October 2002 · Vol. 51, No. 10

JFP ONLINE

Cancer risk assessment from family history: Gaps in primary care practice

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The authors report no competing interests.

- OBJECTIVE: To determine whether an adequate amount of family history is being collected and recorded by family practitioners to appropriately identify patients at increased risk for cancer.
- STUDY DESIGN: Retrospective chart audit.
- POPULATION: Charts from 500 randomly chosen patients, 40 to 60 years of age, were audited. Of those charts, 400 were from a large academic family practice and 50 charts each were from 2 small community family practices in the greater Philadelphia area.
- OUTCOMES MEASURED: General features of family history taking were recorded, including presence of a family history and date when recorded, evidence of updated family history data, and presence of a genogram. Cancer features recorded included mention of family history of cancer or colon polyps and, if positive, identification of which relative was affected, site of cancer, and age of diagnosis or death.
- RESULTS: Most charts (89%) had some family history information recorded, and 55% listed a family history of cancer, either positive or negative. Of the 356 relatives affected with cancer, an age of diagnosis was documented in only 8%; of 183 first-degree relatives with cancer, only 7% had a documented age of diagnosis. Two percent of all charts had any mention of a family history of colon polyps. Sixty-five percent of family histories were recorded at the first visit, and only 35% had any updated family history information.
- CONCLUSIONS: The number and type of family histories currently being recorded by family practitioners are not adequate to fully assess familial risk of cancer. New strategies will need to be developed to better prepare providers for risk-based clinical decision making.

key words **Cancer; family history; family practice; genetics; screening. (J Fam Pract 2002; 51:000)**

Taking a family history is a significant component of providing comprehensive primary care because family history provides key psychosocial and medical risk information.[1,2] As our understanding of the genetic basis for disease grows, obtaining an accurate and complete family history is likely to gain increasing relevance as a vital source of data to guide counseling and testing. Patients who have a first-degree relative with a colon neoplasm or prostate cancer are advised to screen differently from those who do not.[3] Failure to gather accurate or complete family data prevents the clinician from providing advice that is consistent with screening guidelines. Understanding how primary care clinicians gather family history data is necessary to identify gaps in current performance and to develop strategies to bridge these gaps.

Several studies have used physician self-report to assess the current level of taking a family history in primary care. In 1

study, 90% of surveyed physicians stated that they obtain a family history of cancer from their patients, with 77% to 80% inquiring about a family history of colorectal cancer in their patients who are at least 40 years of age.[3] In another study, 63% to 85% of responding physicians reported obtaining a family history of cancer from 76% to 100% of their patients.[5] Respondents in 1 study reported obtaining family histories of colorectal cancer in only 30.7% of patients, breast cancer in 48.4% of patients, and coronary disease and hypertension in 94.3% of patients.[6] However, data on actual performance of family history taking are sparse.[7,8] The physicians in the Direct Observation of Primary Care study obtained a family history during 51% of new visits and 22% of established visits. A genogram was present in 11% of charts, and documentation of a family history of breast cancer or colorectal cancer was found in 40% of charts. Further analysis from this study showed that providers who more frequently obtained and recorded family history information performed more preventive care services for their patients.[9]

First-degree relatives of cancer patients appear to be interested in and receptive to information about their risk and in the possibility of genetic counseling.[10-14] In fact, many patients overestimate their likelihood of getting cancer based on family history[10]; primary care providers thus have the opportunity to counsel and relieve anxiety in their patients. Family history is an important tool to define risk and guide referral, counseling, and testing.

This article presents the findings of a descriptive study of the review of 500 charts from 3 different family practice offices. We documented general family history components and completeness related to a family history of cancer, including whether enough family history information was collected to appropriately identify patients at increased risk for cancer.

METHODS

Data were collected from 500 patient charts from 3 family practice offices in the greater Philadelphia area. Patients who were in the practice for at least 1 year, made a minimum of 2 visits between June 1, 1997 and June 1, 2000, and were between the ages of 40 and 60 years at 1 of those visits were included. Fifty charts were selected by using a random starting point at each of 2 small (1 to 3 providers) private practices, and 400 charts were randomly selected from all eligible charts in a large academic practice (more than 60 providers). The large practice had nearly 1500 patients who fit the selection criteria, and the total population did not differ from the random sample in mean age, sex, or race ($P < .05$). Total population characteristics were not available for the 2 smaller practices.

Family history data were collected from progress notes and designated family history spaces on flow sheets or chart covers. Family histories consisting only of “none” or “noncontributory” were counted only when they clearly referred to a specific condition. Family births or deaths recorded in a psychosocial context also were not counted as part of the family history unless death from a specific disease was mentioned. The first dated family history was considered to be first for the purpose of this study. Date of birth, race, sex, current primary care provider, if any, and the date first seen in the practice were recorded. The current primary care provider was determined by the physician seen for the majority of recent visits and/or notations in the chart at acute visits. Data collected for the primary care providers included practice site, sex, level of training, and years in practice. Variables collected from family history information included: date of first family history; date of most recent family history; presence of a genogram, presence of a patient-completed family history self-questionnaire; whether any mention was made, positive or negative, of cancer or colon polyps; and whether there was a positive family history of cancer or colon polyps. For individuals with a positive family history of cancer or colon polyps, all details recorded in the chart were abstracted; these included site of cancer or polyp, relationship to patient, age at diagnosis, and age at death. The data were entered into an Access 97 database and stored separately from chart number identifiers. All analyses and tests were done in SAS version 6.12.

RESULTS

Demographic data from the 500 patients whose charts were audited are presented in **Table 1**. Ninety-seven percent of patients had a primary care provider, which included 60 physicians and 3 nurse practitioners. No significant associations were seen with practice site, sex, or level of training of the provider and the presence of family history information in the chart.

Most patients (89%) had some family history information in the chart and 63% had a genogram. This did not differ by sex

or race of the patient. Fifty-seven percent of patients supplied family history information at the first visit to the office; 59% of these patients had no family history data recorded on subsequent visits. Only 31% of charts had updated family history information **Table 2**. For patients who had been in the same practice for at least 5 years and had some family history in the chart, 20% had some updated information within the past 3 years.

Of the 500 charts, 276 (55%) recorded a family history of cancer, positive or negative. Two hundred fifteen patients (43%) had a positive family history of cancer, with a total of 356 relatives affected. The site of cancer was listed for 88% of all family member cancers, with breast, colon, lung, and prostate being the most common cancer locations. The specific relative was identified in 92% of cases, with most being first (51%) or second (37%) degree. Although degree of relative and cancer location were usually recorded, age at diagnosis was listed for only 8% of affected relatives, and age at death was identified for 19% of relatives with cancer.

For patients with affected first-degree relatives, the group with the greatest clinical significance, primary care providers identified the location of the cancer in 93% of cases but listed the ages at diagnosis and death in only 7% and 31%, respectively **Table 3**. Only 7 medical records (1.4%) had any mention of a family history of polyps; of these, 5 (1%) were positive. None listed an age at diagnosis. Five patients in our study met the American Society of Clinical Oncology criteria to be evaluated for genetic breast and ovarian cancer syndrome, and no patients met the criteria for hereditary nonpolyposis colon cancer.

The 2 community practices intermittently used patient self-administered medical intake questionnaires. In our sample, 31 of 500 patients (6%) had a questionnaire in the chart. All patients who completed questionnaires had family history data in their charts. Use of a questionnaire was associated with a greater likelihood that the physician recorded the age of diagnosis for a relative with cancer, although this did not reach significance (20% vs 7%).

DISCUSSION

Despite our finding that providers are documenting family histories in most charts, very few are recording the age of diagnosis in relatives diagnosed with cancer. Age of diagnosis plays a critical role in determining screening recommendations and identifying patients with possible genetic syndromes. For example, the Amsterdam criteria used to identify families with hereditary nonpolyposis colon cancer include knowing whether 1 of 3 relatives with colorectal cancer was diagnosed at younger than 50 years. Breast and ovarian cancer syndrome should be suspected when breast and/or ovarian cancer is diagnosed in 2 first-degree relatives younger than 50 years.[15]

Most physicians obtain family histories at initial visits. If the patient's initial visit is for symptom- or disease-related care, an opportunity to gather family history data may be lost. New tools to consistently capture comprehensive family history data at this first visit may be beneficial. Patient self-administered intake questionnaires may prove valuable in this respect, but only 6% of charts in our study contained such a questionnaire, so we cannot draw conclusions about its impact. We did observe a trend toward gathering more complete family history data in patients who used a questionnaire.

There are no clear guidelines regarding when to update a family history. We arbitrarily chose 3 years as a reasonable period for primary care providers to explore changes in family history status. Updating at any subsequent visit was recorded for 35% of patient charts in which a family history was initially taken. It is not clear that primary care providers are documenting changes in family history in any systematic way. Opportunistic updating likely occurs when a new diagnosis of serious disease in a close family member produces anxiety, stress, or concern in the patient. The value of updating family history and the ideal interval to reexamine family history are unknown.

Several conditions would need to be met for family history updating to have value. (1) A close relative must have developed an important illness in the interval since the last family history was recorded or the update must discover family information that was previously missed. (2) The illness must have a familial component that affects the estimate of the risk of the identified patient. (3) The clinician would need to be aware of the updated information. (4) The clinician must change recommendations to the patient based on this new information. Discovering a new family history of colonic neoplasm satisfies these conditions. Process measures that have the potential to improve updating include adding an

update of family history as an item on a preventive care flow sheet or using periodic self-administered patient questionnaires. Whether adequate improvements in health care would occur to justify these changes in process will need to be studied. If any updating has value, determining the appropriate intervals for systematic updates deserves attention.

Charts in this study included a genogram 63% of the time, a significant increase over the 11% noted in the Direct Observation of Primary Care study.[9] This discrepancy may be explained by differences in practice types because 1 study suggested a higher genogram use in academic medical centers than in community practices.[16] The genogram has been cited as an attractive and efficient way to document family history,[17,18] but over one fourth of the charts that contained family history in our study used the more cumbersome narrative form. Many geneticists predict that our ability to apply genetic testing will grow dramatically over the next decade. Optimal application of this new knowledge will rely on the health care system's capacity to accurately identify risk based on assessment of family history. The 3-generation pedigree is likely to be a key tool in finding individuals who may benefit from testing. However, there is currently no standardized education in family history taking in many undergraduate and graduate medical education programs.[19]

Although patients with a first-degree relative with a history of polyps diagnosed at younger than 60 years are considered to be at increased risk for colorectal cancer,[3] providers infrequently asked about a family history of polyps. This may reflect a recent finding that only 36% of primary care providers recommend screening at the age of 40 years for their patients with a family history of polyps in relatives younger than 60 years.[20] In fact, family history data do not consistently influence behavior: in the same study, gastroenterologists asked about a family history of polyps 93% of the time, but only 37% recommended earlier screening in those with such a history.

The study is limited in its use of only 3 primary care practices, 1 of which was a large academic family practice. However, because the charts of 63 different clinicians were represented, a range of educational backgrounds and personal philosophies toward family history taking was included. Most patients (97%) had a clearly identified primary care provider and patients had been members of the practice for an average of 7.6 years. The sample was specifically chosen to review the charts of individuals who had been enrolled in the same practice for at least 1 year. This may explain the higher rates of family history taking found in this study compared with previously published studies. Given that the vast majority of charts did contain some family history, it is even more compelling that age at diagnosis of cancer was inadequately recorded. This study reflected only what was documented in the patient chart and not direct observation of physician behavior regarding the family history. It is likely that physicians are not recording all responses to inquiries about family history, although the extent of this underreporting is unknown.

CONCLUSION

Findings in this chart review study are consistent with previous work showing that the quantity and type of family history currently being recorded in primary care charts are not adequate to fully assess familial risk. Bridging the gap between recommendations and actual practice will demand interventions to alter primary care practice or the introduction of new models to gather and analyze family data. Further research is also needed to evaluate the impact of improved family history taking on health care costs and outcomes.

· ACKNOWLEDGMENTS ·

The authors thank Howard Rabinowitz, MD, for providing helpful suggestions in the development and execution of this project and Aliza Mansolino for the preparation of the manuscript.

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