Educational needs about cancer family history and genetic counseling for cancer risk among frontline healthcare clinicians in New York City

Katarina M. Sussner, PhD, MPH[1], Lina Jandorf, MA[1], and Heiddis B. Valdimarsdottir, PhD[1,2,3]

Purpose: This study investigated the educational needs of frontline healthcare clinicians about cancer family history and genetic counseling for cancer risk. **Methods:** We conducted a voluntary, anonymous survey among (1) general medicine clinicians, (2) obstetrics/gynecology clinicians, and (3) nurse practitioners at Mount Sinai School of Medicine in New York City. **Results:** A total of 143 clinicians completed the survey (response rate 81%). The majority of clinicians (77.5%) reported regularly completing family histories on cancer risk for their patients, but only 1.7% considered themselves "experts" in interpreting risk to make prevention, screening, and treatment recommendations. Numerous barriers to cancer family history collection were noted. More than half (55.8%) reported referring patients to genetic counseling, although only 14.3% reported confidence in their ability to make appropriate referrals. The majority reported that they would apply genetic counseling for cancer risk in their practice if they had the skills (84.9%). There was some variability found regarding specialty. **Conclusion:** Despite widespread use of family histories for cancer risk, barriers remain to appropriate cancer risk management among frontline healthcare clinicians. Development of educational training programs to assist clinicians with collection of cancer family history information, interpretation, and appropriate referral along with teaching direct application of a modified form of genetic counseling for low-medium risk patients and referral of patients at genetic risk is warranted. ***Genet Med*** **2011:13(9):785–793.**

Key Words: *cancer family history, genetic counseling*

Understanding cancer family history is important to effectively manage cancer risk and mortality, given 25–30% of all cancers are related to a familial history of cancer (including 5–10% as hereditary or inherited predispositions within breast, ovarian, and colon cancers and another 20% by family clusters).[1–3] Increasing evidence suggests that individuals considered at risk for hereditary and genetic cancer syndromes should receive genetic counseling, as genetic counseling provides individuals with a wealth of information including their personal and family risk of developing cancer; the availability of different preventive and surveillance options; and the pros and cons of undergoing genetic testing.[4–6] The US Preventive Task Force[1,7] strongly recommends that all high-risk individuals with a family history suggestive of hereditary breast and ovarian cancer undergo genetic counseling. Similarly, the revised Bethesda Guidelines and National Comprehensive Cancer Center Network clinical practice guidelines provide a framework for identifying individuals who should undergo genetic counseling and testing for hereditary nonpolyposis colorectal cancer and familial adenomatous polyposis.[8,9]

Despite the benefits of genetic counseling for hereditary cancer risk, research suggests that frontline healthcare clinicians who have most frequent contact with at-risk patients may have very limited information about appropriate risk management including referrals for genetic counseling based on collection and interpretation of cancer family history information. In fact, research suggests that family history is the most important tool for diagnosis and risk assessment management in medical genetics, even though translational education in this area to date has been extremely unsophisticated and limited.[10] Family history is considered a cornerstone to screening and managing common diseases and in particular cancer, with approximately 20% of primary care patients having family histories which would place them at increased risk for cancer.[11,12] However, surprisingly, collection of family history in the primary care setting has been grossly underused to date.[13] Barriers to collection of family history are both patient and clinician related. Known patient-related barriers to collection of family history include low knowledge and lack of awareness about relatives' health information, inaccuracies in patient recall, poor communication, and language-related, cultural, and education-related factors, which may impede collection of an accurate family history. For example, although a survey of patients in 2004 found that 96% of respondents believed knowledge of family history was "somewhat" or "very important," $<1/3$ of patients actually collected health information from relatives.[14] From the clinicians' end, known barriers include inadequate time to collect family history due to short office visits, lack of reimbursement for collection, and the lack of clear guidelines to assess low, moderate, and high-risk patients.[10,12,13,15–18]

Due to the increasingly influential role frontline healthcare clinicians will inevitably fill for genetic services for cancer risk in a renewed era which focuses on preventive care as part of healthcare reform, it is imperative to understand the current state of clinical practice related to cancer family history collection and appropriate cancer risk management including genetic counseling referral among these clinicians. We conducted a brief, voluntary, and anonymous survey about the educational needs of frontline healthcare clinicians (defined here as including general medicine clinicians, obstetrics/gynecology [ob/gyn] clinicians, and nurse practitioners) about cancer family history and genetic counseling for cancer risk. The purpose of this survey was to identify needs of frontline healthcare clinicians in this area to inform the development and design of future educational interventions and programs.

From the [1]Department of Oncological Sciences, Cancer Prevention and Control, Mount Sinai School of Medicine, New York City, New York; [2]School of Health and Education, Reykjavik University; and [3]Department of Psychology, University of Iceland, Iceland.

Katarina M. Sussner, PhD, MPH, Division of Cancer Prevention and Control, Department of Oncological Sciences, Mount Sinai School of Medicine, One Gustave L. Levy Place, 1425 Madison Ave, Box 1130, New York City, NY 10029. E-mail: katarina.sussner@mssm.edu.

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MATERIALS AND METHODS

Eligibility criteria for participating in the survey included any clinicians who were currently attending the Grand Rounds session of their respective Departments at Mount Sinai School of Medicine in New York City (NYC) including (1) general medicine; (2) ob/gyn, and (3) nurse practitioners. A trained Research Assistant (RA) attended each Department's Grand Rounds session at a specific date and time, with prior permission of the head of each Grand Rounds Department. The trained RA made a brief announcement at the beginning of the session about the purpose of the survey, handed out surveys, and announced that she would collect surveys at the end of the Grand Rounds session. At the end of the session, the anonymous surveys were returned by the RA to a stored/locked location in the principal investigator's office. The survey responses were entered into a password-protected electronic computer file.

The study was anonymous and had no risk to the subject's employability, reputation, or financial standing. To demonstrate whether there is a need for this information among frontline healthcare clinicians, we purposely chose to conduct this study among general medicine clinicians, ob/gyn clinicians, and nurse practitioners. However, there were no biases in terms of the groups of respondents expected to be more open to or interested in providing genetic counseling or referrals, thus why the proposed needs assessment was deemed critical. Individuals who chose to participate in the survey read a short statement before beginning the survey acknowledging that they were consenting to participating in the anonymous survey and that they could stop their participation at anytime. Individuals were informed that this survey was being completed for research purposes to inform the development of a future educational training for nurses, ob/gyn physicians or practitioners physicians, and general practitioners about cancer family history collection and genetic counseling for cancer risk. No individuals received compensation for completing the survey. The study was approved by the Mount Sinai School of Medicine Institutional Review Board.

Needs assessment survey

The 12-item needs assessment survey included questions related to (1) current state of the cancer family history collection in clinical practice (including how often updated, what kinds of information is included, level of perceived skill interpreting cancer risk based on family history information, and barriers to collecting cancer family history); (2) current state of referrals for genetic counseling and testing for cancer risk in clinical practice (including perceived level of confidence in making appropriate referrals and whether clinicians conduct their own genetic counseling and related perceived level of skill) and influence of advertisements from genetic testing companies; and (3) interest in educational tools and programs to assist with collection of cancer family history information and application of genetic counseling in clinical practice (including importance placed and application of genetic counseling in clinical practice, level of motivation to learn genetic counseling, and interest in attending training workshop for genetic counseling).

Statistics

Descriptive statistics was conducted to measure the frequency of participant responses to each item. Statistical comparisons were calculated to see whether there were any measurable differences on survey items between the three main groups surveyed (1) ob/gyn, (2) general medicine, and (3) nurse practitioners. Logistic regression analyses were calculated (reporting associated odds ratios [ORs], 95% confidence intervals [CI], and P values in the results) for survey items with dichotomous responses. Linear regression analyses were performed (reporting associated beta coefficients, standard errors (SEs), and P values in the results) on survey items with linear responses. All statistical programming was completed with SAS 9.1.3 statistical software.

RESULTS

Sample

A total of 143 clinicians (40% ob/gyn, 21% nurse practitioners, 21% general medicine, and 18% other medical specialties) completed the survey, with a response rate of 81%. For the purposes of making meaningful comparison between clinical practice groups, clinicians who identified themselves as "other medical specialties" were not included in these comparisons.

Current state of cancer family history collection in clinical practice

Table 1 reports survey results related to the current state of cancer family history collection in clinical practice.

Collection of cancer family history information

Although the majority (77.5%) reported regularly completing family histories/pedigrees on cancer risk on their patients, only a quarter of respondents (25.9%) included several key components of a minimum adequate cancer family history (first- and second-degree relatives on both maternal and paternal side, type of cancer, and age at time of cancer diagnosis).[18] Most clinicians reported updating these family histories once a year (57.4%), with the next largest group never updating family histories (22.2%). Less than half (43.4%) of clinicians reported including family history on the paternal side in family histories/pedigrees, family history on the maternal side (48.3%), second-degree relatives (40.6%), or age at time of cancer diagnosis (43.4%). Ob/gyn clinicians had more than six times the odds of reporting the collection of cancer family history information compared with general medicine clinicians and nurse practitioners (OR = 6.3, 95% CI = 2.2–18.2, $P = 0.0006$) and had more than three times the odds of collecting all the necessary information in the family histories collected (OR = 3.3, 95% CI = 1.4–7.8, $P = 0.007$). Nurse practitioners had lower odds of regularly completing family histories on cancer risk for their patients (OR = 0.1, 95% CI = 0.4–0.3, $P < 0.0001$) and lower odds of collecting all the necessary kinds of information required in the family histories (OR = 0.3, 95% CI = 0.1–0.9, $P = 0.05$) compared with ob/gyn and general medicine clinicians.

Perceived skill in interpreting cancer risk based on family history information

Only 1.7% of clinicians considered themselves "experts" in terms of their perceived level of skill in interpreting cancer risk based on family history information and subsequent prevention, screening, and treatment recommendations. Ob/gyn clinicians reported a higher level of perceived skill related to interpreting cancer risk compared with general medicine clinicians and nurse practitioners ($\beta = 0.4$, SE = 0.2, $P = 0.03$). Nurse practitioners report lower levels of skill in interpreting cancer risk compared with the other two groups ($\beta = -0.7$, SE = 0.3, $P = 0.01$).

Table 1. Current state of cancer family history collection in clinical practice

Survey item	Participant responses, *N* (%)	Statistically significant differences between clinical practice groups[a]		
		Ob/Gyn vs. Gen Med and NPs	Gen Med vs. Ob/Gyn and NPs	NPs vs. Ob/Gyn and Gen Med
Do you regularly complete family histories/pedigrees on cancer risk for your patients?				
Yes	110 (77.5)	6.3 (2.2–18.2); $P = 0.0006$	NS	0.1 (0.04–0.3); $P < 0.0001$
No	32 (22.5)			
If "yes," how often do you update these family histories/pedigrees on cancer risk?				
Never	24 (22.2)	NS	NS	NS
Once a year	62 (57.4)			
Several times a year	12 (11.1)			
At every visit, regardless of purpose of visit	10 (9.3)			
If "yes," which of the following kinds of information do these family histories/pedigrees routinely include (all that apply)?				
First-degree relatives	99 (69.2)	3.9 (1.7–9.2); $P = 0.002$	NS	0.2 (0.1–0.5); $P = 0.002$
Second-degree relatives	58 (40.6)	3.1 (1.5–6.7); $P = 0.004$	NS	0.3 (0.1–0.9); $P = 0.02$
Type of cancer	88 (62.4)	3.9 (1.7–8.6); $P = 0.0009$	NS	0.2 (0.01–0.4); $P < 0.0001$
Age at time of diagnosis	62 (43.4)	NS	NS	0.2 (0.1–0.6); $P = 0.003$
Family history maternal	69 (48.3)	NS	NS	0.40 (0.2–0.9); $P = 0.04$
Family history paternal	62 (43.4)	NS	NS	0.40 (0.2–0.9); $P = 0.03$
All above information	37 (25.9)	3.3 (1.4–7.8); $P = 0.007$	NS	0.3 (0.1–0.9); $P = 0.05$
If "yes," how would you rate your level of skill related to interpreting cancer risk (low, moderate, high) based on family history/pedigree information you collect and subsequent prevention, screening, and treatment recommendations (1 = novice, 5 = expert)				
1 = novice	13 (11.3)	0.4 (SE = 0.2); $P = 0.03$	NS	−0.7 (SE = 0.3); $P = 0.01$
2	38 (33.0)			
3	43 (37.4)			
4	19 (16.5)			
5 = expert	2 (1.7)			
Which of the following barriers to collecting cancer family history and risk information do you currently face in your practice (all that apply)?				
Ability to identify low, moderate high risk cases and provide appropriate risk management	42 (29.4)	NS	NS	NS
Language and cultural barriers with patients	36 (25.2)	NS	NS	NS
Lack of patient knowledge about cancer family history	64 (44.8)	NS	2.9 (1.2–6.8); $P = 0.02$	0.09 (0.03–0.3); $P = 0.0002$
Lack of time for practitioner to collect cancer family history information	64 (44.8)	3.8 (1.8–8.2); $P = 0.0006$	NS	0.1 (0.04–0.4); $P = 0.0002$
Lack of time for practitioner to interpret information, provide appropriate risk management and counseling	39 (27.3)	2.7 (1.2–6.3); $P = 0.02$	NS	0.06 (0.008–0.5); $P = 0.0007$

[a]Reporting odds ratios (95% confidence intervals) and *P* values for dichotomous variables. Reporting beta coefficient (standard error) and *P* values for continuous variables.
NS, not significant; Gen Med, general medicine; NP, nurse practitioner.

Perceived barriers to collection of cancer family history

Main perceived barriers to collecting cancer family history and risk information included lack of time on part of the clinician to collect such information (44.8%) and lack of patient knowledge about cancer family history (44.8%). Other barriers included low perceived ability to identify low, moderate, and high-risk cases and provide appropriate risk management (29.4%) and language and cultural barriers with their patients related to collection of cancer family history and risk information (25.2%). Ob/gyn clinicians had higher odds of reporting a lack of time to collect cancer family history information (OR = 3.8, 95% CI = 1.8–8.2, $P = 0.0006$) and lack of time to interpret information and provide appropriate risk management and counseling (OR = 2.7, 95% CI = 1.2–6.3, $P = 0.02$) compared with general medicine clinicians and nurse practitioners. Nurse practitioners had lower odds of reporting a lack of patient knowledge about cancer family history (OR = 0.09, 95% CI = 0.03–0.3, $P = 0.0002$), a lack of time to collect cancer family history information (OR = 0.1, 95% CI = 0.04–0.4, $P = 0.0002$), and a lack of time to interpret information and provide appropriate risk management and counseling (OR = 0.06, 95% CI = 0.008, 0.5, $P = 0.0007$) compared with ob/gyn and general medicine clinicians.

Current state of referrals for genetic counseling and testing in clinical practice and influence of advertisements from genetic testing companies

Table 2 reports the results related to the current state of referrals for genetic counseling and testing in clinical practice and the influence of advertisements from genetic testing companies.

Referral for genetic counseling and testing for cancer risk

Only 16.7% of clinicians reported ordering genetic tests directly for cancer risk. Despite the widespread use of completing family histories on cancer risk, only 44.1% of clinicians reported that they refer patients to genetic counseling for cancer risk, with only 14.3% of clinicians reporting that they felt "confident" or "very confident" in their ability to make appropriate referrals. Ob/gyn clinicians had six times the odds of reporting the ordering of genetic tests directly (OR = 6.0, 95% CI = 1.9–19.1, $P = 0.003$), had eight times the odds of referring patients to genetic counseling for risk (OR = 8.1, 95% CI = 3.5–18.9, $P < 0.0001$), and reported higher confidence in their ability to make appropriate referrals for genetic counseling for cancer risk ($\beta = 1.1$, SE = 0.2, $P < 0.0001$) compared with general medicine clinicians and nurse practitioners. Nurse practitioners had lower odds of referring patients to genetic counseling for cancer risk compared with ob/gyn and general medicine clinicians (OR = 0.1, 95% CI = 0.03–0.4, $P = 0.0005$) and reported less confidence in their ability to make appropriate referrals ($\beta = -1.5$, SE = 0.4, $P = 0.0002$). General medicine clinicians had lower odds of referring patients to genetic counseling compared with ob/gyn and nurse practitioners ($\beta = 0.4$, 95% CI = 0.2–0.9, $P = 0.05$).

Influence of advertising from genetic testing companies in clinical practice

Approximately 23.6% of clinicians reported receiving advertisements from genetic testing companies about their products for cancer risk mutations. The majority of clinicians (66.7%) believed these advertisements did not influence their decision to order genetic tests for patients at all. Ob/gyn clinicians had close to eight times the odds of receiving advertisements compared with general medicine and nurse practitioners (OR = 7.9, 95% CI = 2.7–22.6, $P = 0.0001$). General medicine clinicians had lower odds of receiving advertisements (OR = 0.2, 95% CI = 0.07–0.9, $P = 0.03$) compared with ob/gyn and nurse practitioners, whereas nurse practitioners had statistically significant lower odds of receiving advertisements compared with ob/gyn and general medicine clinicians (OR = 0.2, 95% CI = 0.04–0.8, $P = 0.02$).

Genetic counseling for cancer risk

Approximately 21.6% of clinicians reported that they currently do their own genetic counseling for cancer risk with their patients. None of these clinicians considered themselves an "expert" in terms of their perceived level of skill related to genetic counseling. Meanwhile, 26.7% reported their perceived level of skill as "novice" ("1" on a scale of "1–5") and 30% as "2" on a scale of "1–5." Ob/gyn clinicians had higher odds of doing their own genetic counseling for cancer risk compared with general medicine clinicians and nurse practitioners (OR = 2.7, 95% CI = 1.1–6.9, $P = 0.04$).

Interest in educational tools for assisting collection of cancer family history and programs to assist with collection of cancer family history information and application of genetic counseling in clinical practice

Table 3 reports results related to interest in educational tools and programs to assist with collection of cancer family history information and application of genetic counseling in clinical practice.

Interest in educational tools

Most clinicians were interested (64.1% reporting "interested" to "extremely interested") in an interactive educational tool for completing family histories for cancer risk to assist clinicians in interpreting risk level and communicating appropriate risk recommendations and a tool for patients' use (66.9% reporting "interested" to "extremely interested"). General medicine clinicians reported less interest in a tool for patients' use compared with ob/gyn clinicians and nurse practitioners ($\beta = -0.6$, SE = 0.2, $P = 0.02$).

Importance of genetic counseling and interest in training for genetic counseling

Most clinicians (61.9%) believed it would be important to use genetic counseling in their practice if they felt proficient. In fact, 84.9% said they would apply genetic counseling in their current work setting if they had the skills, and 76.2% were interested in attending a training workshop on genetic counseling for cancer risk with continuing medical education credits available. General medicine clinicians placed lower importance on genetic counseling for cancer risk in their practice ($\beta = -0.9$, SE = 0.21, $P < 0.0001$) and reported lower motivation to learn genetic counseling for cancer risk ($\beta = -0.8$, SE = 0.2, $P = 0.0002$) compared with ob/gyn clinicians and nurse practitioners. Ob/gyn clinicians placed more importance on genetic counseling for cancer risk in their practice ($\beta = 0.7$, SE = 0.2, $P = 0.0003$) and had close to three times the odds of being interested in attending a training workshop on genetic counseling for cancer risk compared with general medicine clinicians and nurse practitioners (OR = 2.7, 95% CI = 1.1–6.6, $P = 0.03$).

Table 2. Current state of referrals for GC and GT in clinical practice and influence of advertisements from GT companies

		Statistically significant differences between clinical practice groups[a]		
	Participant responses, *N* (%)	Ob/Gyn vs. Gen Med and NPs	Gen Med vs. Ob/Gyn and NPs	NPs vs. Ob/Gyn and Gen Med
Do you currently order genetic tests directly for your patients for cancer risk?				
Yes	23 (16.7)	6.0 (1.9–19.1); $P = 0.003$	NS	NS
No	115 (83.1)			
Do you directly receive advertisements from genetic testing companies about their products available for cancer risk mutations?				
Yes	33 (23.6)	7.9 (2.7–22.6); $P = 0.0001$	0.2 (0.07–0.9); $P = 0.03$	0.2 (0.04–0.8); $P = 0.02$
No	107 (76.4)			
If "yes," how much do these advertisements influence your decision to order genetic tests for your patients?				
1 = not at all	24 (66.7)	NS	NS	NS
2 = somewhat	12 (33.3)			
3 = a lot	0 (0)			
Do you currently refer your patients to genetic counseling for cancer risk?				
Yes	60 (44.1)	8.1 (3.5–18.9); $P < 0.0001$	0.4 (0.2–0.9); $P = 0.05$	0.1 (0.03–0.4); $P = 0.0005$
No	76 (55.9)			
If "yes," how confident do you feel about your ability to make appropriate referrals for genetic counseling for cancer risk?				
1 = not at all confident	7 (11.1)	1.1 (SE = 0.2); $P < 0.0001$	NS	−1.5 (SE = 0.4); $P = 0.0002$
2 = somewhat confident	26 (41.3)			
3 = confident	21 (33.3)			
4 = very confident	7 (11.1)			
5 = extremely	2 (3.2)			
Do you currently do your own genetic counseling for cancer risk?				
Yes	30 (21.6)	2.7 (1.1–6.9); $P = 0.04$	NS	NS
No	109 (78.4)			
If "yes" how would you rate your level of skill related to genetic counseling for cancer risk (1 = novice, 5 = expert)?				
1 = novice	8 (26.7)	NS	NS	NS
2	9 (30.0)			
3	8 (26.7)			
4	5 (16.6)			
5 = expert	0 (0)			

[a]Reporting odds ratios (95% confidence intervals) and *P* values for dichotomous variables. Reporting beta coefficient (standard error) and *P* values for continuous variables.
NS, not significant; Gen Med, general medicine; NP, nurse practitioner.

DISCUSSION

Study results inform the literature by documenting the current state of cancer family history collection, referral for genetic counseling practices, and related educational needs of frontline healthcare clinicians in NYC. As we enter the era of healthcare reform which will place a renewed focus on preventive care, such information is particularly timely and relevant as there will be an unprecedented demand on clinicians to understand how to appropriately manage cancer risk. Results found that despite widespread collection of cancer family history, barriers remained related to the lack of completeness of family histories, low perceived skill in the ability to interpret family histories, lack of time on part of the practitioner to collect cancer family history information, and lack of patient knowledge about cancer family history and concerns about ability to identify low, moderate, and high-risk cases and provide appropriate risk management. Although many of these barriers have been previously described in the literature,[10,12,13,15–18] this study advances our understanding one step further by uniquely identifying specific educational and training needs of frontline healthcare clinicians who will increasingly face pressure to manage cancer risk in their patients.

Table 3. Interest in educational tools and programs to assist with a collection of cancer family history information and application of GC in clinical practice

		Statistically significant differences between clinical practice groups[a]		
	Participant responses *N* (%)	Ob/Gyn vs. Gen Med and NPs	Gen Med vs. Ob/Gyn and NPs	NPs vs. Ob/Gyn and Gen Med
How interested would you be in an interactive educational tool (DVD, online program) for completing family histories for cancer risk that would assist you and/or your patients in interpreting risk level and communicating appropriate prevention, screening, and treatment recommendations based on this risk?				
Interest in tool for practitioners' use				
1 = not at all interested	14 (9.9)	NS	NS	NS
2 = somewhat interested	37 (26.1)			
3 = interested	49 (34.5)			
4 = very interested	28 (19.7)			
5 = extremely interested				
Interest in tool for patients' use				
1 = not at all interested	14 (9.9)	NS	−0.6 (SE = 0.2); $P = 0.02$	NS
2 = somewhat interested	9 (6.5)			
3 = interested	37 (26.6)			
4 = very interested	48 (34.5)			
5 = extremely interested	29 (20.9)			
How important do you think using genetic counseling for cancer risk would be in your practice, if you felt proficient in genetic counseling?				
1 = not at all important	6 (4.3)	0.7 (SE = 0.2); $P = 0.0003$	−0.9 (SE = 0.2); $P < 0.0001$	NS
2 = somewhat important	47 (33.8)			
3 = important	35 (25.2)			
4 = very important	39 (28.1)			
5 = extremely important	12 (8.6)			
Would you apply genetic counseling for cancer risk in your current work setting if you had the skills?				
Yes	112 (84.9)	NS	NS	NS
No	20 (15.1)			
What is your level of motivation to learn genetic counseling for cancer risk, if you had the opportunity?				
1 = not at all motivated	12 (8.6)	NS	−0.8 (SE = 0.2); $P = 0.0002$	NS
2 = somewhat motivated	47 (33.8)			
3 = motivated	49 (35.2)			
4 = very motivated	19 (13.7)			
5 = extremely motivated	12 (8.6)			
Would you be interested in attending a professional, no-cost 1–2-day training workshop on genetic counseling for cancer risk (with continuing medical education credits available)?				
Yes		2.7 (1.1–6.6); $P = 0.03$	NS	NS
No				

[a]Reporting odds ratios (95% confidence intervals) and *P* values for dichotomous variables. Reporting beta coefficient (standard error) and *P* values for continuous variables. NS, not significant; Gen Med, general medicine; NP, nurse practitioner.

As previous research shows, complete and accurate family histories are critical to making appropriate referrals for genetics services and clear guidelines for physicians.[19] In line with study findings, research describes how lack of complete family histories may be related to limited knowledge about cancer genetics among clinicians.[20,21] Comprehensiveness and quality of family histories collected by clinicians may be limited by failure to include other information deemed critical to genetic risk

assessment such as information on second-degree relatives and age at time of diagnosis. Furthermore, as family history is dynamic and changing, it is recommended that family history information should be updated regularly,[22] a recommendation not met by almost a quarter of respondents in this study. In fact, results are in accordance with previous literature, which has found that information on second-degree relatives and age at diagnosis are often missing or not updated frequently.[12,23,24] It is, thus, advised that educational trainings for clinicians about cancer family history collection incorporate not only which components should be included in a family history but also include specific instruction on the importance of updating these tools at least once a year to ensure quality.

Study results related to the low perceived skill in interpreting cancer risk among frontline healthcare clinicians fall in line with previous research documenting low ability to assign risk. In theory, guidelines should be used by physicians to correctly estimate categories of patient risk: low, moderate, or high and make appropriate referrals and screening and prevention-related management decisions based on this risk. However, a recent study found that primary care physicians' ability to correctly assign risk was low, even in cases where they reported high levels of confidence in their ability to assign risk; specifically, half of primary care physicians incorrectly assigned a high-risk categorization to a low-risk case.[25] In another study using unannounced standardized (simulated) patients, satisfaction with physician communication was higher for moderate risk cases compared with high-risk case,[26] highlighting that many physicians are unprepared to address complex high-risk scenarios. Results suggest that educational training programs designed for frontline healthcare clinicians should focus on increasing the ability of clinicians to correctly identify risk level and make appropriate risk management recommendations (surveillance, screening, and referral for counseling).

Study results underscore a low perceived ability of clinicians to make appropriate referrals to genetic counseling, specifically. Previous literature demonstrates problems of underreferral for genetic counseling and a lack of identification of patients at highest risk, correlated with insufficient collection of family history, risk assessment, and documentation by medical staff, as well as lack of confidence by clinicians in managing genetic counseling. Sweet et al.[16] examined the extent to which cancer family history completed by physician matched information entered by patients. Results found that many patients had little or no family history documented in medical records and rarely updated beyond the first visit. Most critically, physician-completed information failed to confirm patient information, particularly with patients assigned to a high-risk category, resulting in low referral for genetic counseling by physicians. Of 69 high-risk patients, only 20% had a notation acknowledging high risk in their medical record from their physician. Of those with the notation, only 50% were referred to genetic counseling.

Study results found that of those clinicians who self-report doing their own genetic counseling, clinicians' perceived ability to conduct such counseling is low. Such results are in agreement with previous findings from a nationally representative survey documenting that only a small proportion of physicians felt qualified to provide genetic counseling to their patients directly (29%).[19] However, given that the availability of genetic counseling services may be constrained in some communities,[27,28] compounded by an increasing number of individuals seeking genetic counseling and the increased burden of previously underserved patients entering the system by healthcare reform,[29] there remains the opportunity for clinicians to learn how to conduct a modified or shortened form of genetic counseling through educational trainings to make surveillance and screening recommendations to their patients.

In fact, study results greatly contribute to this body of literature by demonstrating an overwhelming interest in educational tools and programs for clinicians to assist with collection of cancer family history information and to help apply genetic counseling in clinical practice. The desire of clinicians to apply genetic counseling in their work setting themselves was strong, along with the need to feel more confident in having the skills to do so. Additionally, interest in training workshops for clinicians focused on gaining genetic counseling skills was high. Study results documented the need and usefulness of educational tools designed both for patients' and practitioners' dual use. In recent years, several primarily patient-based computerized tools have been developed to assist patients with collecting cancer family history and thereby facilitate more appropriate referral and management for genetic services for cancer risk by clinicians.[13,16,30–35] Through online websites, touch-screen kiosk, and tablet-based formats, the goal of the majority of these tools has been to provide printout pedigrees collected outside of the regular clinician visit for patients to bring to their physicians to help communicate and manage cancer risk. However, to our knowledge, the majority of these tools to date have not directly involved educational training of frontline healthcare clinicians in how to actually interpret patient pedigrees, calculate risk calculations, and/or provide appropriate cancer risk management recommendations to patients. Furthermore, none of these tools teach clinicians how to do appropriate genetic and risk management counseling for low-medium risk women and appropriate referrals to genetic counseling services for those at genetic risk, which is of clear interest to clinicians based on our study results. For this reason, future research should work toward the development of training programs to overcome barriers to appropriate cancer risk management, including educating frontline healthcare clinicians in direct application and interpretation of such computerized tools and instructing patients how to complete patient-based tools. Both these efforts would help substantially reduce the amount of time and knowledge required on the part of the clinician to complete a pedigree by hand, along with help improve the comprehensiveness and quality of family history collected. Another useful training area would be assisting clinicians to conduct a modified or abbreviated form of genetic counseling for their low-medium risk patients to provide appropriate risk management recommendations including surveillance and screening. In fact, as the number of self-referred patients to genetic services increases, research shows that greater emphasis should be on the clinicians' ability to not only provide appropriate referrals but also, perhaps more importantly, be able to effectively communicate and reassure patients who are not at high risk, providing reassurance in place of referral[36–38] and oftentimes dissuading low-risk patients from counseling and testing.[39] Meanwhile, at the same time, training clinicians in how to manage and appropriately refer high-risk patients directly to genetic counseling would be critical.

Finally, a number of statistically significant differences between clinician groups found in this study point to the need for different educational trainings based on clinical practice area. Ob/gyn clinicians had higher odds compared with general medicine and nurse practitioners of completing family histories on their patients, including the necessary information on these histories, ordering genetic tests directly, receiving advertisements from genetic testing companies, referring for genetic counseling, doing their own genetic counseling, and being interested in attending a training for genetic counseling. Ob/gyn clinicians also reported higher perceived levels of skill in inter-

preting cancer risk, confidence making appropriate referrals for genetic counseling, and more importance placed on genetic counseling. Recent literature has shown that the majority of ob/gyn residents regularly complete family histories in their obstetrics practice (90%) and cancer family histories in their gynecology practice (80%), 76% indicating a desire for more information and education about hereditary cancer and genetic testing.[40] In another recent study, however, only two thirds of ob/gyn clinicians felt "partially qualified" to manage genetic counseling for breast and gynecologic genetic screening, with the remainder feeling "not qualified."[41] Previous research has documented differences in knowledge and experience with breast cancer genetic testing between medical oncologists, internists, and ob/gyn clinicians; for example, only 21% of ob/gyns correctly answered all knowledge questions compared with 13% of internist and 40% of oncologists.[42] However, to the authors' knowledge, no previous research has compared general medicine, ob/gyn, and nurse practitioners specifically to date. It is possible that ob/gyn clinicians are more likely to encounter discussions related to these topics given that women may be more likely to discuss issues related to their reproductive organs with their ob/gyn compared with their general medicine clinician or nurse practitioner. In addition, the role of ob/gyn clinicians in identifying hereditary cancers among women may be particularly critical given many women are exclusively cared for by their ob/gyn clinician.[40] It remains unclear whether ob/gyn clinicians have actually experienced more training in making appropriate referrals and managing cancer risk compared with other clinician groups. Given the more limited role nurse practitioners have in medical decisions in general, it was not particularly surprising that nurse practitioners had lower odds of completing family histories, of referring for genetic counseling and reported less skill in interpreting cancer risk and less confidence in ability to make appropriate referrals. However, it may be critical that nurse practitioners assume a larger role in the care and management of cancer risk, as primary care faces increased demands underscoring the need for training of this group. Finally, as study results documented that general medicine clinicians had lower odds of referring for genetic counseling, reported less interest in educational tools for patients' use, less importance on genetic counseling in their practice, and less motivation to learn genetic counseling, educational efforts to train clinicians may want to target efforts specifically to this group, particularly to focus on training to recognize and refer appropriate patients.

Study limitations

There are a few study limitations which should be noted. First, by virtue of using a self-administered survey design, this study only reported clinicians' perceived practices regarding cancer family history collection and genetic counseling for cancer risk. We did not evaluate actual clinicians' practices or investigate patient records to see whether reported practices matched those in actual practice, which should be undertaken in future research. Second, given this was a voluntary survey, it is possible that the study is biased by including only those individuals who are interested in cancer family history and genetic counseling. In other words, some percentages could be inflated due to more interest in this sample. However, as the response rate was very high (81%), potential selection bias of participants is less likely to be a concern. Third, this study did not collect sociodemographic information on survey participants, which does not make it possible to analyze possible differences such as years' training, ethnicity of clinician, age, or gender. Fourth, as we wanted to collect information pertinent to cancer family history across cancers and not just breast cancer alone (*BRCA1/2*), we did not include ethnicity/ancestry as a key component to be included as part of routine cancer family history collection.[18] However, it would be useful to determine the extent to which ethnicity/ancestry is noted in family histories in future studies. Finally, as this study only investigated these specific practice groups at one particular hospital in NYC, study results may not be generalizable to other clinician groups or outside of this particular hospital in NYC. By administering the survey at Grand Rounds sessions, however, in which a diverse collection of clinicians in a particular practice group are in attendance (residency clinicians and attending clinicians), we hoped to capture a wide range of experiences and years of clinical training, which would make the results more applicable to a greater audience.

CONCLUSIONS

Ultimately, study results capture the current state of cancer family history collection, referrals for genetic counseling, and related educational needs among a diverse group of frontline healthcare clinicians (including general medicine, ob/gyn, and nurse practitioners) in NYC. Despite the widespread use of family histories on cancer risk for patients, there remain barriers to appropriate cancer risk management including referral for genetic counseling among these groups. The development of educational tools and training programs to assist clinicians with collection of cancer family history information, interpretation, and appropriate referral along with teaching direct application of a modified form of genetic counseling for low-medium risk patients and referral of patients at genetic risk is warranted.

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