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Journal

American Journal of Epidemiology, 150(6)

ISSN

0002-9262

Authors

Mandelson, Margaret T
LaCroix, Andrea Z
Anderson, Lynda A
et al.

Publication Date

1999-09-15

DOI

10.1093/oxfordjournals.aje.a010060

Peer reviewed

American Journal of Epidemiology

Vol. 150, No. 6
Printed in U.S.A.

Comparison of Self-reported Fecal Occult Blood Testing with Automated Laboratory Records among Older Women in a Health Maintenance Organization

Margaret T. Mandelson,[1] Andrea Z. LaCroix,[1] Lynda A. Anderson,[2] Marion R. Nadel,[2] and Nancy C. Lee[2]

Screening guidelines for colorectal cancer recommend annual fecal occult blood (FOB) testing for adults aged 50 years and older. Self-reported history of screening is frequently the sole source of data available to researchers and clinicians. This study validated FOB testing in a sample of 1,021 older women. Testing rates based on self-reported data exceeded rates based on computerized laboratory records by 13.9%. Agreement was moderate (kappa = 0.52; 95% confidence interval 0.47, 0.58). Sensitivity was 0.92 and specificity 0.58. Logistic regression analysis showed that older age and physician encouragement for FOB testing were associated with accurate recall ($p < 0.05$). Self-report is the most commonly available information about the occurrence and timing of cancer detection procedures. These data suggest cautious use of self-reported screening by FOB for clinical decision making and for research and surveillance. *Am J Epidemiol* 1999;150:617–21.

colorectal neoplasms; medical audit; occult blood; screening; validity

Although there is substantial evidence that colorectal cancer mortality can be reduced through detection and treatment of early-stage cancers and identification and removal of precursor polyp lesions, the prevalence of colorectal cancer screening in this country is low (1). Recent screening guidelines recommend annual fecal occult blood (FOB) testing and/or periodic flexible sigmoidoscopy for adults aged 50 years and older (2–6), yet only 17 percent of women who responded to the National Health Interview Survey were screened by FOB in the previous year (1). A potential problem in monitoring adherence to these guidelines is that most evaluations are based on self-reported history of screening, which is frequently the sole source of data available to epidemiologists and to clinicians.

Most studies that validate self-reported cancer screening data have focused on Pap smears and mammograms (7–15). Four studies (16–19) validated colorectal cancer screening by FOB testing as well as a number of other procedures (16–18). In general, these studies found that patients tend to over-report prior screening, but the results are somewhat inconsistent because of differences in populations and study design. Furthermore, none focused on older women, a population that participates in breast cancer screening at increasingly higher rates (1) but that underutilizes colorectal cancer screening tests. The purpose of this study was to validate self-reported FOB testing in a sample of older women.

MATERIALS AND METHODS

Women eligible for this study were aged between 50 and 79 years, had an identified primary care physician, and had belonged to Group Health Cooperative (GHC) of Puget Sound, a staff model health maintenance organization (HMO) that serves more than 420,000 enrollees in western Washington State, for at least 2 years prior to January 1, 1995. Of the approximately 43,000 GHC women who met these criteria, 1,520 were randomly sampled from the GHC enrollment file to participate in a telephone survey. Details of study methods have been previously reported (20).

Computer-assisted telephone surveys were conducted between June and November 1995 and included questions on demographic information as well as on four important health promotion factors: 1) colorectal cancer screening; 2) hormone replacement therapy; 3) smoking status; and 4) physical activity. Survey contents, recruitment methods, and informed consent procedures were approved by human subjects

Received for publication May 20, 1998, and accepted for publication February 18, 1999.

Abbreviations: FOB, fecal occult blood; GHC, Group Health Cooperative; HMO, health maintenance organization.

[1] Center for Health Studies, Group Health Cooperative, Seattle, WA.
[2] National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA.
Reprint requests to Dr. Margaret T. Mandelson, Center for Health Studies, Group Health Cooperative, 1730 Minor Ave., Suite 1600, Seattle, WA 98101.

committees at GHC, the University of Washington, and the Centers for Disease Control and Prevention.

Of the 1,520 women who were invited to participate in the telephone survey, 125 were subsequently found to be ineligible. Of the remaining 1,395 women, 1,120 (80.3 percent) agreed to participate and completed the telephone interview, however, data was lost from one respondent because of a software problem. The present study further excluded women enrolled in GHC for less than 5 years ($n = 82$), women who reported prior colorectal cancer ($n = 9$), women with missing information on whether they had ever been tested ($n = 5$), and women with missing information on when their most recent FOB test occurred ($n = 2$). Thus, data on 1,021 women were found to be acceptable for analysis.

Self-reported information on FOB testing was ascertained by responses to structured questions about ever-testing by FOB, the main reason why the most recent test was performed (e.g., as part of routine physical examination/screening or because of a specific health problem), and time since the most recent test. Women were asked to limit their response to stool sampling that they performed at home. Episodes of office-based testing were excluded, because these results are interpreted by the physician and not recorded in the GHC laboratory file. The data were linked to GHC computerized laboratory records to validate survey response. Kappa coefficients were calculated to determine the extent of agreement between self-report and laboratory records. We considered kappa values between 0.41 and 0.60 moderate; values between 0.61 and 0.80, substantial; and those between 0.81 and 1.00, almost perfect (21). The validity of self-reported data was evaluated by the following operating characteristics: sensitivity, specificity, and positive predictive value. Finally, the associations between characteristics and likelihood of accurate reporting in the 5 years prior to survey were evaluated through logistic regression analysis (22).

RESULTS

Seventy percent of the study women reported that they had undergone at least one FOB test in the 5 years prior to survey. Their responses, categorized by selected characteristics and factors related to testing, are shown in table 1. These factors included older age, recency of mammography, smoking status, and personal history of colorectal polyps. Testing rates were higher among the 10 percent of study women with a first-degree family history of colorectal cancer (78.4 percent vs. 69.5 percent), however, this finding was not statistically significant. Self-reported occult blood testing was also related to women's knowledge and personal attitudes. Rates were highest among women who agreed or strongly agreed with the statement that "FOB testing is a good way to find colorectal cancer early" (71.8 percent), and lower among women who disagreed with this statement (51.4 percent) or reported that they didn't know (60.0 percent, $p < 0.01$). Similarly, almost three-quarters of women who believed that "FOB testing is important for me to do" reported that they had a test in the previous 5 years; rates for testing were lower among other study women ($p < 0.001$). Finally, almost 90 percent of women whose physicians strongly encouraged colorectal cancer screening reported that they had a test in the past 5 years, whereas only about half of all women whose doctors did not encourage screening or were neutral on this topic reported having a test in the past 5 years ($p < 0.001$).

The proportion of women who reported testing within the past 5 years exceeded the proportion based on computerized laboratory records (table 2). Agreement between self-report by questionnaire and medical record data was moderate (kappa 0.47–0.58), and 74.1 percent of the 719 women who recalled having a test in the past 5 years were confirmed by record review. Sensitivity of self-report was as high as 92.4 percent for women who had a test record in the computerized laboratory file and who reported this event in the study survey. Forty-two percent of subjects with no record of having a test in the previous 5 years reported that one occurred, resulting in a specificity of 58.1 percent. Comparing survey results with laboratory records extending back 7 years did not appreciably alter study findings (kappa 0.50–0.61).

Older age and provider encouragement toward testing were significantly associated with accurate recall of FOB testing, which indicates increased sensitivity and specificity of self-report among older women and women whose physicians were "somewhat" or "very encouraging" (table 3). For example, women aged 70–80 years were almost three times more likely to accurately report their testing experience than women aged 50–59 years during the interview (relative risk = 2.99, 95 percent confidence interval 2.21, 4.22). Accuracy of recall was not related to education, race, family history of colorectal cancer, or personal history of polyps. In addition, recency of testing within the past 5 years and reason for test were not related to valid survey responses, and inclusion of these factors into the logistic model did not alter the results.

DISCUSSION

Our findings showed fair agreement between self-reported and computerized medical record-documented fecal occult blood testing with relatively high sensitivity (92.4 percent) and low specificity (58.1 percent). We found evidence that older women and women

TABLE 1. Percent of women who reported prior fecal occult blood (FOB) testing, by selected characteristics, Group Health Cooperative of Puget Sound, 1995

Characteristic	No.	% of total	% who reported FOB testing in previous 5 years
Total sample	1,021	100.0	70.4
Age at interview (years)			
50–59	391	38.3	59.1
60–69	295	28.9	73.6
70–80	335	32.8	80.9
Race			
White	904	89.7	70.7
African American	52	5.2	65.4
Asian	43	4.3	72.1
Other	9	0.9	100.0
Education			
<12 years	95	9.3	70.5
High school graduate	274	26.9	66.8
Attended college	306	30.0	72.6
College graduate	344	33.8	71.2
No. of years since last routine preventive examination**			
≤1	668	65.8	74.6
1–2	229	22.5	69.0
2–5	84	8.3	64.3
≥5	35	3.4	17.1
Ever had a mammogram**			
No	48	4.7	33.3
Yes	971	95.3	72.4
No. of years since last mammogram**			
≤1	548	53.9	74.8
1–2	282	27.8	74.5
2–5	112	11.0	61.6
≥5	26	2.6	46.2
Never	48	4.7	33.3
Smoking status*			
Never	512	50.2	71.5
Former	393	38.5	72.3
Current	115	11.3	59.1
Personal history of colorectal polyps***			
No	934	91.9	69.3
Yes	82	8.1	82.9
First-degree family history of colorectal cancer			
No	919	90.0	69.5
Yes	102	10.0	78.4
Having FOB testing is a good way to find colorectal cancer early***			
Agree or strongly agree	929	91.0	71.8
Disagree or strongly disagree	37	3.6	51.4
Don't know	55	5.4	60.0
Having FOB testing is important for me to do**			
Agree or strongly agree	925	90.6	74.3
Disagree or strongly disagree	70	6.9	35.7
Don't know	26	2.6	26.9
Patient's assessment of extent to which provider encourages colon cancer screening**			
Not at all or neutral	415	41.7	53.3
Somewhat	230	23.1	76.5
Very	351	35.2	88.9

p for trend in self-reported FOB testing: ** $p < 0.001$; * $p < 0.05$; *** $p < 0.01$.

whose physicians strongly encourage colorectal cancer screening were most likely to accurately recall testing within the past 5 years.

The low specificity found in this study could be due to underestimation of the time since last FOB test, if some women who reported that they had been tested in

TABLE 2. Number of women and accuracy of self-reported fecal occult blood testing compared with computerized laboratory record, Group Health Cooperative of Puget Sound, 1995

Laboratory record: Yes	No	Yes	No	Positive predictive value (%)	Sensitivity (%)	Specificity (%)	False negative (%)	False positive (%)
Self-report: Yes	Yes	No	No					
533	186	44	258	74.1	92.4	58.1	7.6	41.9
a	*b*	*c*	*d*	*a/a + b*	*a/a + c*	*d/b + d*	*c/a + c*	*b/b + d*

the past 5 years were actually tested in the more distant past. This possibility is supported by studies of breast and cervical cancer screening (9, 11, 23) which have reported that women recalled the date of their last Pap smear or mammogram as more recent than is shown by medical records. In general, previous studies that have compared self-report and medical records of cancer screening showed results similar to those reported here in that inaccurate reporters tended to overestimate, rather than underestimate, their actual screening histories. In our study, testing rates by self-report were 13.9 percent higher than the prevalence in this population based on computerized laboratory records, a finding that is in substantial agreement with a prior study that validated FOB testing in an HMO population in the previous 2 years (18).

Not surprisingly, women with a medical history of colorectal polyps were significantly more likely to report that they had an FOB test in the previous 5 years. However, family history of colorectal cancer

TABLE 3. Relation between demographic characteristics, health history, and attitudes and beliefs about colon cancer screening and validated self-report of prior screening by fecal occult blood testing, Group Health Cooperative of Puget Sound, 1995

Variable	% agreement between self-report and medical record	Adjusted relative risk*	95% confidence interval
Age (years)			
50–59	41.9	1.00	
60–69	62.0	2.34	1.67, 3.27
70–80	68.7	2.99	2.12, 4.22
Race			
White	57.3	1.00	
African American	48.1	0.62	0.33, 1.16
Asian	62.8	1.30	0.64, 2.60
Other	55.6	0.99	0.24, 4.05
Education			
<12 years	55.8	1.00	
High school graduate	55.5	1.01	0.59, 1.72
Attended college	57.5	1.19	0.70, 2.03
College graduate	56.4	1.15	0.68, 2.00
Family history of colon cancer			
No	55.9	1.00	
Yes	61.8	1.21	0.75, 1.97
Personal history of colorectal polyps			
No	55.4	1.00	
Yes	69.5	1.32	0.76, 2.27
Smoking status			
Never	57.4	1.00	
Former	59.0	1.14	0.84, 1.52
Current	44.4	0.70	0.44, 1.09
Patient's assessment of extent to which provider encourages colon cancer screening			
Not at all or neutral	42.4	1.00	
Somewhat	58.3	2.09	1.47, 2.96
Very	73.5	3.71	2.68, 5.13

* Likelihood of accurate recall of fecal occult blood testing was adjusted for all variables listed.

was only modestly related to recent testing patterns. Moreover, neither factor was independently associated with accurate recall of testing among women who reported that they had a test within the past 5 years.

We considered the results from computerized laboratory data the "gold standard" against which to compare self-reported information about FOB testing, and we did not review data from individual patients' charts. "Paper" medical records may not always be a better source of information for prior screening than patient self-report, particularly for procedures that rely on physician documentation in the chart and in cases where patients receive care from multiple primary care providers, each with individual medical records. Although incomplete computerized data would result in estimates of recall accuracy that are spuriously low, we do not believe it to be a large source of bias in this study, which was based on a single centralized data source independent of individual physician record-keeping practices. Nevertheless, some women who received testing outside of GHC may have reported that it occurred within the HMO system and would thus be erroneously considered "false positive" on self-report. While we have no direct knowledge of FOB testing outside of the HMO, we consider this a remote source of bias because members receive virtually all of their care from GHC physicians.

Self-report is the most commonly available information about the occurrence and timing of cancer detection procedures, but the findings of this study show that self-report should be used cautiously for both clinical decision making and for research and surveillance.

ACKNOWLEDGMENTS

This research was supported by the Centers for Disease Control and Prevention and by grant no. CA71869 from the National Cancer Institute.

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