Knowledge, attitudes, and perceived barriers towards genetic testing across three rural Illinois communities

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Abstract

Genetic testing is becoming more prevalent in detecting risk and guiding cancer treatment in our increasingly personalized medicine model. However, few studies have examined underserved populations' perceptions of genetic testing, especially those of rural dwelling populations. We asked residents of three rural communities to complete a self-administered survey gauging their knowledge, attitudes, and perceived barriers for genetic testing. 64.8% of participants of the overall study completed the survey. Most participants were aware of genetic testing for cancer screening (69.0%) and would likely share results with their family (88.5% if it indicated low risk, 85.9% for high risk). Some barriers were noted, including genetic testing not offered in a clinic nearby (46.9%), insurance company knowing the results (54.0%), cost (49.1%), and no accessible genetic counselors with whom to discuss results (45.6%). Our rural participants were generally knowledgeable about genetic testing, but this may not be reflective of all rural populations. Opportunities exist to mitigate use barriers, expand the utilization of telehealth services and regulatory agency-approved assays, and increase knowledge regarding privacy and protections offered by statute, such as the Genetic Information Nondiscrimination Act (US) and General Data Protection Regulation (Europe).

Keywords Rural · Genetic testing · Underserved population perceptions · Personalized medicine

Background

Genetic testing for diseases like cancer is increasingly incorporated into the clinical setting and has been integrated into public

health and preventive medicine guidelines (Fisk Green et al. 2015). The World Health Organization puts out guidelines in 2002 regarding genetic testing and counseling (WHO 2002). The Office of Disease Prevention and Health Promotion included a genomics section for the first time in its most recent Healthy People 2020 objectives, aiming to improve rates of genetic counseling among women with a family history of breast or ovarian cancer and rates of genetic testing for Lynch syndrome among individuals newly diagnosed with colorectal cancer (US Department of Health and Human Services 2018). Since 2013, the United States Preventive Services Task Force (USPSTF) has provided a grade B recommendation that women with a family history of breast or ovarian cancers be screened and considered for genetic counseling and possible testing for mutations in breast cancer susceptibility genes (*BRCA1* and *BRCA2*) (Moyer 2014). With this USPSTF recommendation, Affordable Care Act regulations and Medicare guidelines require such counseling to be covered by private insurers and Medicare. A panel of European experts determined that women with a family history of breast cancer should be tested for *BRCA1/2*, *TP53*, and *PALB2* and sent for genetic counseling (Singer et al. 2019). Additionally, with the emergence of precision medicine as a targeted approach to more precisely predict

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risk and detect and treat diseases, genetic testing will be increasingly utilized.

Although insurance coverage for genetic testing has improved, there exist other barriers to testing utilization. For example, there needs to be knowledge that such tests exist, accessibility should be equitable, and results presumed confidential. All these may be compromised to some extent and in some locations as studies have reported that racial/ethnic minorities and rural individuals are less aware of testing availability; racial/ethnic minorities are more concerned about result misuse or confidentiality; and underserved populations have less test access (Peters et al. 2005; Mai et al. 2014; Salloom et al. 2018; Suther and Kiros 2009; Thompson et al. 2003; Hall and Olopade 2006). Rural populations are notoriously underserved, and while previous studies have explored the rural perceptions of genetic research, and other studies have evaluated perceptions of genetic testing in other underserved populations, there have been few studies that examined rural communities' perceptions of genetic testing (MacDowell et al. 2010; MacDowell et al. 2009; Tanner et al. 2015; Fullenkamp et al. 2013). Our objective was to access the knowledge, attitudes, and barriers towards genetic testing among participants in three rural communities in IL.

Methods

Study population

We engaged three rural communities in IL as part of a study to evaluate the genetic heterogeneity of isolated rural communities. Isolated communities were defined as towns of roughly 1500 residents that were at least 20 miles from a town of a population greater than 5000 following the precedent of previous similar study (Portas et al. 2010). The process of identifying and engaging of these communities is described elsewhere (Dean et al. 2017). This study was approved by the Springfield Committee for Research Involving Human Subjects. Informed consent was obtained from all individual participants included in the study.

Survey administration and design

We engaged community champions to help determine the most locally appropriate way to recruit study participants. Ultimately, recruitment events were held in each rural community at easily accessible local venues such as churches and community centers. Participants provided informed consent to participate in this study, which includes providing a saliva sample and completing a genealogy log. While the main focus of the study was indeed to evaluate genetic heterogeneity across isolated communities, we were also interested in community knowledge, attitudes, and perceptions of genetic

testing, and participants were asked to complete an optional survey on this topic. Inclusion criteria were age 18 years or older and residence in the study town of interest. Surveys were self-administered.

This survey was developed to assess participant knowledge and attitudes towards genetic testing as well as perceived barriers to seeking genetic testing. The survey was informed by the Health Belief Model and constructs relevant to perceptions and barriers related to genetic testing that were identified in previous studies (Streecher and Rosenstock 1997; Cyr et al. 2010; Taylor et al. 2013; Dean et al. 2017). Participant data collected included demographic characteristics (e.g., age, gender, and educational attainment) and occupational status (working, retired, other). Eleven items of the survey evaluated knowledge and attitudes towards genetic testing using either a dichotomous or Likert scale answer options. An additional panel of 11 questions assessed participants' perceptions of barriers to genetic testing. Participants were asked to identify if a barrier was a major reason, minor reason, or not a reason that they would not get genetic testing.

Analysis

Frequencies and percentages of demographic characteristics and responses to survey questions were calculated. A barrier score was created by coding a response of “not a reason” as “0,” “minor reason” as “1,” and “major reason” as “2” and summing across all questions. Potential scores could range from 0 to 20, with 20 indicating the greatest level of perceived barriers. Wilcoxon sum rank tests were performed to assess the differences in barrier scores across demographic groups. All analyses were performed in SAS 9.4.

Results

Characteristics of the study population

Of the 176 individuals who participated in the overall study, 114 (64.8%) completed the optional survey. The majority of participants were female (64.0%) (Table 1). Most participants had at least some college education (79.1%). Roughly half of the participants (50.9%) were aged 61 or older, and 51.8% of the participants were retired. Characteristics of the counties where the sites are located can be found in Table 2.

Knowledge, perceptions, and attitudes to genetic testing

More than two thirds of the survey participants (69.0%) were aware of genetic screening modalities for cancer, while less than half (46.0%) were aware of genetic screening for other diseases (Table 3). We also found that, if participants received genetic testing, 90.3% would want to know the test results. If

Table 1 Demographics of survey respondents

	<i>n</i> (%) / mean (SD)
Gender	
Male	41 (36.0%)
Female	73 (64.0%)
Education	
Less than a high school/high-school degree	25 (21.9%)
Some college	37 (32.5%)
Associate's degree	14 (12.3%)
Bachelor's degree	23 (20.2%)
Graduate/professional degree	15 (13.2%)
Age	59.5 ± 16.4
Age groups	
18–44	19 (16.7%)
45–60	37 (33.4%)
61–74	37 (32.5%)
75+	21 (18.4%)
Employment status	
Working	48 (42.1%)
Retired	59 (51.8%)
Other (student, homemaker, unemployed)	7 (6.1%)
Site	
1	59 (51.8%)
2	25 (21.9%)
3	30 (26.3%)

survey participants were to receive genetic test results, 88.5% would tell their family if the tests determined they were low risk for disease and 85.9% were very/somewhat likely to tell their family if the test determined they were high risk. Further, 91.8% responded they knew that a positive genetic test does not guarantee a future diagnosis.

Test results influencing behavior change were mixed, with 88.8% saying they were very/somewhat likely to change their lifestyle due to a positive result, but nearly equal number very/somewhat likely and very/somewhat unlikely (37.2% vs 33.6%, respectively) to change their decision to have children

due to the risk of a deadly disease. Overall, recent genetic advances are thought to be a good thing (87.6% very/somewhat good), but with a notable minority believing that scientists will go “too far” (37.2% very/somewhat afraid). Most participants (66.9%) thought that celebrities and the media influence public perception of genetic testing.

Perceived barriers to genetic testing

We found that relatively few individuals identified barriers. For example, only 4 of the 11 barriers queried did greater than 40% of the participants that indicate a minor or major barrier. More than half of the survey participants (54.0%) identified concern that their insurance company would know the results as a minor or major barrier, and just under half of participants indicated cost as a minor or major barrier to seeking genetic testing. Further, almost half of the participants noted that testing not being offered at a clinic nearby (46.9%) and stated that not having a genetic counselor nearby to discuss results (45.6%) were barriers for testing (Table 4). The median barrier score among participants was 4.0 (range 0 to 16) (Table 5). The median barrier score for males and females statistically significantly varied (2 and 6, respectively, $p = 0.006$). There was no statistically significant difference in the median barrier score across other demographic groups.

Discussion

We surveyed individuals in three rural IL communities who were participating in a genetic heterogeneity study on their knowledge, attitude, and perceived barriers to genetic testing. We found that most participants were aware of genetic testing and generally had a favorable attitude towards testing and sharing results with family. Further, most participants indicated few barriers to seeking genetic testing. However, more than half of the participants noted some level of concern about insurance companies being aware of the results. Further, nearly half of the participants indicated that not having close

Table 2 Demographics of communities surveyed

Site	General location in state	Population range for county	Race ^a (%)	County health ranking quartile ^b	Insurance status ^c (%)
1	Far south	10,000–15,000	White (89.0) Black (8.0)	First (most healthy)	Insured (94.3) Public (43.6)
2	Far north	20,000–25,000	White (97.2) Black (0.5)	First (most healthy)	Insured (94.9) Public (36.5)
3	East central	15,000–20,000	White (92.8) Black (4.7)	Third (less healthy)	Insured (92.7) Public (39.4)

^a United States Census Bureau, 2010 Census

^b Robert Wood Johnson's County Health Rankings and Roadmaps

^c American Community Fact Finder 2018, United States Census Bureau

Table 3 Knowledge, perceptions, and attitudes towards genetic testing

	<i>n</i> (%)
Knowledge	
Aware of Genetic Screening for cancer (e.g., BRCA testing)	78 (69.0)
Aware of genetic screening for other diseases	52 (46.0)
Perceptions and attitudes	
If you were genetically tested for cancer/other diseases, would you want to know the results?	
Yes	102 (90.3)
No	11 (9.7)
If you were to get genetic testing results that said you were at low risk for a disease, how likely would you be to share the results with your family?	
Very likely	79 (69.9)
Somewhat likely	21 (18.6)
Unsure	9 (8.0)
Somewhat unlikely	2 (1.8)
Very unlikely	2 (1.8)
If you were to get genetic testing results that said you were at high risk for a disease, how likely would you be to share the results with your family?	
Very likely	82 (72.6)
Somewhat likely	15 (13.3)
Unsure	12 (10.6)
Somewhat unlikely	2 (1.8)
Very unlikely	2 (1.8)
Do you think having a positive result to a genetic test guarantees you will get cancer or that disease?	
Yes	9 (8.2)
No	101 (91.8)
Do you think knowing you are at high risk for cancer or other potentially deadly disease would influence your decision to have children?	
Very likely	12 (10.6%)
Somewhat likely	30 (26.6)
Unsure	33 (29.2)
Somewhat unlikely	19 (16.8)
Very unlikely	19 (16.8)
Do you think getting a positive result would get you to change your lifestyle, for example quit smoking or eat better?	
Very likely	56 (50.5)
Somewhat likely	37 (33.3)
Unsure	14 (12.6)
Somewhat unlikely	4 (3.6)
Very unlikely	0 (0)
Do you think recent advances in genetics such as screening and personalized medicine are generally good or bad?	
Very good	68 (60.2)
Somewhat good	31 (27.4)
Unsure	14 (12.4)
Somewhat bad	0 (0)
Very bad	0 (0)
Are you afraid scientists will go “too far” with genetic advances (e.g., designer babies or cloning people)?	
Very afraid	12 (10.6)
Somewhat afraid	30 (26.6)
Unsure	33 (29.2)
Not afraid	19 (16.8)
Not at all afraid	19 (16.8)
Do you think celebrities and the media influence public perception of genetic testing?	
A lot	22 (19.6)
Somewhat	53 (47.3)
Unsure	24 (21.4)
Very little	9 (8.0)
Not at all	4 (3.6)

access to genetic testing and/or a genetic counselor nearby to discuss results was either a minor or major barrier.

Our study found that rural survey participants were generally aware of and had favorable attitudes towards genetic testing. Previous studies in rural Appalachian Kentucky have explored the awareness and intention to seek testing for heritable cancers

and found that greater knowledge of genetic testing did not affect intention to seek genetic testing (Kelly et al. 2007; Andrykowski et al. 1996). However, these studies were published in 1996 and 2007. With the growth of both clinical and home-based genetic testing modalities, it is important to understand the relationship between knowledge and attitudes towards genetic testing and

Table 4 Barriers to genetic testing

	<i>n</i> (%)
Afraid of what results would say	
Major reason	8 (7.0)
Minor reason	30 (26.3)
Not a reason	76 (66.7)
Afraid your insurance company would know the results	
Major reason	24 (21.2)
Minor reason	37 (32.7)
Not a reason	52 (46.0)
Afraid of telling your family	
Major reason	7 (6.1)
Minor reason	14 (12.3)
Not a reason	93 (81.6)
Afraid of being fired from your job	
Major reason	2 (1.8)
Minor reason	14 (12.6)
Not a reason	95 (85.6)
Afraid you could not do anything about it (doomed feeling)	
Major reason	15 (13.3)
Minor reason	32 (28.3)
Not a reason	66 (58.4)
Afraid your doctor will not keep the results private	
Major reason	1 (0.9)
Minor reason	18 (15.9)
Not a reason	94 (83.2)
Did not know it was an option	
Major reason	11 (10.0)
Minor reason	16 (14.6)
Not a reason	83 (75.5)
Cost	
Major reason	31 (27.2)
Minor reason	25 (21.9)
Not a reason	58 (50.9)
Not offered at a clinic near me	
Major reason	24 (21.2)
Minor reason	29 (25.7)
Not a reason	60 (53.1)
No genetic counselor nearby to discuss results	
Major reason	17 (14.9)
Minor reason	35 (30.7)
Not a reason	62 (54.4)
No time	
Major reason	10 (8.9)
Minor reason	21 (18.6)
Not a reason	82 (72.6)

how knowledge and attitudes impact subsequent utilization. A recent analysis of the national representative Health Information and National Trends Survey found that, compared with urban

populations, rural populations were less knowledgeable than urban populations about direct-to-consumer genetic testing (Salloum et al. 2018). Future studies should continue to explore the effect of awareness and positive attitudes on genetic testing, especially among rural populations who may be less aware.

Cost was identified as one of the most notable barriers to genetic testing identified in our study. This corroborates previous studies identifying cost as a barrier (Allain et al. 2012). However, policies in recent years have mitigated the cost barrier to genetic testing. As a result of the Affordable Care Act, any preventive recommendation from the USPSTF, like BRCA testing for high-risk women, is required to be covered by private insurance. A recent study found that the utilization of BRCA testing among rural women with employer-sponsored insurance has increased in recent years. This may be due, in part, to reduction of cost barriers to testing. Further, Medicare rules released in March 2018 note that Medicare will now cover FDA-approved genetic tests to guide cancer treatments (CMS 2018). Medicare patients disproportionately live in rural areas. With the growing insurance coverage of genetic testing to assess the risk for developing cancer as well as tests to guide cancer treatments, it is important that patients are aware of this coverage to mitigate the concern of cost burden.

An additional barrier to genetic testing identified in our study sample was the concern that insurance companies may know the results. Similar concerns were identified in previous studies, even studies that were conducted after the Genetic Information Nondiscrimination Act (GINA) was passed in 2008 (Allain et al. 2012; Hall et al. 2005). GINA is a federal law that prohibits employers and insurance companies from discriminating based upon genetic information. However, GINA does not address life, long-term, or disability insurance, and there are state-level laws that may fill these gaps in GINA. It is important for physicians and genetic counselors to be well versed in the details of federal and state law to ensure that patients have the information they need to make decisions on any testing they may seek and/or receive (Prince and Roche 2014).

Concern about not having access to genetic testing or access to a genetic counselor with whom one could discuss testing results was an additional barrier identified by our study sample. Rural populations have less access to any kind of clinical care, particularly specialty care like genetic counseling that is concentrated in urban academic centers (Cohen et al. 2013). Genetic counselors who practice in rural areas find that travel burdens and the lack of referrals from clinicians to their services to be barriers to provision of genetic counseling services (Emmet et al. 2018). Ensuring that providers are adequately aware of the utility and availability of genetic counseling services is important. However, telehealth provides another opportunity to provide important counseling for patients who may seek or have genetic testing performed. Several

Table 5 Barrier scores by demographic group

	Mean (SD)	Median barrier score	<i>p</i> value
Gender			
Male	3.5 (3.6)	2	0.006
Female	5.7 (4.1)	6	
Education			
Less than a high school/high-school degree	4.8 (4.0)	4	0.14
Some college	4.1 (4.0)	4	
Associate's degree	6.6 (3.5)	6.5	
Bachelor's degree	5.6 (4.7)	6	
Graduate/professional degree	3.5 (3.6)	3	
Age groups			
18–44	6.3 (4.9)	5	0.47
45–60	4.6 (3.9)	4	
61–74	4.8 (4.2)	4.5	
75+	3.6 (2.7)	4	
Employment status			
Working	4.8 (3.6)	5.5	0.90
Retired	4.8 (4.4)	4	
Other (student, homemaker, unemployed)	4.6 (4.1)	4	

studies have shown that this approach is effective in providing such services to rural populations and that rural residents are receptive to receiving genetic counseling through the utilization of this technology, which may even be more cost-effective than in-person sessions (Buchanan et al. 2015; McDonald et al. 2014; Hilgart et al. 2012).

Our study adds to the limited knowledge regarding rural residents and their acceptance of genetic testing. We only found two studies performed outside the USA (both in Great Britain) on a somewhat similar topic. One examined the acceptability of genetic testing for coronary heart disease risk among rural patients in Nottingham (Middlemass et al. 2014). The other discussed the implementation of an information technology-based cancer risk assessment in rural Somerset with related access to genetic testing (Tozer and Lugton 2007). Further work, in more countries and additional models of healthcare, needs to explore how to reach underserved rural populations.

Our study was not without its limitations. First, our study sample may not be “typical” or representative of rural populations elsewhere. For example, the majority of participants had at least some college education, which may be reflective of selection bias from recruitment. Additionally, individuals who consent to participate in a genetic study are likely to be knowledgeable regarding genetic testing and may have a more favorable attitude towards testing. Our relatively small sample size prevented us from being able to explore the differences in knowledge, attitudes, and perceived barriers by demographic characteristics. In addition, our study did not differentiate the implications of testing for single known gene mutations versus multiplex gene panels, which may include a number of variants of unknown significance that harbor greater

uncertainty in pathogenicity and clinical relevance (Lerner-Ellis et al. 2015). Despite these limitations, our study is one of the first studies to explicate barriers to genetic testing and examine knowledge, attitudes, and beliefs in rural populations outside of Appalachia.

We found that in our rural study sample, survey participants were knowledgeable and receptive to genetic testing services. Barriers that were identified by participants include cost, concerns of discrimination by insurance companies, and the lack of access to testing or genetic counselors to discuss results. There are opportunities to address these barriers by ensuring that health care providers are knowledgeable about insurance coverage for genetic testing and legislation that prohibits discrimination based upon genetic information so that providers can educate their patients. Further, to address the lack of access to genetic counseling services, telehealth has proven to be a modality to provide genetic counseling services to rural populations with high patient satisfaction and potentially less cost than in-person counseling sessions. Increased expansion of such services in rural areas throughout the country may help reduce this barrier and ensure rural patients have better access to genetic testing and counseling.

Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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