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## Accuracy of Reported Family History of Diabetes Mellitus

### Results From San Luis Valley Diabetes Study

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There are two possible sources of bias in the assessment of family history of diabetes: 1) a person with diabetes may be more likely to report a diabetic relative than a nondiabetic person would be, and 2) relatives of individuals with diabetes may be more likely to be tested for diabetes than relatives of nondiabetic individuals. We conducted a study on a subsample of families of subjects in the San Luis Valley Diabetes Study to examine these issues. A sample of 5 White and 5 Hispanic subjects (probands) with diabetic glucose tolerance tests and the same number with normal glucose tolerance were selected. The 20 probands all provided contact information on their 227 primary family members. Ninety-two percent of the family members had interviews completed by themselves or, if deceased, by surrogates other than the proband. Family members were asked by telephone if they had ever been tested for diabetes, when they had been most recently tested, why they had been tested, and if they had ever been told they had diabetes. The results showed that study subjects accurately reported family history of diabetes, because there were no discrepancies between proband and family reports. A positive family history of diabetes was associated with increased reported screening in Hispanics, but a similar effect in White families was not seen. Women were also more likely to report being screened than men regardless of whether there was a positive family history of diabetes. These data indicate that, although diabetic and control subjects accurately report their family history of known diabetes, indications of differential screening exist that may alter the amount of known and subsequently reported diabetes in families. *Diabetes Care* 13:796–98, 1990

of diabetic individuals may be more likely to be tested for diabetes than relatives of nondiabetic individuals (1,2). The Tecumseh Community Health Study reported that only 35% of direct family history reports by participants were confirmed with interviews of family members (3). We conducted a study on a sample of families of subjects in the San Luis Valley Diabetes Study to examine these issues (4).

#### RESEARCH DESIGN AND METHODS

A sample of 20 study subjects was selected who had a baseline clinic visit in the month of April of any year between 1984 and 1987. Subjects were selected sequentially until 5 non-Hispanic White and 5 Hispanic subjects with diabetic glucose tolerance tests according to World Health Organization criteria and 5 White and 5 Hispanic subjects with normal glucose tolerance tests at the baseline clinic visit had been identified (5). These subjects are referred to as probands. We selected at least 2 of each group of 5 to have reported a positive family history of diabetes mellitus at the baseline clinic visit. A positive family history was defined as at least one member of the primary family other than the proband with diabetes, including parents, siblings, and children of the proband. When examining the differences in reported screening by family history, any history of diabetes, including the proband's status, was used to classify families as positive or negative. The family members were telephoned and asked if they had ever been tested for diabetes, and details were requested.

Because data on family members do not represent independent observations, we used the family as the unit of analysis. To test for differences between family subgroups of interest, the average proportion within families was used as a summary measure, and analysis of variance was used to test for significance of differences.

There were 227 primary family members; 145 family members (64%) were alive and could be located. Only

Family history reports are often the only source of information available regarding mortality and morbidity of family members of study subjects in epidemiological research. There are two possible sources of bias in the historical assessment of a family history of diabetes: 1) a person with diabetes may be more likely to have knowledge of and/or report a diabetic relative than a nondiabetic person, and 2) relatives

2 (1.4%) refused to be interviewed. Fourteen family members (6%) who were alive could not be located for interviews; 10 were from families reported to have negative family histories for diabetes, and 4 were from families with a positive family history. Thirteen were <20 yr of age and were excluded. Sixty-eight family members (30%) were deceased. All information on deceased family members was obtained from a surrogate other than the proband, except for 3 deceased family members who were excluded because no surrogate responder was available. Results of 195 family members are summarized herein.

## RESULTS

The mean  $\pm$  SE age of the proband sample at the baseline clinic visit was  $55.2 \pm 5.0$  yr compared with  $55.5 \pm 0.78$  yr for all San Luis Valley Study subjects. The age distributions of family members of diabetic and nondiabetic probands did not differ significantly. Families of diabetic subjects had an average of 12.6 members, and families of control subjects had an average of 10.1 members.

The report of a positive or negative family history was compared between probands and their family members in 9 families where the proband had reported a positive history and in 11 where the report was negative. There was complete agreement between proband and family history reports in all cases (data not shown). This complete agreement was surprising but may have been due to a relatively small sample of families.

Next, we examined whether reported screening for diabetes occurred differentially among families with and without a family history of diabetes and whether reported screening varied by ethnicity. An average of 23% of members within families did not know whether they had ever been screened for diabetes (44 family members). The proportion of family members who did not know about screening was lower in families with a positive history (17%) than in families with a negative history (38%,  $P = 0.05$ ). Knowledge of screening did not differ significantly by ethnicity.

Table 1 shows that, among White families, there was no significant difference in the average proportion of family members reporting ever being screened for dia-

betes when those with and without a positive family history were compared. Among Hispanic families, we observed that a higher proportion of people with a positive family history reported screening compared with families with a negative history (58.5 vs. 20.8%,  $P = 0.07$ ). For Hispanics reporting screening in the last 3 yr, the difference by family history status was significant (32.6% for positive history vs. 5.6% for negative history,  $P = 0.04$ ). Although Hispanics with a negative family history reported less screening than Whites, the differences seen between ethnic groups were not statistically significant by two-way analysis of variance with or without appropriate interaction terms (data not shown).

Table 2 examines the reasons for screening among family members. Women were more likely to report screening for diabetes (36.0%) than men (19.8%,  $P = 0.009$ ). This additional screening was due to symptoms other than those associated with diabetes, a family history of diabetes, or pregnancy.

## DISCUSSION

These data suggest that both nondiabetic and diabetic people give an accurate family history of diabetes. Although there were only 20 families, 195 family members were questioned. When analyzed on a family basis, complete agreement on family history was found.

We wanted to determine whether the knowledge of any diabetic person in the family altered the screening habits of family members. Among Whites, family history status made no difference in reported screening of family members. However, among Hispanics, those families with a negative history had less reported screening, especially in the past 3 yr, than among Hispanic families with a positive family history.

To determine whether this pattern occurred in a larger sample of subjects, we examined reported screening trends by family history status in the entire nondiabetic control population. Hispanic control subjects with a positive family history were 24% more likely to report having been tested for diabetes than Hispanics with a negative family history ( $P < 0.001$ ,  $n = 176$ ). Whites showed a nonsignificant increase of 10% ( $P = 0.13$ ,  $n = 271$ ) in reported diabetes testing with a positive

**TABLE 1**  
Percentage of family members reporting screening for diabetes

	White			Hispanic		
	Family history positive	Family history negative	<i>P</i>	Family history positive	Family history negative	<i>P</i>
<i>n</i>	7 (49)	3 (11)		7 (67)	3 (24)	
Ever tested	44.4	61.7	0.36	58.5	20.8	0.07
Tested <3 yr	29.4	46.7	0.13	32.6	5.6	0.04

Forty-four family members did not know whether they were screened and were excluded from the data. *n* = families and *n* in parentheses is total family members.

**TABLE 2**  
**Reported reasons for screening among family members**

	Women		Men	
	n	%	n	%
Proportion of family members tested	36/100	36.0*	19/95	19.8*
Reasons for testing				
Routine screening	12	33.3	12	63.2
Other symptoms	9	25.0	2	10.5
Family history of diabetes	6	16.7	2	10.5
Diabetes symptoms	1	2.8	0	0.0
Pregnancy	5	13.9	0	0.0
Other†	3	8.3	3	15.8
Total screened for all reasons	36	100.0	19	100.0

\*P = 0.009.

†Includes 4 people seen as control subjects in San Luis Valley Diabetes Study.

family history (data not shown). These results suggest that bias in the knowledge of a positive family history may exist by ethnicity, possibly due to differential screening.

If the ethnic difference is real, it should result in a lower detected prevalence of diabetes only in Hispanic families where there are no members with diabetes if screening tests are being conducted with the same frequency that they are reported. However, one possible explanation for these observed results is that screening tests are being conducted by physicians uniformly across the subgroups that we studied, and it is only the knowledge of the occurrence and results of these tests that differs. This could result if family members of Hispanics with diabetes request or are told results more often than family members of nondiabetic Hispanics. This possibility is supported by the observation that among families with no history of diabetes, the proportion not knowing whether they had ever been screened was higher. However, this does not explain the ethnic patterns, because there were no significant differences in knowledge of screening by ethnicity.

Another possible explanation for the ethnic difference could lie in medical care use patterns. If Hispanics were to use less medical care, then the opportunity to be screened for diabetes would be different, and this difference could be further exaggerated by a negative family history. Analyses of the frequency of reported physician visits and blood pressure screenings among nondiabetic control subjects in the study population showed no significant differences by ethnicity (data not

shown). Thus, differential medical care use seems an unlikely explanation for the low rate of reported screening in Hispanics with a negative family history.

Women were more likely to report having been screened than men, but because there usually are approximately equal numbers in most families, except at older ages, sex will probably not be a major source of bias in the estimates of family history of diabetes. Because women use medical care more often than men, the excess in reported screening may be the result of more frequent opportunities for testing (6). We have no information on the frequency of medical visits in this family study subgroup.

Our findings suggest that known diabetes in families is accurately reported by both diabetic and control subjects. Overall, only a moderate percentage (48.4%) of the family members reported ever having been tested for diabetes. Without individual screening of all family members, the actual amount of undiagnosed diabetes in families cannot be ascertained.

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Received for publication 7 December 1988 and accepted in revised form 17 January 1990.

ACKNOWLEDGMENTS

This work was supported by National Institutes of Health Grant DK-30747.

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