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Interviews with primary care physicians regarding taking and interpreting the cancer family history

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Background. The cancer family history can be used to stratify risk and guide management regarding screening and prevention of cancer.

Objective. The current study was designed to gain understanding of specific barriers to obtaining and using the cancer family history for the primary care physician.

Methods. Interviews were conducted with structured samples of specialists in family medicine, general internal medicine and gynaecology in three settings in two north-eastern states. A medical anthropologist conducted interviews based on a topical outline; transcripts were systematically analyzed by a research team to identify major themes expressed by participants.

Results. Among 40 urban, suburban and rural physicians interviewed, 40% were women and medical school graduation years ranged from 1963 to 2000. These physicians regarded cancer family history as important, but process and content were not standardized. Major barriers to more focused use of this information included limitations of patients' family history knowledge; time needed to clarify and interpret this information and the lack of clear and accessible guidelines to assist in collection, interpretation and management decisions for average, moderate and higher risk patients. Language and cultural barriers made it more difficult to collect family histories in some populations.

Conclusions. Barriers to effective application of cancer family history information included limitations of patients' family history information; lack of methods to systematically and efficiently focus on the most useful information and lack of accessible guidance for risk stratification and management. Results suggest a need for support addressing these concerns to better utilize several readily available cancer risk management opportunities.

Keywords. Cancer genetics, family history, preventive medicine, primary care, risk assessment.

Introduction

A family history can assist in assessing risk for cancer development and management options for a number of malignancies.[1–8] The ideal family history for this purpose should include cancer type and age of onset for first- and second-degree relatives from both the maternal and paternal sides.[9] Approximately 20% of primary care patients will have family histories that would place them at increased risk.[10,11] Using a cancer family history for prioritization of screening and prevention opportunities may be cost effective.[12]

Advances in cancer genetics and increased public awareness regarding the importance of cancer family history suggest that primary care physicians will be called upon more often to evaluate family history information.[13] However, current information suggests that the family histories typically taken in primary care are not sufficiently detailed to identify individuals at risk.[10,11,14,15] Older literature suggested that knowledge, confidence and prior training may influence family history taking.[16–22] More recent literature addresses barriers encountered regarding applications of genetics in general.[23–27] The current study was undertaken to gain a more detailed understanding, from the perspective of the physician, of specific barriers to obtaining and using the cancer family history in primary care.

Methods

Family and internal medicine physicians and gynaecologists were recruited for personal interviews from

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urban and suburban Boston and rural Vermont. Urban physicians were recruited from a large health centre and affiliated network of community health centres serving ethnically and economically diverse populations. Suburban physicians were recruited from a health care organization serving suburban communities in eastern Massachusetts. Rural physicians were recruited from a statewide rural health network, excluding one urbanized county.

The sampling goal was to maximize the chances of identifying factors relevant to use of the cancer family history. A stratified purposeful strategy was used to recruit physicians with a broad range of characteristics including gender, year of graduation from medical school and practice type, size and setting.[28] Physicians were over-sampled for minority status. Institutional Review Boards at all participating institutions approved the study.

Recruitment

Recruitment was initiated through letters, including an opt-out card, sent from their affiliated institution to physicians meeting the sampling criteria. Physicians not opting out were sent a follow-up letter and contacted. Initial contact attempts targeted physicians across the spectrum of sampling characteristics; later efforts targeted physicians with characteristics lacking in the participant pool. The number of opt-out cards, contact refusal and dropouts was negligible (<1%). Recruitment ended when a diverse sample had been recruited and data saturation had been achieved.[29] The overall ratio of completed interviews to introductory letters was approximately 1:10.

Implementation of interviews

Interviews were conducted in-person or by telephone by one person (AS), a cultural anthropologist. Interviews were organized around a semi-structured outline developed by the investigator team and reviewed by an expert panel; topics were selected based on reviews of related research and research team judgements about the importance of each to the objectives (Table 1). Each topic was used as a starting point and explored in differing levels of detail depending on relevance to the interviewee. Interviews lasted 30–90 minutes and were audiorecorded (one physician requested not to be audiorecorded and detailed notes were taken by the interviewer).

Data processing and analysis

Interview recordings were transcribed and checked for accuracy. Formal analysis was undertaken using Atlas-ti, a software programme used to organize and analyze qualitative data. Coding was done by one person (AS) in close collaboration with the investigator team. Analysis involved an iterative process of coding, display of relationship patterns and memos.[30] Descriptive topic codes based on the interview guide were applied initially; the coding scheme was elaborated further based on themes and patterns identified from reviews of the transcripts and initial coded outputs. Independent observations were obtained from expert panel members who reviewed a subset of transcripts. Once coding was completed, data were organized and condensed, using a series of matrices to define code patterns, frequencies and participant characteristics.

TABLE 1 *Interview guide topics*

Medical background, training and your current practice.
Training in taking family histories, cancer risk assessment and genetics.
Attitudes towards cancer risk assessment and the taking of cancer family histories.
Collection of family history.
Assessment and interpretation of cancer risk.
Awareness and use of guidelines or protocols for the collection and interpretation of cancer family histories.
Perceived institutional and patient-related barriers or facilitators for taking and maintaining family histories.
Need for educational and support resources.

Results

Forty interviews were conducted with primary care physicians between May 2003 and May 2006. The sample was 40% female and largely Caucasian (78.5%), although major ethnic groups were represented (Table 2). Medical school graduation years ranged from 1963 to 2000 (mean 1985, median 1986). All quotes are followed by the number of interview. See Table 3 for characteristics of each interview.

Family history taking

These physicians unanimously described family history as important. Taking a cancer family history was seen as an essential component of identifying and managing individuals at increased risk. One internist stated: ''I do a family tree. I think it's invaluable ... I think it's incredibly important.'' (#10) Another internist stated: ''I think of a physical [and family history] as really addressing prevention and screening.'' (#11)

These physicians universally reported taking a family history for new patients. Only 50% (20/40) updated family histories during routine or annual examinations, and few (2/40) obtained family history information regardless of the visit type. Approaches to taking family histories varied considerably and physicians rarely referenced standard protocols or tools. One family physician simply stated: ''part of the tradition of the physical is you do the family history.'' (#12) Only gynaecologists mentioned using any guidelines for the taking a family history.

Physicians who used patient-completed forms (13/40) did not rely on forms alone. One internist stated: ''I would rather take longer and actually listen

TABLE 2 *Provider demographics (n = 40)*

	n	%
Gender		
Male	24	60
Female	16	40
Ethnicity		
Caucasian	31	77.5
Asian	7	17.5
African-American	2	5
Years from medical school graduation		
Fifteen or less	15	37.5
More than fifteen	25	62.5
Practice environment		
Solo	8	20
Group	23	57.5
Tertiary	9	22.5
Primary care specialty		
Obstetrics/gynecology	9	22.5
Family practice	14	35
Internal medicine	17	42.5
Practice location		
Urban	12	30
Rural	13	32.5
Suburban	15	37.5

TABLE 3 *Characteristics of quoted physicians*

Interview number	Gender	Primary care specialty	Practice location
01	Male	Internist	Suburban
02	Male	Family medicine	Rural
04	Male	Family medicine	Suburban
08	Female	Family medicine	Rural
10	Female	Internist	Suburban
11	Female	Internist	Suburban
12	Male	Family medicine	Suburban
16	Male	Obstetrics/gynecology	Suburban
18	Female	Family	Rural
19	Female	Obstetrics/gynecology	Urban
21	Female	Obstetrics/gynecology	Urban
22	Male	Family	Rural
24	Male	Obstetrics/gynecology	Suburban
25	Female	Family medicine	Suburban
27	Female	Internist	Urban
30	Male	Internist	Rural
31	Female	Obstetrics/gynecology	Suburban
32	Male	Family medicine	Urban
35	Female	Family medicine	Rural
36	Male	Obstetrics/gynecology	Rural
40	Male	Internist	Urban

to what people are saying to me. And pulling at the threads of what they're saying. Because I think you leave things out if you already pre-program people to answer box questions.'' (#10) Another stated: ''there's other questions as to whether or not they filled it out correctly.'' (#30) Nearly half (18/40) commented that obtaining a family history in person was important. Reasons included obtaining greater detail, building a relationship with a new patient and literacy issues. One internist stated: ''It would probably be easier to get people to fill in forms, but I get to know my patients if I actually talk to them. And they get to know me too. And I find that building trust between the two of us is a big piece of the continuity for me.'' (#01) And a gynaecologist commented: ''... it just seems to be more personal and more intimate, and maybe another way to talk to someone, get to know them a little bit.'' (#36)

Family history quality

Physicians typically obtained information on a few family members or asked general questions about cancer occurrence. Sixty-five per cent collected at least a first-degree family history (parents, siblings and children). Only 28% routinely obtained history information beyond first-degree relatives. One family physician stated: ''typically what I'll do is ask about those individuals [first degree] and then I'll ask sort of more sweeping questions about the second degree relatives.'' (#32)

Less than half (16/40) reported asking about specific cancer types, with breast and colon being most common, followed by prostate and ovarian cancer. Types of cancers asked about correlated with perceptions that screening would be impacted by the finding. One family physician said he focused on: ''colon cancer, breast cancer, and maybe prostate cancer .... Those things change my behaviors and therefore I search for them.'' (#02) Information regarding age at cancer diagnosis was not gathered routinely. Those who reported asking about age indicated that they would use that information to change screening recommendations. Very few specifically inquired about other information such as family members with multiple primary or bilateral cancers.

Lack of time was a salient barrier to detailed collection of family history data. This issue was well-illustrated by a physician who stated: ''I suppose if I had enormous time on my hands and I had already done a [first generation history] I might try to take it back a generation .... It's a trade-off between doing nothing at all and not having more than a few minutes.'' (#32) Another physician explained: ''It takes more time ... I would say that the single most scarce, important resource in my practice is time. It's a barrier to everything ... You tell me what I should leave out, and I'll put [family history] in.'' (#40)

Some patients were perceived as providing poor information about their family history. One family physician stated: ''One of the biggest barriers is getting good data. Most people don't really know. And what they know isn't very accurate ...'' (#02) Some physicians reported that vague or inaccurate information about type of cancer was a particular problem. For example, a physician described a patient who reported his father having early colon cancer: ''We set him up

for a colonoscopy. And then he calls back and says, 'Oh, no it was prostate cancer.' [laughter] Well, it's all down there. '' (#04)

Physicians from urban settings commented that an accurate family history was often difficult to obtain due to complex family relationships, such as children with little knowledge or contact with one parent or immigrants with dispersed families. Language was often a barrier to obtaining an accurate family history, even though translation services were available. A third of participants reported language-related issues, and 62% of these were in urban settings.

Physicians in suburban settings described patients who were more interested in obtaining a test than providing data that would inform a decision about the test. These patients aggressively sought preventive care, bringing information from the Internet or media stories to visits. While discussing ovarian cancer, a suburban physician stated: ''every once in a while a news program will talk about it because someone famous got cancer, and then they'll come in [saying], 'I want an ultrasound, I want a CA125.' I get that more than anything else.'' (#16)

Rural physicians were more likely to characterize patients as placing low value on preventive care. One physician stated: ''we still have a fair amount of sturdy old Vermonters—they don't want to complain ..... It's their culture. They will come in for acute medical issues.'' (#18) These same physicians had exceptional access to family history information because multiple family members were cared for by one practice. One family physician stated: ''I do have multigenerational families of patients ... so I can pull a file and find out how old the father was when he had his first MI.'' (#22)

Interpreting family history information

Physicians tended to be confident regarding identification of average or slightly above average risk. A gynaecologist stated: ''a woman will come in and she's 42 and her mother who's 75 was just diagnosed with breast cancer and she perceives herself as being at very high risk ... and she needs to hear, 'now you have a family history, but your mother got it when she was 75, so that doesn't put you at super duper high risk.''' (#31)

Many physicians were less confident regarding their ability to identify higher risk for cancer. One stated: ''there seem to be certain guidelines that you go by with the more common cancers ... you have to start getting mammograms ten years before the relative was diagnosed, or the same for colon cancer screening, but for other things I'm often in the dark.'' (#25)

Another pattern emerged when a family history was seen as warranting attention primarily because of an unusually large number of affected relatives. One physician stated: ''Well, I feel like I don't know very much about it, but I'm not sure how much more I need to know than to say, 'Oh, that could be a familial pattern and maybe somebody should look at it.'... if somebody tells me, 'My mother had breast cancer, my aunt just had her uterus out, they weren't sure if there was a tumor, and my brother had colon cancer,' I say, 'Umm, that's too many.''' (#21)

Many participants felt they lacked time to keep up with the flow of new information and recommended practices. A gynaecologist stated: ''there's always more to learn. Every day, somebody's figuring out something new, and something that's genetically—all disease occurs at the molecular level.'' (#19) An internist stated: ''I think that things change quickly enough that I'm never quite sure that I'm on the cutting edge, as it were, in terms of my knowledge about a familial pattern.'' (#30)

The perceived lack of guidelines was a barrier to interpreting family history and assessing risk for cancer. A physician stated: ''I do think that [guidelines] would be helpful, because I always wonder if I'm up to date. I'm never really sure ... you do have some guidelines to refer to, so, that touchstone I think could be helpful. Like what patterns in the family history should I be more aware of than I perhaps am?'' (#27)

Guidelines for identification and management of familial cancer risk

The majority were not aware of guidelines or recommendations for interpretation of family history information or management of higher risk individuals. One physician stated: ''As far as interpretation of that data [family history], I don't know of any guidelines in terms of when to refer patients for genetic counseling, so that we do based on our own experience.'' (#31) Twenty-three per cent (10/44) of interviews were conducted after the US Preventive Services Task Force published specific guidelines for referral for genetic risk assessment for BRCA mutation testing for breast and ovarian cancer susceptibility. None of the physicians interviewed mentioned this guideline.[31]

Some physicians were aware of models to assess cancer risk. Twenty per cent reported ever using the Gail Model[32] and some (3/8) no longer use it. One gynaecologist stated: ''I have used the Gail Model in breast cancer risk assessment. However ... I've found limited enthusiasm by patients.'' (#24)

Some physicians were aware that guidelines exist but were not knowledgeable regarding their content; one family physician stated: ''I'm aware there's something around breast cancer and there are other algorithms that are specifically ranking your risk based on genetic data.'' (#02) A family physician stated: ''it's still in the realm of the individual doctor taking more or less of an interest and making independent decisions, rather than having a protocol, a policy.'' (#12)

Many physicians contrasted cancer and cardiovascular risk. Regarding risk assessment one stated: ''with

cancer, no, I don't think so. I know we do with heart disease. You plug the numbers into it to see what the person's risk is. But I'm not aware of anything for cancers.'' (#08) Some suggested that cardiovascular guidelines are clear and published in the primary care literature whereas cancer is felt to be heterogeneous and recommendations have not been developed in association with primary care physicians.[33,34] A physician stated: ''If there was a national—strong force on the nationwide level ... with some consistent protocols for genetic screening, which we hope will have doctors saying, 'okay, this is something I've got to start integrating into my practice.' Genetics hasn't had that kind of real push the way, say, blood pressure control or diabetic control has. Really explicit well published protocols would be helpful.'' (#12)

Many stated a need for concise, practical guidelines or recommendations. One family physician suggested that guidelines should be; ''easy to find (in a widely read journal), easy to follow and repetitive.'' (#25) Another stated: ''I would like, from the National Cancer Institute, an annual recommendation, and I want them to tell me the evidence, so A-B-C-D-E, and ... it's laminated for the wall, and it's replicable for the patient chart.'' (#35) These views were summarized vividly by one family physician who stated: ''I see a need for a real national body, a powerful national body that can speak to me, ... provide the protocols and also provide web-based tools for me to learn about stuff that's quick and easy.'' (#12)

Discussion

This study provides detailed and candid information regarding use of family history for cancer risk and management from three types of primary care physicians practicing in three types of settings. The information obtained from these in-depth interviews was sufficiently rich and comprehensive to enable identification of common themes. These physicians believed that family history is an important tool for identification of cancer risk and routinely collect family history information. However, significant barriers to obtaining an optimal family history emerged from these interviews, including gaps in patient knowledge of family history, time constraints and a need for accessible guidelines for systematic and efficient identification of cancer risk.

The physicians interviewed unanimously agreed on the importance of family history, consistent with the findings of previous studies.[35,36] They routinely took a family history with new patients, but less commonly updated the information. These results were close to those of Acton *et al.*[22] who found that 94% of primary care physicians obtained a cancer family history; however, only 52% regularly updated that history; similar results have been reported elsewhere.[37,38] Family histories sometimes lacked focus on cancers for which risk interpretation consensus statements were available, such as information on second-degree relatives and age of diagnosis for affected relatives.

The physicians interviewed described several barriers to more consistent and complete collection of the family history information needed for cancer risk management. Concern was often expressed about patients' knowledge of a cancer family history, with examples of uncertain or ambiguous information provided. All these physicians collected family history information through direct interview of patients, even if they also used a patient-completed form, because of the need to clarify information. Continued emphasis on improving patient knowledge of their family history and communicating this information efficiently to physicians appears to be an important response to the needs identified.[13]

Time constraints were described in concrete terms by many physicians. Lack of patient visit time to assemble the appropriate information was a prominent concern. Additionally, the time required to keep current regarding emerging new information was a major concern. The perceived lack of accessible guidelines for interpretation of information and for matching management to risk levels was a commonly expressed barrier; brief, well-focused guidance on risk stratification for the most common and highest priority situations was seen as not available. Concerns about time constraints suggested a strong need for more efficient protocols to obtain, organize and interpret the most relevant information.

A closely related theme emerged concerning confidence in ability to interpret family history information. The information collected was typically used to encourage adherence to average screening or reassuring 'worried well' individuals at average risk. Knowledge of methods to identify higher risk patients was recognized as an area needing development since only very broad methods for identification were mentioned in these interviews. Confidence in ability to identify the larger numbers of moderately increased risk patients was not discussed as explicitly but appears to be an important area of need for further support. Although these concerns could be attributed in part to limitations in the family history information available from patients,[39] many participants focused on lack of useful guidelines as the key issue.

The rapidly changing field of genetics also may be prompting physicians to ask for concise, practical, easily used guidelines or recommendations written specifically for primary care physicians. This need was an overriding theme uncovered in physician interviews. There are excellent and comprehensive references, websites and online resources regarding cancer genetics [40–43]; however, primary care physicians do not have

the time to search for and digest the information within these resources.

Guidelines for collection and interpretation of family history information and management of individuals at increased risk have been identified by others as important for primary care physicians.[21] In a qualitative study, primary care physicians indicated a lack of confidence in interpreting family history information and making appropriate referrals and asked for clear and concise referral guidelines.[20] In another study, several areas of concern emerged; among these needs were standardization of care and clarification of the role of the primary care provider.[44] A UK survey of general physicians identified that only 8% of physicians followed a practice policy on familial breast cancer risk management.[45]

Limitations

Although the study successfully recruited primary care physicians from multiple specialties and diverse settings, those who had stronger opinions about the topics may have been more likely to participate; the low refusal rate among those contacted limits this concern. The physicians recruited were members of large health care organizations or a large statewide network in two states, potentially limiting generalizability of findings. We were not able to identify and interview physicians from some ethnic backgrounds. The self-reports that were the focus of this study might be considered a limitation; however, many of the themes identified were consistent with other published reports.[14,20,22,35–39]

Conclusions

We found that this group of primary care physicians generally takes and values cancer family histories, but gaps in family history information and applications to risk stratification reduce the value of this information. Physicians identified several barriers to more effective use of family history information, including lack of methods to engage patient efforts to make optimal use of their cancer family history; lack of efficient methods to facilitate systematic focus on the most important family history information and lack of accessible guidance for risk stratification and management. These results suggest a need for substantial new support addressing these concerns of primary care physicians in the areas of cancer risk identification and management.

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