk in rural Appalachia. *Purpose:* This study examined perceptions of genetic testing in a population sample of Kentuckians, with a focus on Appalachian and rural differences. The goals were to examine cultural and psychosocial factors that may predict intentions to test for hereditary cancer, need for help with information seeking for decision making about genetic testing for hereditary cancer, and amount of help needed with information seeking for decision making about genetic testing for hereditary cancer in this population. *Methods:* Analysis of data from a general social survey of adults using random-digit dialing in Kentucky (N = 882). *Findings:* An ordinal regression found that younger age, having a family history of cancer, and greater worry predicted greater intentions to seek genetic testing. A logistic regression found that having more education, excellent subjective knowledge of genetics, and less worry about cancer predicted less need for help in seeking information about testing. An ordinal regression found that less subjective knowledge of genetics and greater worry predicted greater amount of help needed. *Conclusions:* Additional counseling to explain limitations of genetic testing may be needed. Further, those with less knowledge about genetics and more worry about hereditary cancer may have greater need for help with information seeking for decision making, a need that may be further exacerbated by the lack of medical professionals, particularly genetic counselors, who may provide information about genetic testing in rural, Appalachian Kentucky.

and controlling cancer led to the inclusion of the Appalachia Cancer Network among the National Cancer Institute's Special Populations Networks. Although Appalachia is culturally diverse, consistent is a tendency toward more conservative religious beliefs,⁵ a focus on the family, and an importance of knowing family history.⁶ Hence, Appalachians may be more aware of family history of cancer due to close kinship ties.

When considering family history of cancer, three types of cancers are possible: sporadic, familial, or hereditary. Hereditary cancers are associated with early age of onset, multiple primary cancers, multiple family members affected, and a located hereditary genetic mutation and/or diagnostic criteria. Familial cancers are usually not associated with located hereditary mutations/diagnostic criteria and may have later age of cancer onset. Sporadic cancers are believed to be random, perhaps due to environmental exposures. Currently, genetic testing is of little utility to those with familial or sporadic cancer. Lay individuals may not understand the limitations of genetic testing for cancers that "run in the family," and their intentions to test may be driven by other factors.

¹Human Cancer Genetics, the Ohio State University, Columbus, Ohio.

²School of Library and Information Science, University of South Florida, Tampa, Fla.

³College of Communications and Information Science, University of Kentucky, Lexington, Ky.

⁴School of Information Sciences, University of Tennessee, Knoxville, Tenn.

Approximately half the area of Kentucky falls within Appalachia,¹ a region marked by disproportionately high poverty rates,² health professional shortages,² and cancer incidence and mortality.^{3,4} The high burden of cancer and the challenges in preventing

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Few studies have examined the relationship of religion/spirituality with intentions to test. Two investigations of the relationship of religion/spirituality to genetic testing had mixed results. A study of predominately Mormons found no relationship between religion or religiosity and interest in genetic testing for colon cancer,⁷ while another of women with familial breast cancer found that greater spiritual faith was associated with decreased likelihood of genetic testing.⁸ Thus, it is unclear if Appalachians with greater religiosity would be interested in genetic testing.

Studies have examined the relationship of knowledge/subjective knowledge and distress to intentions to test, and results are mixed. Knowledge/subjective knowledge of cancer genetics was not associated with the intention to test in some studies^{9,10} but was positively associated in others.^{11,12} Further, most studies find a positive relationship between distress and interest in testing.^{9,13,14} Yet, no relationship was found between distress and interest in testing in a study by Andrykowski et al.,¹⁰ which included residents of Kentucky and a more general assessment of well-being. The lack of consistency of study of Andrykowski et al.¹⁰ with prior studies merits further investigation as the results could indicate that the population of Kentucky is somehow unique or that the measure of distress was too general to affect interest in testing. Thus, the current study includes a more situation-specific measure of distress (ie, worry about hereditary cancer) and examines subgroups of Kentuckians (ie, Appalachians).

Little research has examined the consumer's need for assistance in gathering information to make a decision regarding genetic testing. In the cancer treatment literature, desire for physician assistance is high, with only 1%-22% of cancer patients preferring to make decisions regarding treatment (ie, surgery) without a physician's assistance.¹⁵⁻¹⁷ One study of interest in cancer genetic testing found that most individuals needed help seeking cancer genetic information,¹⁸ but it did not examine the amount of help needed, religiosity, or focus on subpopulations. Understanding what assistance consumers need is important before prescribing particular courses of action for how genetic counseling or testing should be delivered.

The Comprehensive Model of Information Seeking (CMIS),¹⁹ the theoretical framework for this study, has been empirically tested in the context of cancer. The CMIS specifies the antecedents that explain why people become information seekers, the information carrier characteristics that shape how people seek information, and the information-seeking actions reflecting the

nature of the search itself. Antecedents, which include background factors (ie, demographics and direct experience) and personal relevance factors (ie, salience), are associated with action (ie, information seeking). In the current study, antecedents include the demographic of religiosity. Family history is considered as a proxy for direct experience with cancer.²⁰ Worry and knowledge are personal relevance factors. These factors will be investigated for their association with intentions to have genetic testing and need for help with seeking information to make decisions regarding genetic testing. The current study, guided by the CMIS, is the first to examine Appalachian and rural differences in intentions to test, need for help with information seeking in decision making, amount of help needed, worries about hereditary cancers, family history of cancer, religiosity, and subjective knowledge of genetics.

Methods

Participants. Individuals aged 18 years and older living in Kentucky were eligible to participate. A total of 2,329 eligible respondents were randomly selected and contacted as part of a general social survey, and 882 individuals agreed to participate for a participation rate of 38%, similar to the Behavioral Risk Factor Surveillance System.²¹ Additional details regarding the complete sample are available in a companion study.^{18,22} Table 1 outlines the demographics.

Procedure. This cross-sectional study utilized Waksberg random-digit dialing procedures to obtain a sample of Kentuckians. Trained interviewers conducted this telephone survey as a part of a larger social survey conducted by the University of Kentucky Survey Research Center.

Measures. In the CMIS, *antecedents* are background factors, and here include demographic and experiential factors. Demographics included gender, age, marital status, education, county of residence, household income, race, and frequency of religious attendance (religiosity). Religiosity is classified in its traditional sense as a demographic factor rather than beliefs, as attendance may not truly reflect beliefs. County of residence was then used to determine if the individual resided in a federally designated Appalachian county¹ or in a rural area (for purposes of this study, only counties with a Rural-Urban Continuum Code²³ of 8-9 were considered rural, while those with Rural-Urban Continuum Code of 1-7 were considered nonrural). For the proxy experiential factor of family history of cancer, participants were asked if there were any types of cancers that run in their family (yes/no). *Salience*, or personal relevance factors, included worry and

Table 1. Comparison of Appalachian Versus Non-Appalachian Kentuckians and Rural Versus Nonrural Kentuckians on Key Demographic and Psychosocial Variables in a Statewide Telephone-Administered Survey Regarding Interest in Genetic Testing

		Appalachian, N (%)	Non-Appalachian, N (%)	Nonrural (RUCC 1-7)†, N (%)	Rural (RUCC 8-9)†, N (%)
Gender	Male	93 (37.96)	259 (40.66)	271 (39.28)	50 (42.37)
	Female	152 (62.04)	378 (59.34)	419 (60.72)	68 (57.63)
Race*	White	211 (95.04)	520 (90.75)	551 (90.03)	110 (98.21)
	Nonwhite	11 (4.96)	53 (9.25)	61 (9.97)	2 (1.79)
Rural*	Rural (RUCC 8-9)†	74 (30.20)	44 (7.82)		
	Nonrural (RUCC 1-7)†	171 (69.80)	519 (92.18)		
Age (years)	40 or younger	79 (32.51)	196 (31.11)	209 (30.56)	47 (40.52)
	41-60	103 (42.39)	274 (43.49)	298 (43.57)	39 (33.62)
	61 or older	61 (25.10)	160 (25.40)	177 (25.87)	30 (25.86)
Education*	Did not complete high school	47 (21.08)	62 (10.76)	77 (12.48)	24 (21.62)
	High school diploma/GED	88 (39.46)	195 (33.85)	215 (34.85)	48 (43.24)
	Some college	45 (20.18)	148 (25.70)	150 (24.31)	24 (21.62)
	Bachelor's degree or more	43 (19.28)	171 (29.69)	175 (28.36)	15 (13.52)
Religiosity (attendance)	Every week	75 (35.89)	205 (38.53)	223 (39.12)	39 (36.45)
	Almost every week	49 (23.44)	139 (26.13)	147 (25.79)	19 (17.76)
	Once or twice a month	85 (40.67)	188 (33.34)	200 (35.09)	49 (45.79)
Family history of cancer	No family history	108 (46.96)	258 (41.81)	382 (57.70)	66 (58.93)
	Family history	122 (53.04)	359 (58.19)	280 (42.30)	46 (41.07)
Subjective knowledge of genetics	Excellent	23 (10.00)	72 (11.76)	70 (10.70)	14 (12.28)
	Good	89 (38.70)	232 (37.91)	250 (38.23)	51 (44.74)
	Fair	92 (40.00)	211 (34.48)	230 (35.17)	42 (36.84)
	Poor	26 (11.30)	97 (15.85)	104 (15.90)	7 (6.14)
Worry about cancer*	Never	60 (25.97)	186 (30.00)	195 (29.46)	29 (25.22)
	Rarely	60 (25.97)	206 (33.23)	206 (31.12)	33 (28.70)
	Sometimes	60 (25.97)	171 (27.58)	175 (26.44)	38 (33.04)
	Often	51 (22.09)	57 (9.19)	86 (12.98)	15 (13.04)

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* $P < .05$.
 † Rural-Urban Continuum Codes.

subjective knowledge. Participants were asked how frequently they worried about cancer (“worry”: never, rarely, sometimes, often). Subjective knowledge of genetics was assessed with an item from Andrykowski et al.,¹⁰ which asked about respondents’ knowledge on a 4-point Likert-type scale (“knowledge”: poor, fair, good, excellent). *Actions* included intention to test and need for help with information seeking. Participants were asked if they would have a genetic test to determine their risk for inherited cancer if it were readily available (“intentions”: definitely no, probably no, it depends, probably yes, definitely yes). They were also asked if they needed help with information seeking for decision making about genetic testing

(“need”: yes, no). For those desiring help, participants were asked the amount of help needed (“amount”: none, little, some, a lot).

Statistical Analyses. Frequency data were computed to describe the sample. All predictors were considered categorical. For purposes of analysis, a number of variables were transformed based on the distribution of responses. Specifically, religiosity was categorized as (1) every week; (2) almost every week/1-2 times per month; or (3) less. Need was classified as (1) none/a little; (2) some; or (3) a lot. Intentions was categorized as (1) definitely not/probably not/depends; (2) probably yes; or (3) definitely yes.

Likelihood ratios (for nominal, binary responses) and Somers' d and Mann-Whitney *U* tests (for ordinal outcomes) were computed to compare Appalachian versus non-Appalachian and rural versus nonrural participants on demographic and psychosocial variables. Three regression models were fit for the outcomes of intentions, need, and amount. A model fitting approach was used whereby each predictor was examined for its explanatory power for the outcomes of interest.²⁴ Potential predictor variables included gender, age, education, rural, Appalachian, religiosity, family history of cancer, knowledge, and worry.

Results

Participants were predominantly female (n = 530; male: n = 352), non-Appalachian (n = 637; Appalachian: n = 245), and nonrural (n = 690; rural: n = 118). Table 1 compares Appalachian/non-Appalachian and rural/nonrural participants. Appalachians were more likely to be female, rural, and white than non-Appalachians. Appalachians also had less education and more worry than non-Appalachians. Rural participants had less education and were more likely to be white than nonrural participants. Table 2 includes descriptives and regression models for the outcomes of interest (intentions, need, and amount).

An ordinal regression model was fit for the outcome of intentions, with gender, age, education, rural, Appalachian, religiosity, family history, knowledge, and worry entered as potential predictors. The model was significant ($\chi^2(7) = 101.69, P < .001$); age, family history, and worry were significant. Compared to those who were 40 and younger, those who were 41-60 had .71 times the odds, and those 61 and older had .57 times the odds of higher intentions. Those with a family history of cancer had 1.45 times the odds of higher intentions than those without a family history. Further, compared to those reporting they never worry, those reporting that they rarely worry had 1.41 times the odds of higher intentions, those reporting that they sometimes worry had 2.25 times the odds of higher intentions, and those reporting that they often worry had 5.56 times the odds of higher intentions. A trend indicated that Appalachians had a 1.31 times the odds of higher intentions than those not from Appalachia.

A logistic regression was fit for the outcome of need, with gender, age, education, rural, Appalachian, religiosity, family history, knowledge, and worry entered as potential predictors. The model was significant ($\chi^2(9) = 61.31, P = .001$); education, knowledge, and worry were significant. Compared to those not completing high school, those with a high

school diploma/GED had 1.85 times the odds of no need, those with some college had 2.67 times the odds of no need, and those with a bachelor's degree or more had 2.55 times the odds of no need. Compared to those reporting less knowledge, those reporting excellent knowledge had 2.51 times the odds of no need. Finally, compared to those reporting they never worry, those reporting that they rarely worry had .58 times the odds of no need, those reporting that they sometimes worry had .63 times the odds of no need, and those reporting that they often worry had .36 times the odds of no need.

A second ordinal regression model was fit for the outcome of amount, with gender, age, education, rural, Appalachian, religiosity, family history, knowledge, and worry entered as potential predictors. The model was significant ($\chi^2(19) = 24.49, P < .001$); knowledge and worry were significant. Compared to those reporting poor knowledge, those reporting fair knowledge had .54 times the odds of greater amount, those reporting good knowledge had .41 times the odds of greater amount, and those reporting excellent knowledge had .44 times the odds of greater amount. Further, compared to those reporting they never worry, those reporting that they sometimes worry had 1.75 times the odds of great amount and those reporting that they often worry had 2.33 times the odds of greater amount. A trend found that those who rarely worry had 1.48 times the odds of greater amount than those who never worry.

Discussion

Demographic and psychosocial variables were compared for Appalachian versus non-Appalachian and rural versus nonrural participants. Appalachians had more worry about hereditary cancers than non-Appalachians. With Appalachians' greater incidence of and mortality from cancer, this worry is understandable. Further, Appalachians were more likely to be rural and less educated, perhaps resulting in fewer resources to manage this worry. Also, Appalachians did not differ from non-Appalachians on family history, religiosity, and subjective knowledge of genetics. These findings would not seem to support cultural differences in religiosity and family awareness.^{5,6}

Predictors of intentions to test, need for help with information seeking, and amount of help needed also were examined. Family history was related to intentions to test. Objectively, genetic testing is more relevant to those with a family history of cancer. The finding that individuals with a family history did not have greater need for help with information seeking is,

Table 2. Regression Models (With Odds Ratios and Their 95% Confidence Intervals [CI]) for Demographic and Personal Relevance Factors With Associations to Key Outcome Variables (Intentions to Test, Need for Help, and Amount of Help Needed) in a Statewide Telephone-Administered Survey of Kentuckians

Frequencies	Definitely Not/Probably Not/Depends, n (%)	Probably Yes, n (%)	Definitely Yes, n (%)	Odds Ratio	95% CI
Ordinal regression for intentions to test					
Age (years)					
40 or older (n = 266)	79 (29.70)	99 (37.22)	88 (33.08)	1	1
41-60 (n = 354)*	137 (38.70)	119 (33.62)	98 (27.68)	0.71	0.52-0.96
61 or younger (n = 207)*	93 (44.92)	67 (32.37)	47 (22.71)	0.57	0.41-0.82
Appalachian					
Not Appalachian (n = 605)	245 (40.50)	201 (33.22)	159 (26.28)	1	1
Appalachian (n = 230)**	68 (29.56)	87 (37.83)	75 (32.61)	1.31	0.98-1.76
Family history of cancer					
No family history (n = 357)	109 (30.53)	115 (32.22)	133 (37.25)	1	1
Family history (n = 470)*	197 (41.91)	173 (36.81)	100 (21.28)	1.45	1.10-1.92
Worry about cancer					
Never (n = 239)	126 (52.72)	66 (27.62)	47 (19.66)	1	1
Rarely (n = 264)*	105 (39.77)	109 (41.29)	50 (18.94)	1.41	1.00-1.97
Sometimes (n = 224)*	66 (29.46)	82 (36.61)	76 (33.93)	2.25	1.58-3.21
Often (n = 105)*	15 (14.28)	29 (27.62)	61 (58.10)	5.56	3.44-9.01
Frequencies	Yes, n (%)	No, n (%)			
Logistic regression for need for help with information seeking for decision making					
Education					
Did not complete high school (n = 107)	89 (83.18)	18 (16.82)		1	1
High school diploma/GED (n = 282)*	204 (72.34)	78 (27.66)		1.85	1.02-3.35
Some college (n = 193)*	120 (62.18)	73 (37.82)		2.67	1.45-4.92
Bachelor's degree or more (n = 214)*	128 (59.81)	86 (40.19)		2.55	1.39-4.69
Subjective knowledge of genetics					
Poor (n = 91)	68 (74.73)	23 (25.27)		1	1
Fair (n = 317)	235 (74.13)	82 (25.87)		0.83	0.47-1.46
Good (n = 303)	204 (67.33)	99 (32.67)		1.14	0.65-1.99
Excellent (n = 123)*	57 (46.34)	66 (53.66)		2.51	1.34-4.70
Worry about cancer					
Never (n = 243)	139 (57.20)	104 (42.80)		1	1
Rarely (n = 266)*	185 (69.55)	81 (30.45)		0.58	0.39-0.86
Sometimes (n = 228)*	160 (70.18)	68 (29.82)		0.63	0.42-0.94
Often (n = 106)*	86 (81.13)	20 (18.87)		0.36	0.20-0.64
Frequencies	None/A Little, n (%)	Some, n (%)	A Lot, n (%)		
Ordinal regression for amount of help needed with information seeking for decision making					
Subjective knowledge of genetics					
Poor (n = 70)	14 (20.00)	18 (25.71)	38 (54.29)	1	1
Fair (n = 232)*	57 (24.57)	86 (37.07)	89 (38.36)	0.54	0.32-0.91
Good (n = 202)*	49 (24.26)	101 (50.00)	52 (25.74)	0.41	0.24-0.69
Excellent (n = 57)*	16 (28.07)	21 (36.84)	20 (35.09)	0.44	0.23-0.86
Worry about cancer					
Never (n = 134)	45 (33.58)	51 (38.06)	38 (28.36)	1	1
Rarely (n = 184)**	44 (23.91)	78 (42.39)	62 (33.70)	1.48	0.98-2.25
Sometimes (n = 160)*	31 (19.37)	69 (43.13)	60 (37.50)	1.75	1.13-2.69
Often (n = 88)*	16 (18.18)	30 (34.09)	42 (47.73)	2.33	1.39-3.91

* $P < .05$.

** $P < .1$.

however, consistent with the CMIS and, more specifically, the GENIS2 model (Genetic Information-Seeking Skills).²⁵ Further, increased frequency of religious practice was not associated with decreased intentions to test, consistent with Croyle and Lerman⁷, and help in decision making was not supported. Thus, those higher and lower in religiosity may be equally interested in genetic testing and seeking information about cancer genetics.

Consistent with a prior study of Kentuckians,¹⁰ subjective knowledge of genetics was not related to intentions to test. Yet, greater subjective knowledge was related to needing help and a greater amount of help needed. Individuals needing a greater amount of help with information seeking may recognize their lack of knowledge and desire other sources to assist them in decision making about genetic testing. This desire is problematic as there are no registered cancer genetic counselors in Appalachian Kentucky and only 3 in the entire state of Kentucky.²⁶ Case et al. found that individuals would pursue a variety of sources for information about inherited cancers;²² thus, those not receiving help with decision making from health professionals may consult other, less-authoritative sources for help with decision making.

Worry predicted intentions to test, need for help with information seeking, and amount of help needed. Thus, the difference between studies finding a relationship between distress and testing^{9,13,14,27} and the study finding no relationship¹⁰ was less likely due to population studied and more likely due to the measure used. Further, the positive relationship between worry and intentions to test, need for help with information seeking, and amount of help needed is concerning. Those with more worry and less understanding may (1) pursue testing when detecting a mutation is unlikely; (2) receive an uninformative negative result; (3) be unable to interpret the result; and (4) inappropriately decrease cancer screening.

The CMIS was a useful framework for investigating intentions to test and help in decision making. Although subjective knowledge was not related to intentions to test, those reporting greater worry had greater intentions to test. Less subjective knowledge and greater worry predicted need for help in decision making. Hence, examining antecedents (eg, county of origin and family history of cancer) and personal relevance factors (eg, knowledge and distress) is critical to understanding information seeking. Future studies should examine additional components of the model such as beliefs about hereditary cancer and the utility of testing. Indeed, determining the extent to which Appalachians understand the ability of a genetic test to find a mutation associated with hereditary

cancer is an important next step in developing interventions to encourage rational information seeking with genetic testing.

Certain limitations should be noted. First, we did not include personal history or extent of family history; hence, we cannot be certain that testing is more relevant for those reporting cancers that “run in the family.” Further, due to limitations in survey length, we used single items to assess knowledge and worry, making it difficult to assess objective knowledge or different facets of worry. Yet, because this single worry item was highly predictive of intentions to test, this item could be used in a clinical setting to target those needing additional resources to understand the complexities of genetic testing. Also, a higher response rate may have yielded a more representative sample. Most importantly, the larger social survey of Kentuckians was not designed to focus on Appalachians. Future studies should include more intensive piloting of instruments in Appalachians.

In conclusion, more situation-specific measures of worry are needed when considering the link between psychosocial variables and health action. For Appalachian Kentuckians, greater worry about hereditary cancer was associated with greater intentions to test, and additional studies should explore the reasons for greater intentions to test in Appalachians with greater worry. Further, less subjective knowledge and greater worry were associated with greater need for help in decision making. Thus, individuals from more rural populations with closer family relationships and greater worry may need special counseling to explain the benefits, risks, and limitations of testing. In addition, those with less knowledge about genetics may desire help with information seeking for decision making, and this supports the role of genetic counselors and their necessity in rural, Appalachian Kentucky.

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Query No.	Query	Remark
1	Please replace "GED" in the sentence "Compared to ..." and in Tables 1 and 2 with its expansion.	
2	In the sentence "Further, increased frequency of ..." the citation "Croyle et al." has been changed as "Croyle and Lerman" following the list. Please check if the change made is correct.	
3	In reference 1, please provide the document name.	
4	In reference 2, please provide the names of the editors.	
5	In reference 3, please provide the names of the editors. Also note that the chapter title "Health care services in Appalachia" is same as that given in reference 2. Please check.	
6	In reference 5, please provide the name of the publisher.	
7	In reference 18, please provide page range.	
8	In reference 19, the spelling of the city "Creerskill" has been changed as "Cresskill." Please check if the change made is correct.	
9	In reference 23, please provide the document title and accessed date.	
10	In the footnote of Table 1, the value of P "05" in the footnote has been changed as ".05." Please check if the change made is correct.	