Improving access to cancer genetic services: perspectives of high-risk clients in a community-based setting

Ilana Miller¹ · Samantha Greenberg^{1,2} · Beverly M. Yashar¹ · Monica L. Marvin¹

Received: 14 August 2018 / Accepted: 8 April 2019 / Published online: 24 April 2019
© Springer-Verlag GmbH Germany, part of Springer Nature 2019

Abstract

Cancer genetic services are underutilized by high-risk clients in community-based health settings. To understand this disparity, 108 Planned Parenthood high-risk clients completed a utilization-focused survey. Clients expressed interest (78.8%) and intention (75.0%) in seeking genetic services. Personal/familial implications for cancer risk were the strongest motivators for seeking services (63.0–79.6%). Finances (39.6%) and worry (37.0%) were the biggest barriers. To reduce disparities in access to cancer genetics services, clinicians must understand clients' concerns and tailor their recommendations.

Keywords Cancer genetic services · Underserved population · Screening tool

Introduction

Genetic counseling and consideration of genetic testing for BRCA1/2 and other cancer predisposing genes are recommended for individuals with early onset cancer, multiple primary cancers, or a strong family history of cancer (“BRCA1 and BRCA2: Cancer Risk and Genetic Testing Fact Sheet” 2017; “NCCN Clinical Practice Guidelines in Oncology” 2016). Genetic testing can improve health outcomes by leading to increased screening, chemoprevention, and/or prophylactic surgery (Randall and Armstrong 2016). However, health care disparities exist with underutilization of cancer genetic services by individuals with lower socioeconomic and educational status (Armstrong et al. 2014; Levy et al. 2011; Randall and Armstrong 2016; Ward et al. 2004). Therefore, community-based programs have implemented screening tools to identify high-risk women and increase awareness of genetic services in underserved populations (Bellcross 2017). One tool, Planned Parenthood Federation of America’s (PPFA) Breast Cancer Risk Screening

Questionnaire (BRSQ), collects targeted personal and family history to identify women who would benefit from genetic services and related resources. Working with PPFA and their clientele provides a unique opportunity to evaluate a group of young women of low socioeconomic status who typically underutilize genetic services. (“NCCN Clinical Practice Guidelines in Oncology” 2016; Planned Parenthood Federation of America Inc. 2016; Planned Parenthood Federation of America 2016). This study explores the motivations and barriers of high-risk women identified through the BRSQ. Our results provide insight into the attitudes of a cohort of young, healthy individuals at a high risk for cancer, improve understanding of the reasons for underutilization of genetic services, and identify ways to improve genetic service utilization.

Methods

Participants Women ages 18 and over who screened positive on the BRSQ were recruited between September 2015 and January 2016 at 14 PPFA clinics in Michigan. They were asked to complete a paper-based survey at the end of the health care visit by their health care provider. Results were gathered from anonymous survey collection boxes at each of the 12 clinics (2 clinics did not collect any surveys), anonymized but linked to individual clinics.

✉ Monica L. Marvin
monicama@umich.edu

¹ Department of Human Genetics, University of Michigan, 4909 Buhl Building, 1241 E Catherine St, Ann Arbor, MI 48109-5618, USA

² Present address: Huntsman Cancer Institute, 2000 Circle of Hope Drive, Salt Lake City, UT 84112, USA

Survey instruments A novel 10-item survey was developed that focused on evaluating participants' attitudes towards and interest in genetic counseling. Content areas included:

- 1) Participant demographics (age, zip code, highest education level, genetic counseling discussion with the provider)
- 2) Intention to seek genetic services (interest in learning about personal cancer risk and likelihood to follow-up with a genetic counseling referral)
- 3) Motivators ($n = 8$), barriers ($n = 11$), and informational needs ($n = 11$) influencing interest in genetic counseling (participants selected all that applied; therefore, the endorsement percentage totals for these categories may exceed 100%)
- 4) Family history of breast/ovarian cancer (participants identified which relatives had a cancer history)

Response options included multiple choice and 5-point scales (1—not at all interested/not at all likely, 5—very interested/very likely). The motivators/barriers to genetic counseling were developed from previously used survey instruments (Anderson et al. 2012; Sheppard et al. 2014). While the final survey instrument was not piloted, input from key experts, including study team members and PPFA clinicians, helped establish validity.

Data analysis Responses to questions with 5-point scales were converted to discrete numerical values, and responses of 4/5 were categorized as interest or intention. Participant zip codes reported in an open-response format were assigned a numerical code based on county and assigned to a low or high poverty group based on the 2010 US poverty rate (US Census Bureau 2010).

Results were analyzed using SPSS Statistics 23 and included means comparative analyses, demographic descriptives, and factor analyses of motivators, barriers, and informational needs. The factor analyses generated thematic groupings were comprised of the most often co-selected items in (i) Motivators (ii) Barriers and (iii) Informational needs. The final column of Table 2 (“Loading of Component Factor”) signifies how strongly that factor correlated with the other factors in that group; a higher number demonstrates a stronger correlation.

Results

Study population One hundred twelve surveys were collected from 12 clinics, and 108 surveys were completed in entirety and eligible for analyses. Six (50%) clinics collected 10 or more surveys. The majority of participants were under the age of 40 (96.3%), reported high school as their highest

completed level of education (76.9%), and lived in a high poverty county (63.4%) (Table 1). All participants had at least one family member with a history of breast/ovarian cancer. One participant reported a personal history of cancer. Most participants (95.4%) indicated that their provider (majority of which were advanced practice clinicians) discussed genetic counseling with them.

Client's interest and intention to seek genetic services The majority of participants reported that they were both interested in understanding their inherited cancer risk (78.8%) and intended to seek genetic counseling (75.0%).

Motivators to seek genetic services All motivators were identified by at least one participant. Factor analysis of motivators identified three thematic groupings: (i) personal impact, (ii) accessibility, and (iii) provider directive (Table 2). The majority (63.0–79.6%) of participants endorsed personal impact motivators.

Barriers to pursue genetic services Participants identified fewer barriers than motivators (Table 2). The “I don't have any insurance” and “I think genetic counseling is too expensive” barriers were combined into a single “financial burden” barrier. The “I don't care much about genetics” barrier was not endorsed by any participants and was not included in the factor analysis. Factor analysis of barriers identified three thematic groupings: (i) personal impact, (ii) accessibility, and (iii) financial burden. Similar to motivators, the “personal impact” grouping was endorsed by the majority of participants.

Informational needs to seek genetic services All informational need options were endorsed by at least one respondent. The factor analysis identified two thematic groupings: (i) accessibility and (ii) knowledge, with “accessibility” receiving more responses than “knowledge” (Table 2).

There were no differences in interest or intention level when clients were grouped by family history, age, or education level.

Discussion

This study explored the perspectives of young healthy women of low socioeconomic status referred to cancer genetic services after screening positive on the BRSQ in Michigan PPFA clinics. We found that the majority of these high-risk women are interested in cancer genetic services and intend to pursue the genetic counseling referral. However, in spite of this high level of interest and intention, anecdotal evidence suggests that few women identified through the BRSQ ultimately receive cancer genetic services (Greenberg et al. 2018). Though Greenberg et al. identified provider perceived

Table 1 Study population: demographics

	<i>N</i> (%) of participants (<i>N</i> = 108)
Age ^a	
18–24	40 (37.4%)
25–29	34 (31.8%)
30–39	29 (27.1%)
40–49	4 (3.7%)
Highest level of education	
Middle school	3 (2.8%)
High school	83 (76.9%)
Bachelors'	20 (18.5%)
Masters' degree or higher	2 (1.9%)
County of residence ^{a,b}	
Wayne, MI	20 (18.7%)
Jackson, MI	19 (17.8%)
Genesee, MI	12 (11.2%)
Oakland, MI	12 (11.2%)
Ingham, MI	11 (10.3%)
Washtenaw, MI	9 (8.4%)
Macomb, MI	7 (6.5%)
Livingston, MI	6 (5.6%)
Other counties with <i>N</i> ≤ 3	11 (10.3%)
Poverty rate of county ^a	
Above 2010 national poverty rate ¹²	68 (63.6%)
Below 2010 national poverty rate ¹²	39 (36.4%)
Family members with breast/ovarian cancer ^c	
Self	1 (0.9%)
First degree relative	
Mother	41 (38.0%)
Sister	2 (1.9%)
Second degree relative	
Grandparent	45 (41.7%)
Aunt/uncle	60 (55.6%)
Cousin	11 (10.2%)
Discussion of genetic counseling with planned parenthood provider	103 (95.4%)

^a (*N* = 107) because one participant did not report this measure^b County of residence assigned by client-reported zip code^c No participants reported a father, brother, or child with a history of breast or ovarian cancer

explanations for this disparity, the patient perspective is crucial in identifying appropriate interventions. For participants in the current study, personal impact (management of personal/family risk) was the strongest motivator and worries about cancer risk and the perceived costs of genetic services were the strongest deterrents in intention to seek genetic services. These results are concordant with previous research in healthy individuals of diverse backgrounds as well as in young breast cancer survivors (Anderson et al. 2012; Armstrong et al. 2014; Levy et al. 2011; Ward et al. 2004).

These barriers highlight the important roles referring clinicians can play in anticipating and normalizing worry about

personal cancer risks and the economics of using genetic services. The fact that non-genetics providers often feel unprepared to address such questions about genetic services may add to patients' worry and anxiety (Greenberg et al. 2018). Initiatives to increase provider awareness and understanding of genetic service may enable providers to have more informed conversations with their patients regarding genetics referrals. Furthermore, discussing general cancer prevention or surveillance options with high-risk patients, such as breast imaging, chemoprevention, and surgical options, may help patients appreciate how knowledge of cancer risk can inform ongoing care and lead to early detection/prevention of cancer.

Table 2 Motivators, barriers, and informational needs clients desire before seeking genetic services

Thematic grouping of motivators	Motivators	<i>N</i> (%) of clients endorsing motivator (<i>N</i> = 108)	Loading of component in factor
Personal impact	Desire to know future cancer risk	86 (79.6%)	Component 1—0.571
	Benefit to family's future	74 (68.5%)	Component 1—0.710
	Impact in future health care decisions	68 (63.0%)	Component 1—0.560
Accessibility	Certain that insurance would cover services	55 (50.9%)	Component 2—0.611
	Clinic is close to home	16 (14.8%)	Component 2—0.697
	Ability to obtain genetic counseling by phone	7 (6.5%)	Component 2—0.448
Provider directive	Provider instruction	35 (32.4%)	Component 3—0.859
Thematic grouping of barriers	Barriers	<i>N</i> (%) of clients endorsing barrier (<i>N</i> = 108)	Loading of component in factor
Personal Impact	Worrying about having hereditary cancer	40 (37.0%)	Component 1—0.573
	No desire to know future cancer risk	10 (9.3%)	Component 1—0.783
	Not worried about developing cancer	4 (3.7%)	Component 1—0.586
	No impact on future health care decisions	3 (2.8%)	Component 1—0.100
Financial burden	No insurance	24 (22.0%)	Component 3—0.471
	Too expensive	19 (17.6%)	Component 3—0.515
Accessibility	Too busy	16 (14.8%)	Component 2—0.387
	Limited knowledge of genetics	5 (4.6%)	Component 2—0.247
	Clinic is too far from home	2 (1.9%)	Component 2—0.493
Thematic grouping of informational needs	Informational Need	<i>N</i> (%) of clients endorsing informational need (<i>N</i> = 108)	Loading of component in factor
Accessibility	Whether my insurance will cover genetic counseling	75 (69.4%)	Component 1—0.881
	Whether my insurance will cover genetic testing	75 (69.4%)	Component 1—0.898
	Where the nearest genetics center is located	53 (49.1%)	Component 1—0.466
Knowledge	Additional information on cancer risk	45 (41.7%)	Component 2—0.779
	Additional information on genetic counseling	43 (39.8%)	Component 2—0.826

Initiating this conversation at the time of referral may help patients anticipate what will happen during the genetic counseling appointment, alleviate some of the worry associated with the referral, and increase uptake of genetic services. Resources such as the “consumer-facing” section of the National Society of Genetic Counselors’ website (<http://aboutgeneticcounselors.com/>) may help guide these conversations and provide clinicians with examples of patient-friendly language to describe what to expect at a genetic counseling appointment.

In clients of lower socioeconomic status, it is not surprising that concerns about the financial burden of genetic services were common. Improved awareness of the financial landscape of genetic services is important as providers offer referrals. However, the dynamic nature of insurance coverage for genetic services complicates this discussion and makes partnerships with cancer genetics programs important. Cancer genetics programs often have personnel who can help referring providers and clients better understand the costs, coverage

policies, and financial assistance available related to genetic services.

Given Planned Parenthood’s commitment to provide maximal patient and clinic anonymity, the demographic information collected, as well as the denominator of patients recruited to participate, were limited. Important questions that we were not able to address in our study include the impact of race, ethnicity, specific family history, and type of provider seen on intent to seek genetic services and related barriers. We found, however, that young, healthy, high-risk women desire genetic counseling, but a variety of mitigating factors exist. To realize the full potential of community-based programs, ongoing communication and collaboration between community providers, genetics professionals, and clients are essential. Ongoing research from our group continues to explore the patient’s perspectives on the barriers to genetic services to inform efforts to reduce health care disparities in the provision of genetic services.

Acknowledgments The authors on this paper would like to thank the Planned Parenthood Federation of America staff and Mary Kint Petit at Planned Parenthood of Michigan for their support of this research. Many thanks to Mark Pearlman, Debra Duquette, and Kara Milliron for their assistance in survey development.

Funding information Partial funding for this project was provided by the National Society of Genetic Counselors Education Special Interest Group and the University of Michigan Genetic Counseling Research Grant.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Studies with human subjects All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study. The study was approved for exemption through University of Michigan IRB HUM00103068.

References

- Anderson B, McLosky J, Wasilevich E, Lyon-Callo S, Duquette D, Copeland G (2012) Barriers and facilitators for utilization of genetic counseling and risk assessment services in young female breast cancer survivors. *J Cancer Epidemiol* 2012
- Armstrong K, Micco E, Carney A, Stopfer J (2014) Racial differences in the use of BRCA1/2 testing among women with a family history of breast and ovarian cancer. *J Am Med Assoc* 293(14):1729–1736
- Bellcross C (2017) Identification and genetic counseling referral of women at risk for hereditary breast and ovarian cancer [webinar recording]. Retrieved from <http://breeze.mdch.train.org/p1xh57abhms/?launcher=false&fcsContent=true&pbMode=normal>
- BRCA1 and BRCA2: Cancer Risk and Genetic Testing Fact Sheet - National Cancer Institute (n.d.) Retrieved May 22, 2017, from <https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet>
- Greenberg S, Yashar B, Pearlman M, Duquette D, Milliron K, Marvin M (2018) Evaluating and improving the implementation of a community-based hereditary cancer screening program. *J Community Genet*
- Levy DE, Byfield SD, Comstock CB, Garber JE, Syngal S, Crown WH, Shields AE (2011) Underutilization of BRCA1/2 testing to guide breast cancer treatment: black and Hispanic women particularly at risk. *Genet Med* 13(4):349–355. <https://doi.org/10.1097/GIM.0b013e3182091ba4>
- NCCN Clinical practice guidelines in oncology. (2016). Retrieved from https://www.nccn.org/professionals/physician_gls/f_guidelines.asp
- Planned Parenthood Federation of America (2016) The urgent need for planned parenthood health centers. Retrieved March 12, 2017, from https://www.plannedparenthood.org/files/4014/6773/0282/20160620_Defunding_fs_d1_4.pdf
- Planned Parenthood Federation of America Inc. (2016) Planned parenthood by the number. Retrieved March 12, 2017, from https://www.plannedparenthood.org/files/7214/6833/9709/20160711_FS_PPNumbers_d1.pdf
- Randall T, Armstrong K (2016) Health care disparities in hereditary ovarian cancer: are we reaching the underserved population? *Curr Treat Options in Oncol* 17(39)
- Sheppard VB, Graves KD, Christopher J, Hurtado-de-Mendoza A, Talley C, Williams KP (2014) African American women's limited knowledge and experiences with genetic counseling for hereditary breast cancer. *J Genet Couns* 23(3):311–322. <https://doi.org/10.1007/s10897-013-9663-6>
- US Census Bureau, D. I. D (2010) Small area income and poverty estimates for 2010. Retrieved from <https://www.census.gov/did/www/saipa/data/statecounty/data/2010.html>
- Ward E, Jemal A, Cokkinides V, Singh GK, Cardinez C, Ghafoor A, Thun M (2004) Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin* 54(2):78–93. <https://doi.org/10.3322/canjclin.54.2.78>

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.