Cancer Genetic Risk Assessment and Referral Patterns in Primary Care

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Purpose: This study was undertaken to describe cancer risk assessment practices among primary care providers (PCPs). *Methods:* An electronic survey was sent to PCPs affiliated with a single insurance carrier. Demographic and practice characteristics associated with cancer genetic risk assessment and testing activities were described. Latent class analysis supported by likelihood ratio tests was used to define PCP profiles with respect to the level of engagement in genetic risk assessment and referral activity based on demographic and practice characteristics. *Results:* 860 physicians responded to the survey (39% family practice, 29% internal medicine, 22% obstetrics/ gynecology (OB/GYN), 10% other). Most respondents (83%) reported that they routinely assess hereditary cancer risk; however, only 33% reported that they take a full, three-generation pedigree for risk assessment. OB/GYN specialty, female gender, and physician access to a genetic counselor were independent predictors of referral to cancer genetics specialists. Three profiles of PCPs, based upon referral practice and extent of involvement in genetics evaluation, were defined. *Conclusion:* Profiles of physician characteristics associated with varying levels of engagement with cancer genetic risk assessment and testing can be identified. These profiles may ultimately be useful in targeting decision support tools and services.

Introduction

ECENT REPORTS have highlighted a trend from the de-Recent Reports never the assessment and prevention services from academic centers to the primary care setting (Acheson and Wiesner, 2004; Bennett, 2004; Epplein et al., 2005). This changing care pattern has been supported by a number of medical professional organizations and government health agencies as a logical mechanism to provide longitudinal and family-centered care in the local community (McKelvey and Evans, 2003; Collins, 2004; Buchanan et al., 2005; Martin and Wilikofsky, 2005). Several factors are accelerating this shift to the primary care setting, including the increase in the number of available genetic technologies, the limited availability of cancer genetic counselors, increased patient demand (driven in part by direct to consumer advertisements), and marketing by the manufacturers of genetic tests to physicians (Acheson and Wiesner, 2004; Calzone et al., 2005; Myers et al., 2006; Tracy, 2007; Chapman, 2008; Mennuti, 2008). As the prevalence and marketing of cancer genetic tests increases, primary care physicians will more commonly be called upon to make decisions about genetic evaluation, risk assessment, and referral (Collins, 2004). Further, recent studies have suggested that low-risk individuals are being referred inappropriately for cancer genetic evaluation (White *et al.*, 2008), highlighting the importance of understanding current risk assessment practices in primary care.

Despite the increasing role of genetics in clinical care, there is a reported variability in the delivery of these services in the primary care setting (Shields *et al.*, 2008). Freedman and colleagues (2003) found that only 28.8% of the primary care providers (PCPs) feel qualified to provide genetic counseling to their patients. Another survey of the U.S. physicians found that only 27% had referred a patient for genetic cancer risk assessment or testing in the prior 12 months (Wideroff *et al.*, 2003). This suggests that a large proportion of patients are not receiving these services either in the office or elsewhere in their communities.

Several medical professional societies have suggested a role of PCPs as the primary surveyors of cancer genetic risk assessment and genetic testing (Collins, 2004). Given the complexity of genetic services, it may be unrealistic to expect that PCPs will serve as the main source of cancer genetic risk evaluation and management for their patients (Greendale and Pyeritz, 2001). Alternatively, some PCPs may provide these services in their office, and others may prefer to refer to

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genetics professionals. Each group will require different decision support tools. To date, there is little known about the characteristics of those PCPs who refer patients to genetics professionals and those who do not.

The objective of this national survey was to describe the cancer genetic risk assessment and referral practices of primary care physicians contracted with a large national health insurance company. We sought to define categories of PCPs based on their activity in genetic risk assessment and referral practice. It is anticipated that these categories could ultimately guide the development of tailored decision support tools for PCPs.

Materials and Methods

Participants

A survey of primary care physicians contracted with Aetna was undertaken. Aetna is a national health insurance company providing health benefits to 17.6 million people in all 50 states. An electronic survey was sent to a convenience sample of 24,066 primary care physicians contracted with Aetna for whom verified email addresses were available. Family medicine, internal medicine, and obstetrics–gynecology (OB–GYN) specialists were considered as primary care physicians. The study sample represents 24.6% of all the PCPs contracted with Aetna nationwide.

Survey administration

Physicians eligible to participate in the electronic survey were sent by Aetna an electronic invitation to participate in the study, a description of the study, and a web link to the survey. An incentive of a \$5 donation to a genetics patient advocacy group was provided for each completed survey. Up to three reminder emails were sent to invited study participants who did not open the prior email.

The study was reviewed and was considered exempt from institutional review board (IRB) approval by the Fox Chase Cancer Center IRB.

Measures

The survey instrument included 26 items covering the following domains: provider demographics, cancer genetic risk assessment practices, referral practices, and comfort with cancer genetics information. The survey was designed specifically for this study, guided by literature review and expert opinion of the research team. The research team included cancer clinical geneticists, a certified genetic counselor, a medical oncologist, an obstetrician-gynecologist, and a biostatistician. Some survey items were based on previously published tools to assess cancer genetic practices in a similar target population of physicians (Myers et al., 2006; Brandt et al., 2008; Lowstuter et al., 2008; Shields et al., 2008). Before implementation, the survey was evaluated by oncologists, internal medicine physicians, and family medicine physicians, to assess relevance and face validity of survey items. Modifications were made to the survey based on this feedback before administration.

Provider demographics and practice characteristic variables included medical specialty, age, gender, years in practice, practice structure (e.g., solo practice, group practice), location of practice, affiliation with a teaching hospital, and access to genetic counseling services (e.g., onsite, within 10 miles, between 10 miles and 30 miles, phone based, or no access).

Cancer genetic risk assessment practices were assessed with the question "How do you currently assess personal and familial risk for hereditary cancer?" (select all that apply from: assess history of cancers by initial intake form, take a family history of first-degree relatives only, ask about ethnicity, take a three-generation family history, ask if patient is concerned about cancer, ask only about early onset cancers [<50 years], use statistical risk assessment tools [e.g., Gail model], and do not routinely assess cancer risk).

Referral practices were assessed with the question "Do you currently refer to a cancer genetic counselor (or cancer center providing cancer genetic services) if a hereditary cancer is suspected?" This branched item directed the respondent to a different set of questions depending on whether they answered "yes" or "no." If the respondent answered "yes," then he/she was asked to answer the following questions: "What factor describes why you refer to a cancer genetic counselor?" (select all that apply from no expertise, patient request, no

TABLE 1. PROVIDER DEMOGRAPHICS (N = 860)

| | n | Percent (%) |
|------------------------------------|-----|-------------|
| Medical specialty | | |
| OB/GYN | 189 | 22.1 |
| Family medicine | 336 | 39.2 |
| Internal medicine | 249 | 29.1 |
| Other | 86 | 9.6 |
| Age, years | | |
| <30 | 6 | 0.7 |
| 30–39 | 172 | 20 |
| 40-49 | 251 | 29.2 |
| 50-59 | 291 | 33.8 |
| 60–69 | 113 | 13.2 |
| >70 | 25 | 2.9 |
| No response | 2 | 0.2 |
| Gender | | |
| Male | 513 | 59.7 |
| Female | 334 | 38.8 |
| No response | 13 | 1.5 |
| Years in practice | | |
| <5 | 102 | 11.9 |
| 5-10 | 165 | 19.2 |
| 11–15 | 121 | 14.1 |
| 16–20 | 117 | 13.6 |
| >20 | 345 | 40.1 |
| No response | 10 | 1.1 |
| Type of practice | | |
| Solo | 427 | 49.7 |
| Single specialty group | 229 | 26.6 |
| Multispecialty group | 119 | 13.9 |
| Group | 76 | 8.8 |
| No response | 9 | 1.0 |
| Location of practice | - | 110 |
| Suburban | 434 | 50.4 |
| Urban | 300 | 34.9 |
| Rural | 114 | 13.3 |
| No response | 111 | 1.4 |
| Affiliation with teaching hospital | 14 | 1.1 |
| Yes | 404 | 46.9 |
| No | 442 | 51.3 |
| No response | 14 | 1.6 |
| | 17 | 1.0 |

OB/GYN, obstetrics/gynecology.

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time to address patient concerns, liability concerns, new referral guidelines, other) and "after referral, do you receive adequate feedback about the results of the genetics consultation" (yes/no). If the respondent answered "no" to the referral question, he/she was asked "the reasons for not referring for cancer genetic consultation?" (select all that apply from uncertain which patients to refer, concerns about cost for testing/ counseling, unknown method of referral, location of referral inconvenient for patient, no appropriate patients, information not useful in patient management, initiated testing themselves, other).

Comfort with cancer genetics information was assessed with questions including: "Do you feel you have sufficient tools to assess risk for cancer accurately" (select from always, often, sometimes, rarely, and never) and "Do you feel comfortable providing screening and prevention recommendations to patients at increased risk for a hereditary cancer syndrome?" (select from very comfortable, somewhat comfortable, neither comfortable nor uncomfortable, somewhat uncomfortable, and very uncomfortable).

Statistical analyses

All survey results were collected using the Survey Monkey (Survey Monkey, Portland, OR) tool. Data were analyzed with STATA 10.0 statistical software (College Station, TX). Fisher's exact test was used to investigate associations between demographic and practice characteristics and genetic risk assessment and referral practices. A multiple logistic regression was used to investigate which variables were independently associated with cancer genetics referral. Previous literature (Shields et al., 2008) supports the rationale for the variable inclusion in the multiple regression analysis regarding referral including academic affiliation, age, and practice characteristics. Latent class analysis techniques were used to investigate whether classes of individuals could be described with respect to genetic risk assessment and referral behavior based on demographics and practice characteristics. (Thacher et al., 2005; Reboussin et al., 2006). The goal of latent class analysis is exploratory and descriptive, and hence hypothesis tests and associated *p*-values are not used to make inferences about the latent groups. Researchers have recently advocated

Table 2. Characteristics of Study Respondents Versus Aetna Physician Population

| Physician | Survey | Aetna | | | |
|---------------------------------------|--|-------|---------|--|--|
| demographic | respondents (%) population (%) p-Value | | | | |
| Age, years | | | | | |
| ≤ <u>3</u> 9 | 20.75 | 20.47 | 0.09 | | |
| 40-49 | 29.25 | 32.62 | | | |
| 50-59 | 33.92 | 29.96 | | | |
| 60–69 | 13.17 | 13.57 | | | |
| 70+ | 2.91 | 3.39 | | | |
| Gender | | | 0.02 | | |
| Male | 35.46 | 39.43 | | | |
| Female | 64.54 | 60.57 | | | |
| Specialty | | | < 0.001 | | |
| OB/GYN | 21.98 | 16.40 | | | |
| Family medicine/ internal medicine | 78.02 | 83.6 | | | |

TABLE 3. CANCER GENETIC RISK ASSESSMENT PRACTICES (N=860)

| Method | n | Percent (%) ^a |
|----------------------------------|-----|--------------------------|
| Assess history of cancers | 678 | 80.5 |
| by initial intake form | | |
| Take a family history of | 460 | 54.6 |
| first-degree relatives only | | |
| Ask about ethnicity | 291 | 34.6 |
| Take a three-generation pedigree | 277 | 32.9 |
| Ask if patient is concerned | 247 | 29.3 |
| about cancer | | |
| Ask only about early | 168 | 20.0 |
| onset cancers (<50 years) | | |
| Use statistical risk | 113 | 13.4 |
| assessment tools | | |
| Do not routinely assess | 60 | 7.1 |
| hereditary cancer risk | | |

^aPercentages will not sum to 100% as multiple methods could be cited by each respondent.

using latent class analyses of multiple characteristics to identify subgroups that would benefit from targeted interventions (Coffman *et al.*, 2007; Sutfin *et al.*, 2009; Thompson *et al.*, 2009). Indeed, latent class analysis is similar to cluster analysis that has been used to design and implement such interventions (Collins *et al.*, 2008; Torres Campos *et al.*, 2009). We used STATA 10.0 for estimation of the latent class probabilities.

For ease of presentation, we chose *a priori* to explore a latent class model with three classes rather than using data-driven statistics to decide on the appropriate number of classes. To assess the fit of our model, we used a likelihood ratio test to investigate whether the three-class model fits better than the one- or two-class model. Future validation of our model would necessitate the use of a different sample with confirmatory, as opposed to exploratory, latent class analysis.

Results

The survey was sent electronically to 24,066 PCPs with valid email address, of whom 6466 email recipients (26.9% of the email addressees) "opened" the email and 860 recipients (3.6% of all the email addressees or 13.4% of the addressees who opened the email) participated in the survey. Demographics of these physicians are summarized in Table 1. There were small differences between the overall Aetna physician population and the respondents in terms of age distribution, gender, and specialty (Table 2).

PCP cancer genetic risk assessment practices

Respondents' cancer genetic risk assessment practices are summarized in Table 3. The majority of respondents (82.9%) reported that they routinely assess hereditary cancer risk but only a minority use structured queries such as a threegeneration pedigree (32.9%) or a quantitative risk assessment tool (e.g., Gail model) (13.4%). Rather, risk assessment tools used are either incomplete (such as inquiry into first-degree relative history only [54.6%]) or employ the initial office intake form upon which to base risk assessment (80.5%). Ethnicity is used by 34.6% of the respondents to guide risk assessment practice.

TABLE 4. Reasons for Referral/Nonreferral to Cancer
Genetics Professionals (n = 795)

| Reason | n | Percent ^a |
|------------------------------------|-----|----------------------|
| Referring physician $(n = 430)$ | | |
| No expertise | 297 | 69.1 |
| Patient request | 229 | 53.3 |
| No time to address | 108 | 25.1 |
| patient concerns | | |
| Liability concerns | 92 | 21.4 |
| New referral guidelines | 72 | 16.7 |
| Other | 42 | 9.8 |
| Nonreferring physician $(n = 365)$ | | |
| Uncertain which patients to refer | 140 | 38.3 |
| Concerns about cost for | 136 | 37.2 |
| counseling/testing | | |
| Unknown method of referral | 90 | 24.6 |
| Location of referral | 83 | 22.7 |
| inconvenient for patient | | |
| No appropriate patients | 66 | 18.0 |
| Information not useful in | 34 | 9.3 |
| patient management | | |
| Initiated testing themselves | 33 | 9.0 |
| Other | 30 | 8.2 |

^aPercentages will not sum to 100% as multiple methods could be cited by each respondent.

PCP cancer genetic referral practices

Data related to cancer genetics referral practices are presented in Table 4 for 795 respondents who answered this item. Among the 54.1% of the PCPs who reported that they refer patients to genetic specialists, the most common reasons for initiating the referrals is their own personal lack of expertise to provide the service in their office (69.1%) and patient-initiated request (53.3%). Less frequently cited reasons for referral to genetics clinicians include concern about lack of time to provide the service themselves (25.1%), liability concerns (21.4%), and guidelines from medical professional or other health agencies (16.7%) recommending referral to a trained genetics clinician.

Among the 46% of the respondents who reported that they do not refer to genetics clinicians, the most frequently cited reasons for nonreferring were uncertainty about which patients are medically appropriate to refer (38.3%) and concerns about cost for counseling and testing (37.2%). Significant logistical reasons for not referring to genetics specialists were uncertainty about how to make a referral (24.6%) and the belief that the location of genetics referral is inconvenient to the patient (22.7%). Interestingly, only 9.3% of the non-referring PCPs reported that the information obtained from genetics evaluation would *not* be useful in patient management. Nine percent of the PCPs who do not refer to genetics specialists report that they initiate testing themselves.

Variables associated with cancer genetics referral

In univariate analysis, OB-GYN specialty type (p < 0.0005), female gender (p < 0.0005), and teaching hospital affiliation (p = 0.015) were associated with referral to cancer genetics specialists (Table 5). Reported use of more robust forms of risk assessment such as taking a three-generation family history, ethnicity, or statistical tools was associated with increased

 TABLE 5. FACTORS ASSOCIATED WITH REFERRAL TO CANCER

 GENETICS SPECIALISTS

| | Referral | | | | | | |
|--------------------------------|----------|----------------|------------|----------|------|------|----------------|
| | Yes | (n, 4 | %) | No | (n, | %) | p-Value |
| Demographics | | | | | | | |
| aGender | | | | | | | < 0.0005 |
| Male | | (46.5 | | | | | |
| Female | 203 | (62.7 | 7) | 121 | (37 | .3) | |
| Age, years | | | | | | ~ | 0.406 |
| <50 | | (51.1 | | | | | |
| 50+ | 224 | (54.0 |)) | 191 | (46 | .0) | 0.000 - |
| ^a Specialty | 1 40 | | • • | 10 | (00 | | < 0.0005 |
| OB/GYN | | (77.2 | | | (22 | | |
| Internal medicine | | (38.8 | | 145 | | | |
| Family medicine | 155 | (46.5 |) | 176 | (55 | .5) | 0.371 |
| Years in practice <5 | 54 | (51 4 | 5) | 45 | (45 | 4) | 0.571 |
| < 5 5–10 | | (54.6 (49.1 | | 43 82 | (45) | | |
| 11–15 | | (53.8 | | | (46 | | |
| 16-20 | | (45.7 | | | (54) | | |
| 20+ | | (55.4 | | 149 | | | |
| Academic affiliation | 105 | (55 | r) | 14/ | (11 | .0) | 0.142 |
| Teaching hospital | 223 | (56.9 | 3) | 169 | (43 | 1) | 0.142 |
| Nonteaching hospital | | (51.7 | | | | | |
| ^a Access to genetic | 227 | (01.7 |) | 207 | (10 | .0) | < 0.0005 |
| counselor | | | | | | | 10.0000 |
| >10 miles | 135 | (31.3 | 3) | 296 | (68 | .7) | |
| Within 10 miles | | (75.7 | | | (24 | | |
| Cancer genetic risk assessm | | | | | (| , | |
| Take a three-generation | 1 | | | - | | | < 0.0005 |
| pedigree | | | | | | | |
| Yes | 169 | (62.1 | l) | 103 | (37 | .9) | |
| No | | (48.0 | | | | | |
| Ask for ethnicity | | | <i>.</i> | | | , | < 0.0005 |
| Yes | 178 | (61.8 | 3) | 110 | (38 | .2) | |
| No | 261 | (47.7 | 7) | 286 | (52 | .3) | |
| Use statistical | | | | | | | < 0.0005 |
| assessment tools | | | | | | | |
| Yes | | (73.9 | | | | | |
| No | | (49.3 | | | (50 | .7) | |
| Comfort with cancer genetic | cs in | form | ati | on | | | |
| Sufficient risk assessment | | | | | | | 0.201 |
| tools | | | | | | | |
| Always/often | | (56.5 | | | | | |
| Sometimes | | (51.0 | | 177 | | | |
| Rarely/never | 81 | (48.8 | 3) | 85 | (51 | .2) | |
| Comfort providing | | | | | | | 0.300 |
| screening/prevention | | | | | | | |
| recommendations | 000 | / F 4 - | | 0F (| | | |
| Very comfortable/ | 300 | (54.1 | 15) | 254 | (45 | .85) | |
| somewhat comfortable | 105 | (50.4 | | 10/ | (10 | 000 | |
| Somewhat | 137 | (50.1 | 18) | 136 | (49 | .82) | |
| uncomfortable/very | | | | | | | |
| uncomfortable/neither | | | | | | | |
| comfortable nor | | | | | | | |
| uncomfortable | | | | | | | |

^aStatistically significant after multiple logistic regression analysis.

referral compared to those that did not use these methods (p < 0.0005 for all the above methods). Physicians with limited access (>10 miles) to a genetic counselor were less likely to refer (69% do not refer) compared to those with access to a genetic counselor within 10 miles (31% do not refer)

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TABLE 6. LATENT CLASS MODEL PROFILE OF PRIMARY CARE PROVIDERS (STANDARD ERRORS IN PARENTHESES)

| | Class I: nonreferring, minimally involved % (SE) | Class II: referring, actively involved % (SE) | Class III: referring, moderately involved % (SE) |
|--|--|---|--|
| Demographics | | | |
| Age 50+ | 48% (0.03) | 53% (0.04) | 49% (0.04) |
| Age < 50 | 52% (0.03) | 47% (0.04) | 51% (0.04) |
| Ob/Gyn | 7% (0.02) | 32% (0.03) | 35% (0.04) |
| Family med/internal med/other | 93% (0.02) | 68% (0.03) | 65% (0.04) |
| Teaching hospital | 41% (0.03) | 47% (0.04) | 61% (0.04) |
| Nonteaching hospital | 59% (0.03) | 53% (0.04) | 39% (0.04) |
| Female | 30% (0.03) | 46% (0.04) | 46% (0.04) |
| Male | 70% (0.03) | 54% (0.04) | 54% (0.04) |
| >10 miles access to GC | 82% (0.03) | 33% (0.05) | 23% (0.05) |
| ≤ 10 miles access to GC | 18% (0.03) | 67% (0.05) | 77% (0.05) |
| Practice barriers | | | |
| Sufficient tools to assess risk for cancer | | | |
| Always/often | 28% (0.03) | 61% (0.06) | 8% (0.02) |
| Sometimes/rarely/never | 72% (0.03) | 39% (0.06) | 92% (0.02) |
| Uses pedigree or statistical tools for risk assessment | | | |
| Yes | 26% (0.03) | 60% (0.04) | 31% (0.04) |
| No | 74% (0.03) | 40% (0.04) | 69% (0.04) |
| Comfort with screening/prevention recommendations | | . , | |
| Very/somewhat comfortable providing screening | 62% (0.04) | 100% (^a) | 25% (0.10) |
| Neither comfortable nor uncomfortable, | 38% (0.04) | 0% (a) | 75% (.10) |
| somewhat uncomfortable, and very uncomfortable | | | |
| Referral | | | |
| Yes | 8% (0.05) | 83% (0.05) | 93% (0.05) |
| No | 92% (0.05) | 17% (0.05) | 7% (0.05) |
| Percent of sample | 44% (0.04) | 34% (0.04) | 22% (0.03) |

^aStandard errors are undefined for probabilities on the boundary of the parameter space (0 or 1).

(p < 0.0005). For those with access, 32.3% had this resource within 10 miles, 21.4% within 30 miles, 7.3% onsite, and 8.3% by telephone. Among nonreferring physicians, limited physician access to a genetic counselor was cited far more frequently as a barrier to referral than patient access to a genetic counselor (p < 0.0005), while adjusting for other variables including age, years in practice, sufficient tools for risk assessment, and comfort providing screening recommendations. Therefore, limited physician access to a genetic counselor, as measured by distance from cancer genetic counselor, may be a more significant predictor of nonreferral than patient inconvenience.

After adjusting for variables including age, academic affiliation, access to genetic counselor, having sufficient tools for risk assessment, and comfort providing screening recommendations in multiple logistic regression analysis, OB-GYN specialty, female gender, and access to a genetic counselor remained independent predictors of referral to cancer genetics professionals.

Latent class analysis of referral patterns

Using latent class analysis, we were able to define profiles of three different PCP groups: those who do not refer to cancer genetics professionals (and have minimal involvement, themselves); those who refer and also actively provide cancer risk assessment services; and those who refer with less involvement in cancer risk assessment services themselves. Likelihood ratio tests showed that the three-class model fits much better than the two-class model (chi-square = 118.38, 10 df, p < 0.001) and that the two-class model fits better than the one-class model (chi-square = 291.78, 10 df, p < 0.001). The characteristics of the three different classes of primary care physicians are displayed in Table 6.

According to the latent class model, Class I PCPs (nonreferring, minimally involved with respect to cancer risk assessment) account for 44% of the sample. These physicians typically are family medicine or internal medicine specialists (93%), male (70%), do not have sufficient tools to assess cancer risk (72%), do not use robust risk assessment tools such as a three-generation pedigree or statistical models (74%), and have limited access to genetic counselors (82%). Ninety-two percent of the members of this group do not refer to genetic counselors.

Class II PCPs (those who refer and also actively provide cancer risk assessment services themselves) account for 34% of the sample. These physicians include family medicine and internal medicine PCPs (68%) as well as OB/GYN (32%) specialists, and do not have a gender dominance (males 54% and females 46%). Sixty percent use robust tools such as a three-generation pedigree or statistical models and 61% report having sufficient tools for risk assessment. The majority of these PCPs (67%) have access to a genetic counselor within 10 miles. In this class of PCPs, 83% refer to the genetic counselors.

Class III PCPs (refer to genetic specialist but provide less cancer risk assessment services themselves) account for 22% of the sample. Similar to Class II, there is a mixture of family medicine and internal medicine PCPs (65%) as well as OB/GYN specialists (35%), and males (46%) and females (54%) are represented. Ninety-two percent of the PCPs in this group feel they do not have sufficient risk assessment tools. Additionally, 69% of the PCPs in Class III do not use pedigree or statistical tools to assess cancer risk. Seventy-seven percent of these PCPs have access to a genetic counselor within 10 miles, and 93% of this class refer to a genetic counselor.

Discussion

In this study, we describe the risk assessment and referral practices among a national sample of PCPs. To our knowledge, this is the first study to describe PCP referral patterns based on an integration of both demographics and self-reported attitudes. Primary care OB/GYN specialists, women, those with teaching hospital affiliation and those with access to genetic counselors within 10 miles were more likely to refer for cancer genetic risk counseling. Further, an exploratory latent class analysis indicates that perceived availability of assessment tools, reported use of pedigree and statistical tools, and comfort with making screening and prevention recommendations can provide further discrimination of referral tendencies. These observations suggest an opportunity to develop interventions targeted to specific groups of PCPs to address referral barriers.

Overall, only approximately half of the respondents referred to cancer genetics professionals. OB/GYN's and female physicians were most likely to refer, which is consistent with other studies (Freedman *et al.*, 2003). This finding is not surprising as OB/GYNs screen for breast and ovarian cancer and therefore, it is a logical extension of their practice to address genetic risk for these diseases and is supported by other studies (Brandt *et al.*, 2008). Also female patients may feel more comfortable talking about their family history of breast/ovarian cancer with their physicians (Buchanan *et al.*, 2005). The current study did not address whether referral attitudes differ by specific hereditary cancer syndromes, that is, breast/ovary versus colorectal, and hence whether patient gender might impact physician's attitude and behavior.

Physicians affiliated with a teaching hospital (where a genetic counselor is likely to be employed) or with access to a genetic counselor within 10 miles were significantly more likely to refer to a cancer genetic counselor. In fact, our study findings suggest that limited physician access to a genetic counselor, as measured by distance from cancer genetic counselor, appears to be a more significant predictor of nonreferral than perceived patient inconvenience. In light of the potential shortage of genetic professionals, other nontraditional means for both physicians and patients to access genetic counselors and their services (Calzone *et al.*, 2005; Lea, 2006) may be necessary. It is also notable that only 16.7% of the physicians use professional guidelines to guide referral for cancer genetics evaluation. It is possible that guideline dissemination and uptake is incomplete given their recent development (Nelson et al., 2005). It is likely that some physicians need more support in the risk assessment process to effectively implement clinical guidelines. This is supported by data from our survey that 38.3% of the physicians are uncertain about whom to refer. In addition, it was only after the survey was administered that the American College of Obstetrics and Gynecology (2009) published guidelines regarding cancer risk assessment and referral (ACOG Practice Bulletin No. 13). Therefore, one might anticipate that as prevalence and awareness of guidelines improve, their use in primary care practices will increase.

In addition to demographic variables, this study identified three classes of PCPs based on attitudinal differences. Class I represents the nonreferring PCP. Class II and Class III represent two potential subtypes of referring physicians. Class II represents the actively involved, referring PCP and Class III represents the less involved referring PCP. Further research is necessary to confirm these findings and further refine the features, both demographic and attitudinal, that discriminate these groups. This could ultimately permit the development of educational interventions targeted to the needs of particular groups of PCPs. For example, interventions to educate Class I PCPs regarding risk assessment tools and facilitating genetic professional access and referral process may improve delivery of risk counseling. Uncertainties about whom to refer and the method of referral remain major reasons for nonreferral in this study as well as other previous reports (Brandt et al., 2008).

Several limitations of this study must be acknowledged. This study included a survey of physicians affiliated with a large health insurance carrier. The response rate was low, raising the possibility that the respondent population is not representative of the overall population of Aetna PCPs or PCPs affiliated with other insurers. Although absolute differences in demographics between participants and nonparticipants were observed (Table 2), these were of small magnitude. In addition, the study sample was large (n = 860)and included a variety of PCP specialties, practice settings, and geographic locations. We were able to define three classes of physicians who differed in their attitudes and behaviors regarding genetic counseling referrals. Determination of the extent to which these findings are reproducible and applicable to survey nonrespondents or physicians working with other health insurers will require further study.

In summary, these findings suggest that physicians who are OB/GYNs, female, and have local access to a genetic counselor are more likely to refer to genetics professionals; therefore, they may need different decision support tools and education resources compared to physicians who do not refer. These findings may have increasing importance as genomic medicine advances and direct to physician/consumer marketing continues to gain momentum (American College of Medicine Genetics Board of Directors, 2004; Hudson *et al.*, 2007).

The latent class model developed in this study allowed us to further explore attitudinal variation in cancer risk assessment that could lead to a comprehensive understanding of genetic referral patterns. Several national programs, including the Surgeon General Family History Initiative (Wolpert, 2005) and Genetics in Primary Care project (Burke *et al.*, 2002), have been developed to increase awareness about familial disease risk among the public and medical profession. Our data support the contention that PCPs vary in the extent to which they are comfortable with genetic risk assessment and their referral patterns, such that tailoring of genetic support tools may be an appropriate next step in optimizing the approach to genetic evaluation in primary care.

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Disclosure Statement

J. Armstrong and M. Toscano are Aetna employees and own stocks in Aetna. The authors report no other potential conflicts of interest related to this manuscript.

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