Accuracy of Patients' Recall of Pap and Cholesterol Screening

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ABSTRACT

Objectives. This study was undertaken in mid-1994 and assessed how accurately patients recall the recency and result of their most recent cholesterol and Papanicolaou (Pap) tests.

Methods. A cross-sectional, door-to-door community survey was used to gather self-report and, subsequently, pathology laboratory data for 195 individuals.

Results. In regard to cholesterol screening, 30% of individuals who reported being adequately screened were actually inadequately screened, 45% who reported normal cholesterol levels actually had elevated levels, and 21% of inadequately screened individuals and 56% of individuals with elevated levels were not identified by self-report. In terms of Pap screening, 28% of women who reported being adequately screened were actually inadequately screened, 11% of patients who reported a normal Pap test actually had abnormal or inadequate results, and 55% of inadequately screened individuals and 53% of individuals with abnormal or inadequate results were not identified by self-report.

Conclusions. This study revealed self-report to be a less-than-adequate measure of individuals' recall of cholesterol and Pap screening. Relying exclusively on self-report surveys as indicators of screening coverage is likely to result in significant underestimations of the proportion of people who are inadequately screened or whose results indicate a need for intervention. (*Am J Public Health.* 2000;90:1431–1435)

In the public health field, it is necessary to assess both individuals' and populations' adoption of screening behaviors, such as Papanicolaou (Pap), mammography, cholesterol, and blood pressure screening. Reliable, valid, and appropriate measures are prerequisites to any descriptive research or intervention assessment.[1] Without them, it is impossible to accurately assess screening prevalence rates, identify individuals who are less likely to engage in screening, or assess the efficacy of interventions aimed at encouraging screening behaviors.

Self-report is an easy, inexpensive, and widely used method of collecting data on individuals' screening behaviors.[2–6] If prevalence estimates and outcome measures are to be useful, the self-report items must provide accurate data. Previous studies, as well as a recent systematic review, have explored the accuracy of individuals' recall of the recency of screening events.[3,7–14] These studies have consistently shown that self-report data evidence higher rates of compliance with screening recommendations than corresponding gold standard data. One explanation for these discrepancies is a "telescoping" effect whereby individuals recall an event as having occurred more recently than was actually the case.[15,16]

However, none of these earlier studies compared self-reported dates with actual dates of screening in order to quantify such discrepancies. Also, they did not investigate the accuracy of self-reported results of screening tests. Therefore, this study aimed to investigate the accuracy of self-reported screening dates and results as well as that of self-reported screening adequacy (i.e., having been screened within the recommended time frame).

A prerequisite for studies investigating the accuracy of self-reported health information is an adequate gold standard that reliably and accurately assesses the behavior of interest, allows the categorization of individuals into "at-risk" and "not-at-risk" groups, and is appropriate to the self-report question. The only potential gold standards that we considered to fit these criteria were computerized pathology and health insurance records. These data are recorded, coded, and entered into a computer in a standardized way, minimizing the likelihood of reporting or retrieval errors. However, we considered physicians' records unacceptable gold standards because they tend to be handwritten, nonstandardized, and incomplete, especially regarding preventive health data.[17,18]

Health insurance records, in Australia at least, do not include screening test results; thus, pathology laboratory records represented the gold standard for this study. Unfortunately, only two regularly conducted screening behaviors could be investigated: cholesterol tests and, among women, Pap tests. Screening tests such as sigmoidoscopy and fecal occult blood tests, which are common in other countries, are not performed routinely among asymptomatic populations in Australia.

Therefore, we investigated the accuracy of individuals' self-report in relation to the recency and result of their most recent Pap and cholesterol tests. We also assessed potential

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predictors of both consent to validation and more accurate self-reports.

Methods

Sample Selection

This study was undertaken in mid-1994. Australian Bureau of Statistics guidelines ensuring an equal chance of selection for each household were used to randomly select 490 households in a defined rural location.[19] This location was chosen because (1) all of the local health care providers used only 2 pathology laboratories to process their cholesterol and Pap tests, (2) both of these pathology laboratories had computerized records covering the entire period of interest and were willing to participate, (3) the rural setting increased the likelihood of its residents' using one of these local providers, and (4) residents of the area were expected to have no more or less accurate recall than other individuals.

Sample Size Calculation

We aimed to estimate sensitivity and specificity via 95% confidence intervals (CIs) with a maximum width of ±10%. A worst-case scenario in which both sensitivity and specificity were 50% was used to calculate the necessary sample size. These calculations were based on the smallest subset of the population available for analysis (i.e., women eligible for Pap screening). Results indicated that 192 women were required for the sample.[20] On the basis of the group's previous experience, we estimated that 490 households were required to achieve this sample.

Procedure and Materials

Gathering of self-report information. Before any face-to-face contact, the households received letters that explained the survey and suggested a time the interviewer would call. Included with each letter was a nonconsent form to be returned if individuals did not wish to participate. Households not returning this form were visited, approximately 7 to 10 days after distribution of the letters, by trained interviewers who reminded householders about the letter and asked all willing adult members of the household to complete 10-minute face-to-face health surveys. Up to 6 visits were made to each address at different times of the day and evening, both during the week and on weekends, in order to maximize participation.

Self-report survey instrument. The self-report survey, developed by the authors, gathered information on (1) the date (month and year), result, and location of each individual's most recent cholesterol and Pap tests; (2) individuals' degree of certainty regarding the period since their most recent tests; (3) the method (finger prick or syringe) used in their most recent cholesterol test; (4) their eligibility for Pap screening; (5) their perceptions of how often Pap and cholesterol tests should be conducted, the severity of a number of potential problems associated with their most recent Pap test, and the preventability, treatability, and curability of cancer; (6) their smoking status; and (7) their age, country of birth, and education level. Screening behavior questions were neutrally phrased (i.e., potential benefits of or barriers to screening were not mentioned) to minimize any social desirability bias.[21–23]

Gathering of gold standard information. After completing the survey, individuals were asked for permission to access their pathology laboratory records to ascertain the exact date and result of their most recent Pap and cholesterol tests. Consent to validation was sought after completion of the self-report survey to ensure "natural" responses to these questions. Individuals consenting to validation gave their current full name and address and any others used in the previous 5 years.

Pathology laboratories provided the date and result of the most recent cholesterol and Pap tests, if any, for each consenting, eligible individual. Eligibility for validation of cholesterol screening was dependent on individuals (1) reporting having had the test conducted, via syringe, by a participating provider or (2) reporting never having had a cholesterol test. Eligibility for validation of Pap screening was dependent on individuals (1) reporting being eligible for Pap screening (i.e., having an intact uterus and having ever engaged in sexual intercourse) and having had the test conducted by a participating provider or (2) reporting never having had a Pap test. Written consent was obtained from all participants and providers.

Statistical Analyses

Diagnostic statistical tests were conducted to assess the accuracy of the self-reported information. These tests included assessments of sensitivity (proportion of truly at-risk individuals identified by self-report), specificity (proportion of truly not-at-risk individuals identified by self-report), positive predictive value (proportion of self-reported at-risk individuals identified as truly at risk), and negative predictive value (proportion of self-reported not-at-risk individuals identified as truly not at risk).

In addition, 95% confidence intervals were calculated for each of these diagnostic values according to the standard binomial approximation formula.[20] Because this study focused on the proportion of at-risk individuals missed by self-report, we primarily discuss the inverse of the sensitivity and negative predictive value statistics. For example, a sensitivity of 70% of truly at-risk individuals identified seems to be a reasonably good value. However, it implies that 30% of those at risk remain unidentified by self-report, arguably a more persuasive statement.

In assessments of the accuracy of self-reported screening adequacy, individuals who had not been screened within the recommended time frame (2 years for Pap screening,[24] 5 years for cholesterol screening[25]) were considered at risk. In assessments of the accuracy of self-reported screening results, individuals with elevated cholesterol levels (above 5.5 mmol/L,[26] equivalent to approximately 213 mg/dL[27]) or abnormal or inadequate Pap test results were considered at risk.

Because all variables were dichotomous, continuity-adjusted χ^2 analyses were conducted to assess whether a number of demographic and other characteristics were associated with consent to validation or with increased accuracy of self-reported screening adequacy. In instances in which observed or expected values were below 5, 2-tailed Fisher exact tests were conducted instead. Variables associated at the $P \leq .2$ level were then entered into logistic regression analyses. One model involved the predictors of consent to validation, and the other model involved the predictors of increased accuracy of recall. Finally, odds ratios (ORs) were calculated to assess the magnitude of the associations for variables found to be significant predictors.

Results

Sample Characteristics

Of the 490 households randomly selected, 423 (86.3%) were contacted successfully and contained at least 1 eligible person. Of these, 310 (73.3%) consented to participate. They housed 537 eligible individuals, of whom 464 (86.4%) completed the self-report survey. Subsequently, 340 (73.3%) of these individuals consented to validation. Of the 464 survey respondents, 58% were female. Respondents ranged in age from 18 to 88 years, with a median of 41 years; 92% were Australia born. Twenty-seven percent had obtained a degree or other qualification since leaving high school. Our sample was largely representative of government statistics for this region, the only difference being a higher proportion of women.[28,29]

Predictors of Consent to Validation

A logistic regression analysis revealed that individuals consenting to validation were significantly more likely than those refusing to know the recommended cholesterol screening frequency (OR=2.5, 95% CI=1.1, 5.5), to be female (OR=1.8, 95% CI=1.2, 2.9), and (among

TABLE 1—Comparison of Screening Adequacy Based on Self-Report (SR) and Gold Standard (GS) Data: Australia, Mid-1994

	Cholesterol Screening	Pap Screening
No. eligible	195	146
No. inadequately screened (SR and GS)	99	27
No. inadequately screened according to SR and adequately screened according to GS	8	2
No. adequately screened according to SR and inadequately screened according to GS	26	33
No. adequately screened (SR and GS)	62	84
Sensitivity, % (95% confidence interval)	79.2 (72.6, 84.5)	45.0 (36.3, 52.9)
Specificity, % (95% confidence interval)	88.6 (82.8, 92.4)	97.7 (93.2, 99.3)
Negative predictive value, % (95% confidence interval)	70.5 (63.3, 76.6)	71.8 (63.2, 78.4)
Positive predictive value, % (95% confidence interval)	92.5 (87.7, 95.6)	93.1 (86.9, 96.2)

Note. Inadequate screening refers to no cholesterol test in the previous 5 years or no Pap test in the previous 2 years.

women) to know the recommended Pap screening frequency (OR = 5.3, 95% CI = 1.9, 5.3). Variables that did not predict consent to validation were age, education, self-reported smoking status, self-reported screening adequacy, certainty regarding self-reported screening adequacy, and self-reported test results.

Accuracy of Self-Reported Screening Adequacy

Of the 340 individuals consenting to validation, 195 (57.4%) were eligible for validation of their self-reported cholesterol screening adequacy, and 146 (42.9%) were eligible for validation of their self-reported Pap screening adequacy. Table 1 shows a comparison of the number of eligible respondents adequately and inadequately screened, according to self-report and gold standard, and illustrates the sensitivity, specificity, positive predictive value, and negative predictive value of self-reported cholesterol and Pap screening adequacy.

For cholesterol screening, the negative predictive value of 71% indicates that approximately one third of individuals self-reporting that they were adequately screened were actually inadequately screened. The sensitivity of 79% indicates that approximately one fifth of inadequately screened individuals were not identified by self-report. For Pap screening, the negative predictive value of 72% indicates that more than one quarter of women self-reporting that they were adequately screened were actually inadequately screened. The sensitivity of 45% indicates that more than half of the inadequately screened individuals were not identified by self-report.

Accuracy of Self-Reported Results of Screening Tests

Of the 195 individuals eligible for validation of their self-reported cholesterol screening adequacy, 79 reported having had a verifiable test and provided a self-reported screening result. Similarly, of the 146 women eligible for validation of their self-reported Pap screening adequacy, 91 reported having had a verifiable test and provided a self-reported screening result. Table 2 shows a comparison of the number of eligible respondents with normal and abnormal results, according to self-report and gold standard, and illustrates the sensitivity, specificity, positive predictive value, and negative predictive value of self-reported cholesterol and Pap screening results.

For cholesterol screening, the negative predictive value of 55% indicates that almost half of the individuals self-reporting normal cholesterol levels actually had elevated levels. The sensitivity of 44% indicates that more than half of the individuals with elevated cholesterol levels were not identified by self-report. For Pap screening, the negative predictive value of 89% indicates that only approximately one tenth of women self-reporting a normal Pap test actually had an abnormal or inadequate Pap test. However, the sensitivity of 47% indicates that more than half of the women having abnormal or inadequate Pap test results were not identified by self-report.

Accuracy of Self-Reported Screening Dates

Unfortunately, only 35 individuals provided verifiable self-reported cholesterol screening dates, and only 67 women provided verifiable self-reported Pap screening dates, making statistical analyses difficult. Table 3, which summarizes the descriptive analyses conducted, suggests that self-reported dates tended to be more recent than gold standard dates but by only relatively small amounts on average. However, the individuals providing self-reported screening dates were not representative of the total sample.

Odds ratios indicated that individuals who provided self-reported cholesterol screening

TABLE 2—Comparison of Screening Results Based on Self-Report (SR) and Gold Standard (GS) Data: Australia, Mid-1994

	Cholesterol Screening	Pap Screening
No. eligible	79	91
No. elevated/abnormal (SR and GS)	20	8
No. elevated/abnormal according to SR and normal according to GS	3	1
No. normal according to SR and elevated/abnormal according to GS	25	9
No. normal (SR and GS)	31	73
Sensitivity, % (95% confidence interval)	44.4 (33.1, 55.9)	47.1 (35.7, 56.9)
Specificity, % (95% confidence interval)	91.2 (82.6, 96.4)	98.6 (92.3, 99.7)
Negative predictive value, % (95% confidence interval)	55.4 (42.9, 65.7)	89.0 (79.4, 93.8)
Positive predictive value, % (95% confidence interval)	87.0 (76.5, 92.9)	88.9 (79.4, 93.8)

Note. Elevated cholesterol levels were those above 5.5 mmol/L (213 mg/dL); abnormal Pap tests included those with abnormal or inadequate results.

TABLE 3—Comparison of Screening Dates Based on Self-Report (SR) and Gold Standard (GS) Data: Australia, Mid-1994

Type of screening	No	SR Date Same as GS, %	SR Date More Distant Than GS, %	SR Date More Recent Than GS, %	SR Date – GS Date (mo) Minimum	Maximum	Median
Cholesterol	35	11	17	71	−12	+54	+5
Pap	67	25	22	52	−12	+20	+1

Note. Dates involved month and year only.

dates were more likely to be adequately screened (OR=9.3, 95% CI=4.3, 20.4), to have accurately recalled their screening adequacy (OR=7.2, 95% CI=3.4, 15.4), and to be very sure of their self-reported screening adequacy (OR=3.1, 95% CI=1.2, 7.8). Similarly, women who provided self-reported Pap screening dates were more likely to be very sure of their self-reported screening adequacy (OR=5.3, 95% CI=2.3, 12.0) and to be adequately screened (OR=3.8, 95% CI=1.9, 7.8). Therefore, these results are likely to represent very conservative estimates of the inaccuracy of self-reported screening dates.

Predictors of Increased Recall Accuracy

A logistic regression analysis showed that individuals who accurately recalled their cholesterol screening adequacy were significantly more likely than those with inaccurate recall to have had a cholesterol test in the previous 5 years (OR=14.8, 95% CI=6.3, 34.7) and to have had an elevated result on their most recent cholesterol test (OR=3.3, 95% CI=1.3, 8.2). Similarly, women who accurately recalled their Pap screening adequacy were significantly more likely to have had a Pap test in the previous 2 years (OR=10.8, 95% CI=5.0, 23.6).

Variables that did not predict increased accuracy were age, sex, education, certainty regarding screening adequacy, and knowledge of relevant recommended screening frequency. In addition, women's perceptions of the preventability, treatability, and curability of cancer and the result of their most recent Pap test were unrelated to the accuracy of their Pap screening self-report.

Discussion

The accuracy of self-reported screening information in this study was poor. Self-reports failed to identify 21% of those in need of cholesterol screening, 55% of those in need of Pap screening, 56% of those with high cholesterol levels, and 53% of those with abnormal or inadequate Pap test results. There was a trend for both cholesterol screening and Pap tests to be reported as having occurred more recently than they actually had. This finding is in keeping with earlier studies showing such "telescoping" errors in the reporting of event dates.[15,16]

These discrepancies, of 1 month for a biennial test and 5 months for a quinquennial test, may not initially appear to be a major cause for concern. However, individuals who provided self-reported screening dates were much more likely to be adequately screened, to be very sure of their self-reported screening adequacy, and to have accurately recalled their screening adequacy. Therefore, the magnitude of these telescoping errors would probably be increased if all respondents had given a perceived date of screening.

In line with the results just described, adequate screening status was the main predictor of more accurate self-reports, with adequately screened individuals more than 10 times as likely to accurately recall their screening adequacy. The only other predictor of increased accuracy was having an elevated cholesterol test result, suggesting that abnormal results may be more memorable than normal ones.

Some of the inaccuracy in regard to results of screening tests could be due to misinterpretation or inadequate communication between patient and physician. For example, this study used the Australian cutoff point (5.5 mmol/L[26] [213 mg/dL[27]]) to indicate an elevated cholesterol level. Unfortunately, such cutoff points, while quite specific in the literature, can become more vague in clinical practice. Hence, depending on the physician's interpretation or on the other requirements of the consultation, a patient with a cholesterol level of 5.6 mmol/L (217 mg/dL) may not always be told that his or her level is of concern. Similarly, not all physicians have an optimal method of informing patients of their Pap test results, and it is feasible that some women do not receive notification of abnormal or inadequate results.[30,31]

In discussing these findings, it is important to consider some limitations of this study. First, the sample obtained was smaller than expected and less than desirable, especially in terms of the analyses involving only individuals who provided self-reported results and dates for their most recent screening episodes. The smaller than expected sample size in regard to cholesterol screening was largely due to the unexpectedly high proportion of cholesterol tests taken by finger prick and, therefore, inaccessible for validation. Almost half of all respondents and 29% of those consenting to validation reported having had their most recent cholesterol test via finger prick.

This less than optimal sample size was not considered a major problem, because the results regarding the accuracy of recall of screening adequacy were in keeping with those of previous studies.[3,12,14] Even if one takes a cautious view[12] and considers only the maximum values of sensitivity and negative predictive value included in our confidence intervals, few values reach what would be considered optimal levels of accuracy.

Second, the restricted geographic location from which the sample was drawn could raise concerns about the generalizability of the results. However, the consistency of the findings with those of previous research suggests that this is not a major concern.[3,12,14]

Third, pathology laboratory records are not infallible, and some individuals' records may be incorrect or incomplete. It is also possible that individuals had their most recent Pap or cholesterol tests performed at a location other than the one reported, making validation impossible. However, it is unlikely that any such inaccuracies could account for the large discrepancies found between the self-report and pathology laboratory data. Furthermore, providing the laboratories with relevant alternative names and addresses should have minimized any such retrieval errors.

Fourth, although adequate, consent rates could have been higher: 73% of eligible households and 86% of eligible individuals consented to participate in the self-report survey, and 73% of surveyed individuals consented to validation. The survey participants were largely representative of the population from which they were drawn, but significant differences were found between individuals consenting and not consenting to validation, with those not consenting more likely to be female and to know the recommended screening frequencies.

Finally, it is important to note that this study assessed self-report accuracy only in a community survey setting. Such a setting places minimal demands on individuals to respond in a socially desirable way.[21–23] This low-demand setting was selected in an attempt to maximize the accuracy of the self-report data. Therefore, the inaccuracies found in this study

may be magnified under more demanding conditions (e.g., posttest phases of randomized, controlled trials).[32]

Future Directions

This study revealed self-report to be a less than adequate measure of individuals' cholesterol and Pap screening adequacy, recency, and results. Given the findings and limitations of this study, we consider it likely that under more ideal conditions, higher rates of inaccuracies could have been found.

We recommend that studies estimating the prevalence of health risk factors in the general population not use self-report as the only data source. Researchers should investigate alternative methods of estimating prevalence rates and, when possible, use existing objective data sources such as pathology or health insurance records. In instances in which no alternatives to self-report data exist, we recommend that researchers explore the existing literature for previous studies investigating the accuracy of self-report for the behaviors of interest, consider factors that may affect the accuracy of respondents' self-reports, and use strategies to maximize the accuracy of self-reported information.[15,16]

Accepting that self-report data are likely to remain the only feasible data for many studies, we further suggest that researchers routinely report the data collection methods used, highlighting steps taken to maximize accuracy and any adjustments made to compensate for inaccuracies. At a minimum, they should indicate how any inaccuracy is likely to have affected the data collected. When no validation data exist, we suggest that researchers, whenever possible, conduct substudies to gather such data, being sure to routinely report on the adequacy of the gold standard used, the rate of consent to validation, and any predictors of consent to validation.

A valuable direction for future research may involve large-scale health risk factor validation studies among the general population. Such studies could provide data for use in the development of age- and sex-specific correction factors to be applied to self-reported continuous variables such as height, weight, and recency of screening tests. Although adequate gold standards do not exist for all risk factors, data such as those available for Pap and cholesterol tests could be used to provide a general guide to "telescoping" errors in reports of the recency of similar screening tests. □

Contributors

All authors collaborated in the design and planning of the study. S. Newell analyzed the data and wrote the paper. A. Girgis, R. Sanson-Fisher, and M. Ireland contributed to the writing of the paper. S. Newell conducted the study during her PhD candidacy, which was supervised by A. Girgis and R. Sanson-Fisher.

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