

A Comparison of Diabetes Patients' Self-Reported Health Status With Hemoglobin A_{1c} Test Results In 11 California Health Plans

JEFFREY WASSERMAN, PH.D.,^{1*} GIFFORD BOYCE-SMITH, M.D.,² DAVID S.P. HOPKINS, PH.D.,³ VERNON SCHABERT, PH.D.,¹ MAYER B. DAVIDSON, M.D.,⁴ RONALD J. OZMINKOWSKI, PH.D.,¹ ANN ALBRIGHT, PH.D., R.D.,⁵ SEAN KENNEDY, B.S.¹

¹The Medstat Group, Santa Barbara, Calif; ²Blue Shield of California, San Francisco; ³Pacific Business Group on Health, San Francisco; ⁴King-Drew Medical Center, Los Angeles; ⁵University of California, San Francisco.

ABSTRACT

Purpose: To examine the relationship between hemoglobin A_{1c} (HbA_{1c}) test rates and values and various self-reported measures of health status within a sample of diabetes patients drawn from 11 California health plans, with a focus on improving diabetes care in this patient population.

Design: The analysis relies on data obtained from medical records of a sample population of 4,747 diabetes patients and a patient survey mailed to a large subsample of patients included in the medical-records analysis.

Methods: Descriptive methods were used to compare the medical records and survey-data results.

Principal Findings: There were substantive differences noted between diabetes patients' self-reported health status, their level of satisfaction with the care they received, and the actual care they received. There was a large discrepancy between diabetes patients' perceptions of the care they received for their diabetes, which was overwhelmingly positive, and the HbA_{1c} test-frequency rates observed

across the 11 health plans studied, which were low.

Conclusions: Patients' self-reports of health status, satisfaction with care, and extent of control over diabetes — a chronic condition that may have few perceptible symptoms — are associated with significant methodological limitations. Our examination of the relationship between perceived levels of self-management of diabetes and test status indicated that for patients who had at least one HbA_{1c} test, some education during that process may have resulted in behavioral change. Patients who received no tests, however, may remain unaware of their glycemic control and the long-term consequences associated with even mild hyperglycemia. A clear need thus exists to educate diabetes patients about their health status. Health plan and provider group investments in educational efforts aimed at increasing testing rates are likely to lead to improved glycemic control and a reduction in the incidence of diabetes-related complications and related expenditures.

INTRODUCTION

Diabetes mellitus and its complications have a profound effect on the health of our population as well as the U.S. economy. Diabetic retinopathy is the leading cause of blindness in the nation in people between 20 and 74 years of age.¹ Diabetic nephropathy is the leading cause of patients' undergoing dialysis for end-stage renal dis-

ease.² Diabetic peripheral neuropathy is the underlying cause of non-traumatic lower-extremity amputations in diabetes patients.³ More than half of lower-extremity amputations occur in people with diabetes,⁴ who constitute 7.8 percent of adults over 20 years of age in the United States, according to the Third National Health and Nutrition Examination Survey (NHANES III) conducted in 1988-1994.⁵ The prevalence of coronary artery disease is twofold higher in men with diabetes and fourfold higher in women with diabetes, compared to appropriate nondiabetic controls.⁶ Strokes are two to three times more common in people with diabetes than in those without the disease.⁷ Peripheral vascular disease is also much more common in diabetes patients compared to nondiabetic individuals.⁸

These complications may be avoidable. Although control of glycemia has not been shown to have a marked effect on the macrovascular complications of diabetes,⁹ there is irrefutable evidence that near euglycemia will delay, blunt, and possibly prevent the microvascular and neuropathic complications of both type 1 and type 2 diabetes.¹⁰⁻¹² Unfortunately, however, these beneficial effects are seldom achieved. Studies in both type 1 and type 2 diabetes patients show that the development and

*Corresponding Author:
Jeffrey Wasserman, Ph.D.
The Medstat Group
5425 Hollister Avenue, Suite 140
Santa Barbara, Calif. 93111-2348
Phone: (805) 681-5840
Fax: (805) 681-5810
Email: jeffrey@rand.org

This paper has been peer reviewed by appropriate members of MANAGED CARE's Editorial Advisory Board.

progression of retinopathy and nephropathy markedly increased with HbA_{1c} levels >8 percent, increased moderately at HbA_{1c} levels between 7 percent and 8 percent, and increased slightly or not at all with HbA_{1c} levels ≤7 percent.^{10,11,13-15}

The average glycosylated hemoglobin level in 4,449 patients who were followed in HMO settings was 9.51 percent, and it was 9.59 percent in 3,140 patients seen in fee-for-service settings.¹⁶ Other studies also have revealed similar poor control when evaluated by fasting glucose concentrations¹⁷⁻¹⁹ or glycosylated hemoglobin levels.²⁰⁻²³

One of the barriers to achieving near euglycemia is that patients tend to be asymptomatic until one of the neuropathic, retinopathic, or macrovascular complications manifests. Patients therefore may lack ongoing motivation to do the work needed to attain tight glycemic control. Physicians may communicate the severity of the patient's condition to each individual, recommending specific treatments in every case, yet they and other health care professionals face a significant challenge in motivating their asymptomatic patients to achieve near euglycemia. Moreover, continually growing constraints on physicians' time affect their ability to adequately educate patients on the importance of maintaining near euglycemia. All this suggests a need for diabetes patients to have access to diabetes educators.

In this study, the relationship between HbA_{1c} testing rates and HbA_{1c} test values and various self-reported measures of health status were examined for a sample of diabetes patients drawn from 11 California health plans. The study was undertaken on behalf of the California Collaborative Healthcare Reporting Initiative. CCHRI, which comprises representatives from many of California's leading health care purchasers, health plans, and provider groups, is dedicated to measuring and

improving the quality of health care delivered to Californians.

The HbA_{1c} test is a critical indicator of diabetes care. This test, which ideally should be performed at 3-month intervals, provides a measure of plasma glucose control for the previous 3 months. For asymptomatic diabetes patients, HbA_{1c} levels are the most reliable clinical indicators of health status and glycemic control. Nevertheless, studies have shown that many diabetes patients fail to receive this test at least once yearly.²¹ Good control of blood glucose levels has been shown to prevent many complications that are associated with diabetes.¹¹⁻¹⁸

Previous studies of patient-reported outcomes have tended to focus on conditions that have perceptible symptoms and complications. Patients with depression,²⁴ arthritis,²⁵ and ulcers,²⁶ as well as patients recovering from surgery,^{27,28} have accurately reported their health status relative to objective clinical information. Evaluations of conditions like diabetes,²⁹ with few detectable symptoms in the early stages, focus on the internal consistency of patient-reported responses rather than correlations with objective clinical anchors. Patients with hypertension, for instance, another condition without symptoms in its early stages, showed no significant differences in self-reported health status when compared to the self-reports of patients with no chronic conditions.³⁰ It is unlikely that patient reports can be a reliable source for detecting asymptomatic conditions. If patients could report adverse health status for asymptomatic conditions, then these conditions would probably not be significantly underdiagnosed in the general population.

METHODS

The analysis relied on data obtained from two sources: a sample of diabetes patients' medical records and a patient survey that was mailed to

a large subsample of the patients included in the medical-records analysis.

Medical-records data

To measure HbA_{1c} testing-frequency rates and values, we analyzed medical records from 11 of the health plans that agreed to participate in the California Collaborative To Improve Diabetes Management Project, or the Diabetes CQI Project. The project was conducted under the aegis of the CCHRI. All participating plans offered commercial plans, and four of the 11 also covered Medicare beneficiaries.

Specifically, we collected information on the frequency of HbA_{1c} tests performed on the patient population during calendar year 1997. We also analyzed data on the results of the HbA_{1c} tests. During the course of our analysis, we abstracted clinical information from a total of 4,747 medical records obtained from 11 health plans, or approximately 431 records per plan. Diabetes patients were identified using the 1998 specifications for the measure "Eye Exams for People with Diabetes," part of the Health Plan Employer Data and Information Set (HEDIS 3.0/1998). These specifications rely on both pharmacy and encounter data: A patient was identified as having diabetes if pharmacy data indicated that the individual was on insulin or oral hypoglycemics, or if encounter data indicated that the patient had at least two outpatient visits associated with a diagnosis of diabetes or one hospitalization associated with a diagnosis of diabetes. We used a systematic sampling approach, as prescribed by the HEDIS 3.0/1998 specifications, to select records for study.

The medical records were abstracted by nurses and medical-records professionals, all of whom attended a training session and received written instructions elucidating the numerator and denominator criteria. A team of clinicians developed a

standardized data-abstraction form to collect the requisite data. Abstractors used an electronic version of this form to facilitate data collection and entry. To ensure data quality, record-review supervisors "overread" at least 5 percent of the records assigned to each abstractor, and provided timely feedback on errors and other data-quality issues.

Patient-survey data

As part of the Diabetes CQI Project, we mailed a survey instrument to 3,296 persons with diabetes who were enrolled in the 11 participating health plans.* The sampling frames used to select patients for the survey were the patient samples that the plans provided for the medical-records analysis. The purpose of the survey was to create a knowledge base of information about persons with diabetes and the professional care they receive, from the patients' perspectives. The details of the patient-survey process were reported by Freeman, Sullivan & Co. (1999).³¹ The instrument used to collect the survey data was, in many respects, similar to that used in the Diabetes Patient Outcomes Research Team (PORT) project.³²

Analysis

For the most part, descriptive methods were used to compare the medical records and survey data results on the 11 participating health plans. We calculated means and standard deviations for all continuous variables, and compared differences in means using a standard t-test. In addition, we generated frequency distributions for all categorical variables and calculated chi-square statistics.

We also used multivariate statisti-

cal techniques to develop a set of weights that were applied to the survey results. We determined that such weights were appropriate to increase the survey's usefulness, as described below.

We achieved a 43 percent response rate to the mail survey. The response rate varied substantially by plan and plan type. In general, the response rate was higher from beneficiaries of the Medicare plans (53 percent) than from those covered by the commercial plans (39 percent). We conducted a logistic regression analysis to estimate the effects of the various patient factors on the likelihood of responding to the mail survey. Specifically, the logistic regression analysis was used to estimate response probabilities, which in theory may range from 0 percent to 100 percent. The range of survey response probabilities was found to vary from 22 percent to 76 percent. As recommended by Kalton and Kasprzyk,³³ the inverse of these probabilities (1/prob) was used to construct a weighting variable that was applied to all subsequent analyses reported in this paper. The weights were higher for respondents who had lower response probabilities, compared to the weights generated for those with higher response

probabilities (e.g., 1/0.22 > 1/0.76). By applying these response weights, the results of the statistical analyses reported can be more readily generalized to the underlying population of people with diabetes in the 11 participating plans than would be the case if analyses that were not weighted had been conducted.

It should be noted that some of the analyses that were conducted relied on both the medical records and survey data. That is, responses obtained from various survey questions were compared to test results found in the medical records.

RESULTS

In the subsections below, we report the results of our medical-record reviews and patient survey, respectively. We then report the results that were obtained after we merged the medical records and survey data.

Data from medical records

Table 1 shows HbA_{1c} test-related data for each plan participating in the collaborative. The test rate measures the proportion of a plan's diabetic patients that received at least one test in 1997. The overall test rate was 49.2 percent, ranging from a low of 38.5 percent for Plan D to a high of

TABLE 1 HbA_{1c} Test Data by Plan — 1997

Plan	HbA _{1c} Test Rates	Average Number of HbA _{1c} Tests	Change in Average HbA _{1c} Test Values	Proportion of Final HbA _{1c} Values >9.5%
A	47.6	1.9	-0.6*	12.2
B	53.6	2.1	-0.6*	23.3
C	51.8	2.0	-0.8*	27.2
D	38.5	1.8	-0.3	17.5
E	56.7	1.9	-0.4*	24.1
F	46.8	1.8	-0.8*	23.9
G	58.1	1.8	-0.7*	25.1
H	41.7	2.0	-0.7*	35.6
I	49.1	1.8	-0.7*	30.8
J	49.3	1.9	-0.9*	26.7
K	48.2	1.8	-0.7*	19.2

* P<0.05

* The sample size was based on power calculations conducted to determine the number of individuals required to measure the effects of a planned intervention to improve outcomes of care for diabetes patients.

58.1 percent for Plan G. None of the plans' test rates were statistically different from the overall mean rate of 49.2 at the 0.05 level.

Diabetes patients *who had been tested* received, on average, two tests in 1997. Moreover, we observed remarkably little variation across plans in this regard, as the mean number of tests ranged from a low of 1.8 for Plans D, E, and G to a high of 2.1 for Plan B.

In addition to examining the frequency of HbA_{1c} testing, we also calculated average HbA_{1c} test values by plan. Specifically, for patients with two or more tests in 1997, we calculated the average values of the initial and final tests and the differences between the two. Interestingly, the mean values improved for all plans, and all the differences were statistically significant ($P < 0.05$), with the exception of Plan D.

In a further effort to generate insight into how blood glucose control varies across plans, we calculated the percentage of each plan's patients that had HbA_{1c} test values beyond the Diabetes Quality Improvement Project (DQIP)³⁴ threshold of 9.5 percent.† The results indicate that approximately a quarter of the patients included in the sample had final (for 1997) HbA_{1c} values that exceeded 9.5 percent. The plan-specific rates ranged from a low of 12.2 for Plan A to a high of 35.6 for Plan H.

Survey data

Survey response rates differed by age, health plan, plan type, and treatment patterns. About 52 percent of the survey respondents were male and 77 percent were enrolled in commercial plans.

A number of the questions posed in the survey related to the respondents' perceptions of their health status along with their level of satisfac-

† Technically, the relevant DQIP rate also includes people who were not tested.

tion with various aspects of the care they received. For example, 73 percent of the respondents reported that they were in good to excellent health. Moreover, just over 84 percent of the respondents indicated that their health status was at least as good as it was a year ago. Overall, respondents reported that they were quite satisfied with the care they received for their diabetes. Specifically, more than 83 percent rated the quality of care between good and excellent.

Three survey questions related to diabetes management. The first asked respondents to comment on how well controlled their disease was. Response categories ranged from "very well controlled" to "not controlled at all." Overall, 44.4 percent of the commercial patients and 60.4 percent of the Medicare patients stated that their diabetes was either "well controlled" or "very well controlled."

Combined data

Using both the survey and medical-records data, we examined the degree of correspondence between patient self-reports of health status behavior and actual tests administered to patients. As shown in Table 2, in both samples, respondents who had an HbA_{1c} test were *less* likely to say their disease was either well controlled or very well controlled, compared to those who did not have an

HbA_{1c} test in the previous year.‡ This result might seem counterintuitive at first glance, since the purpose of the HbA_{1c} test is to provide definitive information on blood sugar levels and thereby enhance the ability to control diabetes. Only 51.1 percent of the sample received an HbA_{1c} test, however, and these tests may be prescribed more often for those with a history of poor blood-glucose control. Alternatively, the results from the HbA_{1c} test probably came back before the survey was completed, and poor results from that test may have prompted many test takers to report their disease as poorly controlled.

A second survey question asked respondents to describe how well they kept tabs on their disease. As indicated in Table 3, about 54.3 percent of the commercial patients and 68.8 percent of the Medicare patients said they were "always on top" of their disease or "on top of it most of the time." Among the commercial patients, those who had had an HbA_{1c} test sometime during the past year were significantly less likely than those who

‡ The relationship between HbA_{1c} status and perceptions of control over diabetes was statistically significant (P -value of the chi-square < 0.05) for those in commercial plans but not for those in Medicare plans.

TABLE 2 Relationship Between Perceived Control Over Diabetes and HbA_{1c} Test Status

Response	Commercial (weighted n = 2,182)		Medicare (weighted n = 640)	
	No HbA _{1c} Test	Had HbA _{1c} Test	No HbA _{1c} Test	Had HbA _{1c} Test
Very well controlled	12.7	8.3	18.9	14.3
Well controlled	35.2	32.8	42.2	39.5
So-so	42.1	48.6	32.0	34.3
Not well controlled	8.1	9.6	5.6	9.2
Not controlled at all	1.7	0.4	0.6	2.7
No answer	0.3	0.3	0.7	0.0
Total	100%	100%	100%	100%

had not had an HbA_{1c} test to say they were "always on top of their disease" or to say they were "on top of it most of the time" (50.1 percent for those with an HbA_{1c} test, vs. 59.8 percent for those without an HbA_{1c} test.) Again, it may be that the HbA_{1c} test was more often prescribed for patients with a poor history of diabetes self-management or that patients aware of high HbA_{1c} levels were less likely to conclude that they were "on top of their disease." Within the Medicare sample, no relationship was found between HbA_{1c} status and perceptions of self-management. The Medicare sample was much smaller, however, which may explain why no statistically significant results were observed.

DISCUSSION

The results reported in the preceding section present substantial variations between diabetes patients' self-reported health status, their level of satisfaction with the care they received, and the actual care they received for their diabetes. Specifically, we observed a large discrepancy between the patients' perceptions of the care they received for their diabetes, which was overwhelmingly positive, and the frequency of HbA_{1c} testing observed across the 11 health plans, which was disappointingly low.

The low testing-frequency rates that were observed are in line with the results reported by Peters et al.,²¹ which, using 1993 data from a major California-based HMO, found that only 44 percent of the medical records reviewed on diabetes patients had a documented glycated hemoglobin test. Unfortunately, as our results indicate, little progress has been made in the interim by California HMOs. Thus, a considerable opportunity for improvement exists.

Our results, however, are encouraging in the sense that those patients who received at least one test actually averaged almost two tests per year. Furthermore, patients who received

two or more tests actually showed a statistically significant improvement in their HbA_{1c} test values. The occurrence of multiple tests per year is encouraging because it suggests that physicians who order HbA_{1c} tests, and patients who receive them, understand that routine testing is an important part of their diabetes treatment plan. The significant decrease in test values among patients with multiple tests suggests that the initial test results alerted both patients and physicians of the need to take steps to improve blood glucose levels through education, diet, exercise, and, when necessary, medication.

Moreover, in a set of results not reported here, for tested patients we found a high correlation between HbA_{1c} test values and patient reports of their levels of diabetes glucose control and self-management. These results may indicate that patients who received HbA_{1c} tests were aware enough of their results to accurately assess their health status and its relationship to their diabetes management efforts. It is reasonable to assume that the process by which physicians communicated HbA_{1c} results to their patients was also an opportunity for the physician to educate patients on their health status and any need for improved diabetes management practices. These findings,

combined with the observation that twice-tested patients improved their glycemic control, confirm the value of routine HbA_{1c} testing as an education- and health-improvement vehicle for diabetes patients.

One troubling finding is that in spite of the low overall testing rates and percentage of patients with exceedingly high HbA_{1c} levels, most patients reported being in good health and on top of their diabetes management. The most ironic part of that finding is that patients with no HbA_{1c} test in the prior year perceived themselves to be in better health and control than did patients who had received at least one test. Because most patients in this sample had no tangible symptoms, patients without an awareness of their glycemic control may have assumed that "no news is good news." Specifically, untested patients may have assumed that they were in good health and good control in the absence of physical discomfort or objective clinical evidence. Patients who had received HbA_{1c} test results, however, may have been more likely to report poorer health status and control because they had spoken with their physicians about their HbA_{1c} results and obtained a better understanding of what it means to be in good control.

In light of these findings, a clear

TABLE 3 Relationship Between Perceived Levels of Patient Self-Management of Diabetes and HbA_{1c} Test Status

Response	Commercial (weighted n = 2182)		Medicare (weighted n = 640)	
	No HbA _{1c} Test	Had HbA _{1c} Test	No HbA _{1c} Test	Had HbA _{1c} Test
Always on top of the disease	17.9	13.2	30.3	17.7
On top of the disease most of the time	41.0	36.9	38.5	51.3
Sometimes on top of the disease	25.9	26.6	18.7	17.5
Slip up more than patient should	11.8	18.0	8.8	10.8
Slip up way too much	3.0	4.2	1.5	0.00
No Answer	0.6	1.0	2.2	2.8
Total	100%	100%	100%	100%

need exists for educating diabetes patients about their health status. For those patients who received at least one HbA_{1c} test, some educational process may have occurred during the physician-patient interaction that resulted in behavioral change. Patients who received no tests, however, may remain unaware of their degree of glycemic control and the long-term consequences associated with even mild hyperglycemia. Health plan and provider group investments in physician and patient educational efforts aimed at increasing test rates are likely to lead to improved glycemic control and have a high pay-off in terms of reducing the incidence of diabetes-related complications and related expenditures.

Based on the observations gained from this study, increased HbA_{1c} testing rates also may have educational value, encouraging physicians and patients to improve glycemic control and secondary prevention of complications.

Finally, our results suggest that self-reports of health status, satisfaction with care, and extent of control over a patient's disease may not be sufficient indicators of quality of care for chronic conditions with few perceptible symptoms. The reliability of patients' self-reports are most suspect when patients have varying levels of awareness about their disease and clinical outcomes. Additional analysis of the differences in self-reported health status between clinically informed and uninformed patients may further elucidate the implications of using patient reports for asymptomatic conditions. Many chronic illnesses, such as hypertension and hyperlipidemia, have few perceptible symptoms until the patient's condition has advanced to the point of developing vascular complications (e.g., heart attack, stroke). Given this fact and the findings presented here, patients with chronic asymptomatic conditions who report good health status may need more

targeted outreach and education from their physicians and health plans.

ACKNOWLEDGEMENTS

The authors would like to express their sincere appreciation to Bayer Corporation, Bristol-Myers Squibb, the Diabetes Control Program of the California Department of Health Services, Hoechst Marion Roussel, Inc., LifeScan, Parke-Davis, and Pfizer for their generous financial support.

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