

# Effectiveness of a Personal and Family History Questionnaire When Assessing Colorectal Cancer Risk



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**Background:** Few studies have evaluated whether a personal and family history questionnaire (PFHQ) administered at the initial patient encounter improves the provider's ability to appropriately risk stratify patients for colorectal cancer (CRC) screening. The objective of this study was to determine if a PFHQ completed by the patient prior to the initial encounter improved the provider's ability to extract pertinent information relating to CRC risk.

**Methods:** This was a prospective intervention study conducted in the adult outpatient gastroenterology clinic at Penn State Hershey Medical Center. A PFHQ was created based on expert opinion and current screening guidelines. 199 patients evaluated as new encounters between February 2009 and June 2009 completed the questionnaire. We also retrospectively evaluated 186 randomly chosen charts of new patient encounters that had not utilized a questionnaire. A point system was created to score all charts in both the retrospective (without the questionnaire) group as well as the prospective group (with the questionnaire) based on quantity and quality of information documented in the consultation reports relating to CRC risk. Results between the two groups were compared using Wilcoxon Rank Sum test.

**Results:** Both patient and family history scores were significantly lower in the prospective study group that completed the questionnaire ( $p=0.05$ ,  $p<0.01$ , respectively) when compared to the group that did not utilize a questionnaire. Composite scores (personal & family history) were significantly lower in the study group that completed the questionnaire ( $p=0.01$ ).

**Conclusion:** Our study demonstrated that clinician-led history taking was superior to a questionnaire in obtaining quality history that can be used to appropriately risk stratify patients for CRC screening.

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## INTRODUCTION

Colorectal cancer (CRC) remains the third leading cause of cancer in the United States in both men and women. It is also the third leading cause of cancer-related deaths.<sup>1,2</sup> Evidence supports that mortality from CRC is reduced by screening asymptomatic persons.<sup>3-8</sup> Patients who gain the most benefit from current screening modalities are those at increased risk for developing CRC. Thus, it becomes essential to appropriately identify these individuals and refer them for screening measures accordingly.<sup>9-13</sup> Obtaining a personal and family history helps identify risk factors for development of sporadic cancers and potentially identify single-gene disorders such as Hereditary Non-Polyposis Colorectal Cancer (HNPCC).

Questionnaires have been utilized to assist in gathering this type of detailed history. Several modalities have been developed, including paper-based and web-based questionnaires.<sup>14</sup> In fact, Qureshi and colleagues state in their review on family history collection in primary care that it may be logical to have a “disease-specific risk assessment tool, rather than a stand-alone tool,” so that the history can be assessed in the context of disease-specific guidelines, such as CRC screening guidelines.<sup>15</sup> However, little is known about the clinical utility of these tools.

Few studies have attempted to ascertain whether a personal and family history questionnaire (PFHQ) enriches the ability to appropriately risk stratify patients for CRC. The objective of this study was to evaluate if a PFHQ completed by the patient prior to the initial encounter enhances a provider’s ability to extract pertinent information related to CRC risk.

## METHODS

### *Design and Setting*

This was a prospective intervention study that was conducted in the Gastroenterology adult outpatient clinic at the Milton S. Hershey Medical Center in Hershey, Pennsylvania. This institution is a large, academic referral medical center. The study was approved by the departmental scientific review committee and by the institutional review board.

A retrospective review of two hundred randomly chosen charts of patients seen as new consultations between July 2008 and November 2008, herein referred to as the ‘control group’, was conducted to measure outcome parameters prior to intervention. Of these, fourteen charts were excluded due to incomplete

charting. The consultation reports for all the charts were evaluated for information relating to CRC risk. This allowed the investigators to establish a baseline indicator of clinicians’ ability to elicit details pertinent to determining CRC risk.

The prospective portion of the study involved patients evaluated as an initial consultation at the Gastroenterology outpatient clinic between February 2009 and June 2009 (herein referred to as the ‘intervention group’). One hundred ninety-nine patients were recruited for the study. Subjects were approached and consented at time of check-in. Consented participants were asked to complete a PFHQ before their physician encounter. Completed questionnaires were attached to the patient’s chart and given to the practitioners to use at their discretion. Practitioners included attending physicians, gastroenterology fellows and physician assistants. The primary investigator of this study was excluded.

A point system was created as a surrogate marker to measure the amount of useful information gathered and documented from the PFHQ. Only information that could potentially risk stratify a patient’s CRC risk was included. All charts in both the control group (without the questionnaire) as well as the intervention group (with the questionnaire) were scored based on quantity and quality of information documented in the consultation reports relating to CRC risk. We compared the results between the two groups using Wilcoxon Rank Sum test.

### *Development of the Questionnaire*

Content of the questionnaire was solely determined by the most current CRC screening guidelines set forth in 2008 by the American Cancer Society and American Gastroenterological Association.<sup>16</sup> The first section gathered information regarding personal history. Questions in this section surrounded a personal history of polyps, including histology, CRC, inflammatory bowel disease (IBD), and suspected diagnosis of HNPCC or familial adenomatous polyposis (FAP)

With regard to a history of polyps, the number identified and histology are important determinants of risk. In addition to pathologic terms such as “hyperplastic” and “villous”, layman terms such as “benign” and “pre-cancer” were included as an approach to increase user recall. The final question in this section was aimed to identify patients at risk for hereditary syndromes as it addressed the presence of

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Table 1. Point System

| Information   | Points   |
|---|----------|
| Any non-cancer history (e.g. GERD), not including IBD                   | 0.0 each |
| Colonoscopy history (or other CRC screening measure)                    | 1.0 max  |
| Any generic cancer history (i.e. type not specified)                    | 0.5 each |
| Any specific cancer history (i.e. type specified), <b>including IBD</b> | 1.0 each |
| Any CRC qualifiers (e.g. histology, age, relationship, # polyps)        | 0.5 each |
| Non-contributory (or any statement of the like)                         | 0.0 max  |

extra-colonic tumors associated with HNPCC and FAP.

The second section of the questionnaire gathered information regarding family history. It was divided into two subsections: first-degree and second-degree relatives. Patients were asked about family history of CRC, polyps, and any extra-colonic cancers. Histology of polyps (e.g. hyperplastic versus adenomatous) is an important determinant of risk. A majority of patients are unaware of polyp histology, especially with regard to family members. Thus we incorporated time-lines as a way to extrapolate pathology of family members who may have had polyps. For example, if a patient marked that his or her father has had polyps, he or she was asked, “When were they asked to return for testing?” A response of “0-5 years” implied the patient’s father had a pre-malignant polyp whereas a response of “10 years” implied normal tissue or polyps with benign histology (i.e. hyperplastic)

Validity of the questionnaire was determined through discussion with gastroenterologists with expertise in CRC, screening guidelines, and survey design.

### Development of Point-System

A novel point system was created by the investigators to assign points to pertinent information recorded in the initial consultation reports for both the retrospective charts as well as the prospective charts, which utilized the questionnaire (Table 1). Pertinent information was defined as any information that could potentially be useful in determining a patient’s risk for development of CRC in the context of current screening guidelines.

That is, any piece of information that could be cross referenced with current screening CRC guidelines and lead to a decision regarding patient risk: average risk versus increased risk.

Specific information (i.e. personal history of polyps) received a full point. General information that could be helpful, but not necessarily help a practitioner risk-stratify a patient in the context of CRC (e.g. “personal history of cancer” versus “personal history of colorectal cancer”) received 0.5 points.

Qualifying statements with regard to age of onset, family relationship, histology, etc. received an additional 0.5 points each. Non-cancer history with the exception of IBD received zero points, as this information does not help risk stratify patients with regard to CRC. As there is no finite amount of information that can potentially help stratify an individual’s risk, there was no set maximum point value or range.

Thirty randomly chosen patient charts were reviewed prior to the study to obtain a general overview of practitioner language and to gain experience in applying the point system. An independent third-party also reviewed the charts and was asked to apply the point system to each chart. There was no significant difference in the average score given to the pre-study charts between the investigators and the third-party.

### RESULTS

The retrospective arm of the study (control group) was comprised of 186 patients whose initial consultation reports were reviewed and scored. One hundred ninety-nine patients participated in the prospective arm of the study (intervention group) by completing the questionnaire. The demographics of the two groups are shown in Table 2. There was no significant difference in age or gender between the two study groups.

Patient and family history scores were analyzed across both groups with the non-parametric Wilcoxon rank sum test, as data were not found to follow a normal distribution as determined by the Kolmogorov-Smirnov test.

Patient history and family history scores are outlined in Table 3. Mean scores were compared. Both patient and family history scores were significantly lower in the intervention group, the prospective study group that completed the questionnaire ( $p=0.5$  and  $p<0.01$ , respectively). Composite scores (sum of personal and family history scores) were also significantly lower in the intervention group ( $p=0.01$ ).

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Table 2. Demographic Information for Both Groups

|                 | Group 1<br>No questionnaire (N=186) |     | Group 2<br>Questionnaire (N=199) |     | p-value |
|-----------------|-------------------------------------|-----|----------------------------------|-----|---------|
| Age (mean)      | 50.1                                |     | 49                               |     | 0.33    |
| Female (n, %)   | 120                                 | 65% | 133                              | 67% | 0.63    |
| Provider (n, %) |                                     |     |                                  |     |         |
| Attending       | 65                                  | 35% | 117                              | 59% | <0.01   |
| Fellow          | 51                                  | 27% | 52                               | 26% | 0.78    |
| PA              | 69                                  | 37% | 30                               | 15% | <0.01   |
| Resident        | 1                                   | 1%  | 0                                | 0%  | 0.3     |

## DISCUSSION

This study evaluated the impact a PFHQ has on the ability of a provider to extract pertinent information related to CRC risk stratification, and demonstrated two important findings. First, implementation of a PFHQ did not enhance the ability to extract information that could potentially help stratify a patient's risk of developing CRC. Second, using a PFHQ led to significantly lower rates of documentation related to CRC risk-stratification. That is, practitioners extracted and documented more pertinent information that could potentially risk stratify a patient in the control group, the group that did not utilize the questionnaire.

Although many primary care physicians recognize the importance of gathering a family history, studies suggest that most lack the history-taking skills required to risk stratify patients appropriately while also implementing current guidelines.<sup>17-23</sup> One study revealed that only 50% of primary care physicians updated family histories during routine or annual examinations and only 28% routinely obtained history information beyond first-degree relatives; less than half of practitioners inquired about specific cancer types.<sup>17</sup> A recent study surveying 285 primary-care based physicians in Germany, found that less than 75% of physicians routinely inquired about family history. Seventeen percent of the physicians utilized a standardized assessment tool to gather information, only 35% of which stating they routinely update it.<sup>24</sup> Furthermore, although several questionnaires have been formally evaluated, only a few claim to have been clinically validated.<sup>25</sup> The questionnaire in our study was created to extract information that can be cross referenced with current CRC screening guidelines

and that can be used easily by clinicians. By using a standard questionnaire, we hoped to eliminate the variation between practitioner assessments of risk that results from unawareness of current guidelines.

One systematic review reporting the use and outcome of questionnaires identified only four studies that aimed to validate their questionnaire against a reference standard.<sup>26</sup> In all cases, the reference standard was a genetic interview conducted by a trained geneticist. Although geneticists do gather patient histories, typical encounters involve a clinician gathering personal and family history from a patient. Thus, the outcomes of these studies cannot be practically applied to common practice. A recent outcomes study by Vogel and co-workers evaluated the rate at which patients were referred for genetic counseling based on information gathered from a self-administered questionnaire versus a review of the patient's electronic medical record.<sup>27</sup> Similar to other previous studies, results were compared to a structured, genetic interview. The authors did conclude that the questionnaire led to a higher capture rates than a review of the medical record, however the study did not include physician-led interviews. In fact, no study has aimed to determine whether a questionnaire is superior to physician-led history-taking in the assessment of colorectal cancer risk in patients being seen in an outpatient setting. We provide a novel study that aimed to assess if a questionnaire is superior to physician-led history. In our study, significantly less information was extracted from patients when a questionnaire was utilized with respect to personal and family history

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**Table 3. Personal, Family and Composite Scores for Both Groups**

|                              | Group 1<br>No Questionnaire (N=186) |      | Group 2<br>Questionnaire (N=199) |      | p-value |
|------------------------------|-------------------------------------|------|----------------------------------|------|---------|
|                              | Mean                                | SD   | Mean                             | SD   |         |
| <b>Patient History Score</b> | 1.09                                | 1.17 | 0.86                             | 1.07 | 0.05    |
| <b>Provider</b>              |                                     |      |                                  |      |         |
| Attending                    | 1.08                                | 1.09 | 0.76                             | 1.06 | 0.03    |
| Fellow                       | 1.33                                | 1.29 | 1.16                             | 1.11 | 0.79    |
| PA                           | 0.93                                | 1.12 | 0.73                             | 0.94 | 0.49    |
| <b>Family History Score</b>  | 1.45                                | 1.86 | 1.24                             | 1.9  | <0.01   |
| <b>Provider</b>              |                                     |      |                                  |      |         |
| Attending                    | 1.06                                | 1.79 | 0.98                             | 1.94 | 0.2     |
| Fellow                       | 1.35                                | 2.26 | 1.19                             | 1.58 | 0.52    |
| PA                           | 1.88                                | 1.5  | 2.3                              | 1.95 | 0.39    |
| <b>Composite Score</b>       | 2.54                                | 2.27 | 2.09                             | 2.32 | 0.01    |
| <b>Provider</b>              |                                     |      |                                  |      |         |
| Attending                    | 2.14                                | 2.28 | 1.74                             | 2.42 | 0.04    |
| Fellow                       | 2.67                                | 2.7  | 2.36                             | 2.05 | 0.65    |
| PA                           | 2.82                                | 1.85 | 3.03                             | 2.15 | 0.78    |

Lack of time is the most notable barrier to obtaining personal and family history. As questionnaires are meant to be a time-saving tool, we hypothesize that practitioners do not repeat questions pertaining to history when the patient has completed a questionnaire. The questionnaire is only as valuable as the practitioner who reads it. It must be read, and pertinent positive and negative information should be documented in the patient's chart. This, in turn, would then lead to proper assignment of the patient into the 'high risk for CRC' category and appropriate screening could then be recommended and implemented.

Our study provides a novel examination of current practices in a large outpatient gastroenterology clinic. It also examines the behavior and documentation patterns of gastroenterologists when implementing a questionnaire as compared to practices when such a tool is not utilized. Clinicians may be more inclined to remember information they asked themselves rather than information visualized on a questionnaire.

Clinician-led history taking was superior to questionnaires in obtaining quality history that can be used to appropriately risk stratify patients. This suggests that practitioners may neglect to elicit important details in the history pertaining to establishing CRC risk when a questionnaire is available. Therefore, although current studies show that physicians have suboptimal rates of assessing personal and family history, implementation of a questionnaire may be even more detrimental and possible even impede the process of gathering information. Thus, we do not recommend the implementation of questionnaires for the use to history-taking, especially in the context of CRC risk assessment.

There are limitations to this study. The questionnaire created by the study investigators was not validated. However, its content was derived from the most current CRC screening guidelines set forth by the American Cancer Society and American Gastroenterological

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Association in 2008. Moreover, investigators collaborated with experts in CRC screening guidelines when developing the questionnaire. Second, the point system used to analyze the primary outcome was developed and implemented by the study investigators, thus leading to potential bias. However, a subset of randomly chosen charts was analyzed by a third-party and there was no significant difference in the points assigned by investigators and the third-party analyst. Lastly, there were significant differences in the type of provider (e.g. attending versus fellow trainee) conducting the patient interviews between the two groups, which could play a confounding factor. Interestingly however, it was the intervention group, the group evaluated by significantly more attending Gastroenterologists, that scored significantly lower. Thus it appears that less formal training did not influence the negative result.

## CONCLUSION

Clinician-led history-taking was superior to the utilization of a questionnaire as clinicians documented significantly lower rates of information regarding CRC risk when the questionnaire was utilized. This suggests that clinicians may rely too heavily on information-gathering tools such as questionnaires, and that implementation of a questionnaire may negatively impact information gathering and risk stratification.

Questionnaires should not be used as a sole tool to gather personal and family history in the context of CRC risk unless the practitioner actually has time to review, interpret and document what is stated on the questionnaire. ■

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