

Self-Reported Data: Reliability and Role in Determining Program Effectiveness

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This study was conducted to assess the reliability of self-reported hospitalization data, as well as the appropriateness of using self-reported data in evaluating the effectiveness of the Maine Ambulatory Diabetes Education and Follow-Up (ADEF) program. A Maine Blue Cross/Blue Shield (BC/BS) inpatient claims file was used as the reference source to verify self-reported hospitalization data. For a sample of 99 BC/BS subscribers who attended the ADEF program, 77% of the study participants accurately self-reported hospitalization patterns over a 12-mo time period before attending the education program, and 81% of the participants accurately self-reported hospitalization patterns during a post-education follow-up time period. The reference BC/BS claims data documented a reduction in hospitalizations for the study participants similar to that reported using the ADEF self-reported hospitalization data. The Maine Diabetes Control Project used the self-reported hospitalization data in combination with selected reference claims data to secure third-party reimbursement for the Maine ADEF Program.

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Beginning in 1980, the Maine Diabetes Control Project (DCP) established a statewide model outpatient diabetes education program called the Ambulatory Diabetes Education and Follow-Up (ADEF) program. The goals of the ADEF program are to assist persons with diabetes in learning the knowledge, skills, and attitudes necessary to achieve and maintain good diabetes control and to prevent the acute and long-term complications that result in unnecessary hospitalizations for the person with diabetes.

In 1980, preliminary analysis indicated 533 persons with diabetes were physician referred to the ADEF program. Complete preassessment and 1-yr follow-up data were reported for 86.0% (461) of these participants who completed the individualized education program. This group of persons reported 33% (96) fewer hospitalizations in the year after attendance at the ADEF program compared with hospitalization patterns during the year before attending the education classes.¹ Using Maine's 100% hospital discharge data file to estimate an average length of stay for the ADEF participants, the reduction of 96 hospitalizations represented 941 fewer days spent in Maine hospitals, a savings of \$203,791 in reduced hospital costs.

Previous studies by Davidson et al.,² Miller and Goldstein,³ and Runyan⁴ have demonstrated that a coordinated diabetes program that includes a comprehensive assessment,

education, management, and follow-up by experienced health professionals can facilitate a significant improvement in the health status of a person with diabetes participating in such a program. At present, inadequate reimbursement mechanisms exist for ambulatory patient education services to the person with diabetes. Consequently, efforts to integrate outpatient diabetes education into the total process of reimbursable patient care are a national priority of the diabetes community.

In Maine, third-party payers have supported the ADEF program on a demonstration level since 1980, but have awaited a formal evaluation of the education program before making a final endorsement of the program. To evaluate the effectiveness of the ADEF program, the Maine DCP used self-reported hospitalization data provided by the ADEF participants before and after attending the diabetes education classes. Acknowledging the inherent problems associated with self-reported data, a study to assess the reliability of the ADEF self-reported data was designed using claims data from Maine Blue Cross and Blue Shield (BC/BS). In addition, the study addressed the issue of whether the BC/BS claims data would corroborate the effectiveness of the outpatient education program as shown using the ADEF self-reported data. The specific objectives of this article were twofold: (1) to determine if the ADEF self-reported hospitalization data were reliable

indicators of actual hospitalization patterns for 1980 BC/BS subscribers in the ADEF program, and (2) to describe the hospitalization patterns of BC/BS participants 12 mo before and after attendance at the ADEF program using reference claims data.

METHODS

A written physician referral is required for a participant to attend the ADEF program. Upon referral, each participant has a 1-h preassessment interview with the diabetes educator to determine the person's knowledge and understanding of diabetes. During this interview, the educator collects personal background information, health status, relevant medical conditions, and health care utilization data from the person with diabetes, and records this information on a standard data collection form. The ADEF participant then attends an average of 10 h of group classes covering the basics of diabetes such as medications, meal planning, self-monitoring techniques, and foot care. The participant also has a 1-h, one-to-one dietary interview and instruction with a nutritionist and upon completion of the program, a postassessment interview is conducted by the diabetes educator. Follow-up contacts are initiated as deemed necessary by the person with diabetes and the program instructors. Each participant receives a follow-up interview 1 yr after completing the ADEF program, at which point information is collected by the educator about the participant's health status and hospitalization patterns since attending the ADEF classes. Copies of both preassessment and 1-yr follow-up data are forwarded to the DCP.

Study participants included persons with diabetes referred to the ADEF program during 1980 and who reported BC/BS of Maine to be their primary health insurance. The diabetes educators at the ADEF sites were requested to provide the person's BC/BS certificate number for each of the participants selected. When all available certificate numbers were received, the data were forwarded to the Maine Health Data Service (MHDS) at BC/BS of Maine. MHDS is responsible for an inpatient minifile of BC/BS claims data containing a patient profile of subscribers with BC/BS as their primary health insurance coverage and who submitted inpatient claims. For each ADEF participant identified as a BC/BS subscriber, the MHDS personnel searched their inpatient minifile for the requested hospitalization data. For the time period January 1, 1979, through June 30, 1982, a profile was created for each hospital admission of a study participant. The profile listed the participant's ADEF number, hospital name, date of admission, length of stay, primary discharge diagnosis, second-listed discharge diagnosis, primary surgical procedure, age, sex, actual hospital charge, and zip code. The DCP received a computer print-out of the BC/BS listing and added these data to the existing ADEF master computer tape for analysis.

During the preassessment interview with the ADEF participant, hospitalization patterns were collected by the program instructor, and represent the 12-mo period before interview date. The actual number of hospitalizations self-reported

by the participant was recorded by the ADEF instructor on a standardized data collection form. Approximately 12 mo after the ADEF participant completed his individualized education plan, follow-up health status information was collected from the person with diabetes. Hospitalizations reported during the follow-up interview were recorded by the instructor in the following frequency ranges: zero, one, two, three to five, greater than five hospitalizations, and not reported.

To make the BC/BS data compatible with the appropriate time periods represented by ADEF hospitalization data, the following methodology was used. To determine the pre-education time period, the 12 mo before the ADEF preassessment interview date were identified and the BC/BS hospital admission date was used to determine if a hospitalization occurred during the 12 mo before participation in the ADEF program. To determine the posteducation time period, the date of the last ADEF class attended and the follow-up interview date were identified and again the BC/BS hospital admission date was used to determine if hospitalization occurred during this posteducation follow-up time period.

To evaluate the reliability of the ADEF self-reported data, each participant's self-reported hospitalization patterns were compared with the individual's BC/BS records indicating the actual number of hospitalizations for a specific time period. A reliability ratio was then calculated for the number of participants whose self-reported hospitalizations equaled the number of BC/BS reported hospitalizations to the total number of study participants.

BC/BS claims data were analyzed to define the hospitalization patterns incurred by the study participants during the 12-mo period before and after attendance at the ADEF program. In addition to hospitalization patterns, the BC/BS data were used to document any change in hospital length of stay and actual hospital costs incurred by ADEF participants hospitalized during the study period.

RESULTS

In 1980, 604 persons with diabetes were physician referred to the ADEF program. Of these participants, 38.7% (234) were men and 61.3% (370) were women, of whom 76.2% (460) were ≥ 45 yr of age. Hospitalization patterns for the total ADEF population during the 12 mo before attending the outpatient education program indicated that 58.6% (354) self-reported zero hospitalizations and 38.7% (234) of the participants self-reported one or more hospitalizations during this period.

Blue Cross/Blue Shield of Maine was reported as the primary health insurance for 31.3% (189) of the ADEF participants in 1980. Per the data collection protocol of this study, ADEF instructors provided a BC/BS certificate number for the specified 189 ADEF participants and forwarded this information to the MHDS. Upon review of the certificate numbers, 31.7% (60) of the subscribers were unable to be located in the MHDS minifile or did not have a certificate number representing a Maine policy. For these 60 ADEF participants,

TABLE 1
Reporting errors of study participants by age and sex

	Total (N)	Men		Women		No. \geq 45 yr old	
		No.	%	No.	%	No.	%
Total study population	99	33	33.3	66	66.7	73	73.7
Overreporting, pre-ADEF	16	6	37.5	10	62.5	5	31.3
Overreporting, post-ADEF	9	3	33.3	6	66.7	5	55.6
Underreporting, pre-ADEF	7	4	57.1	3	42.9	7	100.0
Underreporting, post-ADEF	10	2	20.0	8	80.0	7	70.0

Maine Diabetes Control Project, 1983.

36.7% (22) were men and 63.3% (38) were women, of whom 75.0% (45) were \geq 45 yr of age. Hospitalization patterns for these 60 participants indicated 61.7% (37) self-reported zero hospitalizations during the 12-mo pre-education period, and 38.3% (23) self-reported one or more hospitalizations during this period.

For the remaining 129 BC/BS subscribers, 17.8% (23) were located in the minifile but did not complete their ADEF educational plan; 5.4% (7) were located in the minifile, but did not have ADEF 1-yr follow-up data. Consequently, complete hospitalization data from the ADEF records and BC/BS records were available for 52.4% (99) of the original 189 participants selected for this study. The final sample population of 99 BC/BS subscribers was 33.3% (33) men and 66.7% (66) women, of whom 73.7% (73) were \geq 45 yr of age. For the 99 ADEF participants, 57.6% (57) self-reported zero hospitalizations during the 12-mo pre-education period, and 42.4% (42) self-reported one or more hospitalization during this period.

Reliability. A reliability ratio was calculated for both the time period before the ADEF program (pre-ADEF) and the time period after the ADEF program (post-ADEF). The ADEF self-reported and BC/BS reported hospitalization data for the pre-ADEF period represent a 12-mo time span. The follow-up time period during which post-ADEF hospitalization data were collected ranges from 6 mo (two participants) to 26 mo (one participant) with a mean of 14.7 ± 3.4 mo. For each participant, the actual follow-up time period under which the ADEF self-reported data were collected was used when abstracting the BC/BS data.

The reliability ratio (R) was 0.768 for pre-ADEF hospitalizations, and 0.808 for post-ADEF hospitalizations. For cases in which ADEF self-reported hospitalizations differed from the BC/BS records, 16.2% (16) overreported their pre-ADEF hospitalizations and 9.1% (9) overreported their post-ADEF hospitalizations. Underreporting of hospitalizations occurred among 7.1% (7) of the participants for the pre-ADEF period, and 10.1% (10) for the post-ADEF period.

Table 1 summarizes the reporting errors of the study participants by sex and age. These data were analyzed to determine if the pre-ADEF time period and the post-ADEF time period had similar distributions of hospitalization reporting

errors. Using the chi-square⁵ test, the results suggested that there was no correlation between the type of reporting error made by the study participants and the time period at which the data were collected ($\chi^2 = 1.08$, $P > 0.25$). Again using the chi-square test, the data were analyzed to determine if a participant's sex was associated with the type of error made when self-reporting hospitalization patterns. Test results indicated that a participant's tendency to overreport or underreport was not correlated with the participant's sex ($\chi^2 = 0.08$, $P > 0.75$).

Of the 99 study participants, 73.7% (73) were \geq 45 yr of age. Consequently, participants with reporting errors were analyzed to determine if the participants $<$ 45 years of age had similar patterns of reporting errors as did the participants \geq 45 yr of age. The resulting chi-square distribution ($\chi^2 = 4.71$, $P < 0.05$) suggested that participants $<$ 45 yr of age were responsible for significantly fewer errors involving underreporting of hospitalizations than were participants \geq 45 yr of age.

Effectiveness. Using the BC/BS claims minifile, the participants' hospitalization patterns incurred during a 12-mo period before attending the educational intervention were compared with the participant's hospitalization patterns during a 12-mo period after completion of the outpatient education classes. Analysis of the claims data for the 99 study participants indicated that 60.6% (60) had zero hospitalizations during the 12-mo period before attending the ADEF program and 39.4% (39) of the participants had one or more hospitalization during this period. One year after participating in the outpatient education program, 74.7% (74) reported zero hospitalizations, and 25.3% (25) of the participants had one or more hospitalization during the follow-up period.

Table 2 presents the BC/BS documented changes in hospitalization patterns for these 99 study participants. As indicated, after completing an individualized education plan in the ADEF program, there were 38.5% (15) fewer people hospitalized and 28.3% (13) fewer hospitalizations. According to the BC/BS records, this reduction in hospitalizations represented 143 inpatient hospital days (36.2% reduction) and a \$31528 (31.7%) reduction in hospital costs among these 99 participants, or \$318 per each of the persons with diabetes.

DISCUSSION

There are inherent problems associated with collecting hospitalization data directly from program participants. Three basic factors affecting the accuracy of such self-reported hospitalization data are: (1) The personal significance attributed to hospitalization. Overreporting and underreporting of hospitalizations could be associated with a person's tendency to exaggerate or minimize the need for medical care. (2) Lack of information regarding actual hospital discharge diagnoses. Inaccuracy in self-reporting the cause of hospitalization could be associated with a person's lack of comprehension concerning the medical condition or reflect a lack of communication between the person and health care providers. (3) Informal determination of 12-mo time period from a given

TABLE 2
Blue Cross/Blue Shield reported hospitalization patterns pre- and post-ADEF program

	Pre-ADEF	Post-ADEF	% Change
Number of participants hospitalized	39	24	-38.5
Number of hospitalizations	46	33	-28.3
Length of stay (days)	395	252	-36.2
Hospital costs (dollars)	99443	67915	-31.7

Maine Diabetes Control Project, 1983.

interview date. Acknowledging the effect of the personal significance associated with a hospitalization, it could be difficult for a person to differentiate between a hospitalization in the 11th or 13th month from a specific interview date.

The reference source used to document the actual record of hospitalization patterns for a participant may also have inherent problems. In using the BC/BS inpatient claims data as the reference for verifying the reliability of the ADEF self-reported data, several assumptions were made. Initially, it was presumed that the ADEF participants' BC/BS insurance coverage was constant over the study period and therefore all hospitalizations were recorded. Second, it was assumed that the BC/BS primary and second-listed discharge diagnoses reflected the actual cause of hospitalization per the person's medical records.

Recognizing the existing limitations of the self-reported and reference claims data, the ADEF self-reported hospitalization data when tested for reliability were demonstrated to be accurate for 77% of the participants, and consequently inaccurate for 23% of the participants in the pre-ADEF time period. In the post-ADEF time period, the self-reported hospitalization data were demonstrated to be accurate for 81% of the participants and inaccurate for 19% of the participants. Study participants whose self-reported hospitalizations were not proven reliable per the BC/BS records demonstrated a propensity to overreport the frequency of hospitalizations during the pre-ADEF time period; however, this finding was not statistically significant. Participants <45 yr of age were found to have significantly fewer errors due to underreporting of hospitalizations than participants \geq 45 yr of age. Acknowledging the small number of participants involved, this significant association suggests that a hospitalization may have a greater impact on a younger person, and would therefore be less likely to be underreported.

Reliability studies have demonstrated that self-reported measures for height and weight are ". . . remarkably accurate . . ." and that the differences from the actual measures although small have systematic errors involving age, sex, body size, and education.⁷ Studies that test the reliability of self-reported hospitalizations, however, are absent from the literature. Consequently, no established degree of reliability has been presented for self-reported hospitalization data to date. A study by Stewart⁸ speculated that the high degree of accuracy associated with self-reported height and weight ". . . can

probably be viewed as an upper bound of the reliability and validity of other self-reported measures, such as health status. That is, one would expect self-reports of less objective characteristics such as health status to be less reliable and valid than self-reports of weight and height. . . ." In this study, a participant's age, sex, or time of reporting were not correlated with a type of reporting error. It is believed that intensified ADEF instructor training in interviewing skills would not compensate for the observed human errors in memory recall. Consequently, it is important for each program and investigator to determine the level of accuracy required from the self-reported data, and adjust data collection methodologies accordingly.

The Maine DCP has used the ADEF self-reported hospitalization data to document a reduction in hospital utilization by ADEF participants and thereby postulated the effectiveness of the outpatient education program. Through the course of this study, the DCP had the opportunity to analyze claims data from the BC/BS inpatient minifile and used this data source to evaluate any changes in health care utilization patterns by selected BC/BS subscribers who participated in the ADEF program. In so doing, the BC/BS claims data corroborated the initial assertion of the DCP that participants in the ADEF program reported a reduction of \approx 30% in hospitalizations after completing the outpatient education program.

Beginning in August 1980, Maine BC/BS agreed to enter into a 3-yr reimbursement demonstration pilot study with hospitals and rural health centers providing the ADEF program. Per the request of BC/BS, the Maine DCP submitted a final report in November 1983 to the Board of Directors of Maine BC/BS: a 32.2% reduction in self-reported hospitalizations was reported for a sample of 813 ADEF participants, as well as the results of the reliability study outlined in this paper for the sample of 99 ADEF participants covered by BC/BS of Maine. On December 21, 1983, the Board of Directors decided to establish the ADEF program as a permanent benefit to Maine BC/BS members <65 yr of age.

Primarily, this study of 99 ADEF participants with BC/BS coverage demonstrated 77% reliability in reporting total hospitalizations for the pre-ADEF time period and 81% reliability in reporting total hospitalizations for the post-ADEF time period. Second, the BC/BS reference data indicated that the study participants had a reduction in hospital utilization similar to that calculated using the ADEF self-reported hospitalization data. According to Windsor et al.,⁹ data collection methodologies should be selected and developed to ensure the ". . . most reliable and valid methods and instruments appropriate to the issues at hand, within the funding and other resources available." The ADEF program was designed as a service program for persons with diabetes and not as a rigorous and tightly controlled research study. In the Maine experience, ADEF self-reported hospitalization data in combination with selected reference claims data have proven to be adequate in evaluating the effectiveness of the ADEF program and in securing third-party reimbursement from Maine BC/BS. However, the DCP acknowledges that the use of

reference data to evaluate program effectiveness is preferable, although such data are not necessarily accessible or available. It is recommended that all programs that choose to use self-reported data conduct a reliability study to qualify the degree of accuracy of the data.

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