

# Health Insurance and the Financial Impact of IDDM in Families With a Child With IDDM

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**OBJECTIVE** — To examine the health insurance experience and out-of-pocket health care costs of families with a child with IDDM.

**RESEARCH DESIGN AND METHODS** — A case-control study of 197 families with a child with IDDM and 142 control families with no diabetic children was conducted. IDDM-affected families were identified from the Allegheny County IDDM Registry. Brothers and sisters of the parents in the IDDM-affected families were asked to participate as control subjects. Health insurance coverage and the money that families spent on health care services and supplies not reimbursed by insurance (out-of-pocket costs) were assessed by questionnaire.

**RESULTS** — No difference was found between the IDDM-affected and control families in the percentages with or without insurance. Families with low household incomes (\$10,000–\$19,999) were at the greatest risk for having no insurance. While coverage provided by private plans was similar between the IDDM-affected and control families, many families had no reimbursement for insulin (10%), syringes (10%), or blood testing strips (30%). Out-of-pocket expenses were 56% higher in the IDDM-affected families than in the control families. Seventeen percent of the IDDM-affected families had expenses over 10% of their household income. This particularly affected families with low household incomes. Pre-existing illness clauses and insurance denial affected only a small proportion of the case families.

**CONCLUSIONS** — These data illustrate that most families with a child with IDDM have health insurance, yet still incur larger out-of-pocket health care costs than do families without the presence of diabetes. IDDM-affected families likely face a number of economic decisions regarding health insurance and the use of health care.

The impact of diabetes on individuals living with the disease is wide ranging. In addition to coping with the health, disability, and social impacts of their diabetes, individuals must also contend with the economic costs of managing diabetes. Out-of-pocket health care costs are a significant concern for many individuals. Recent trends indicate that the burdens of out-of-pocket health care costs are increasing (1–4), with more widespread use of

copayments in standard health care coverage plans and higher premiums (1,2,5,6).

A major mediator of health care costs in the U.S. is health insurance. Health insurance shelters an individual from the financial impact of major medical expenses. Some population groups, though, are more vulnerable to the costs of health care than others. Children and the chronically ill are two such groups (7,8). Children with chronic illnesses may be particularly at risk

for generating high out-of-pocket expenses (9,10). Many have no or poor health insurance coverage (11), while using health services extensively (12,13).

IDDM is a leading chronic disease of childhood. The resources needed to manage IDDM on a daily basis, particularly with intensive treatment, can be extensive and costly. The management of diabetes requires regular and frequent blood glucose testing and insulin adjustments, as well as regular contact with health care professionals. This regimen is integral for preventing both the short- and long-term complications of IDDM.

In the private health insurance market, people with chronic diseases face limits on the availability and choice of policies. One recent study suggests that individuals with IDDM are more likely to have problems obtaining health insurance than are people without IDDM (14). Even if insurance coverage is available, some medical services and supplies, such as outpatient diabetes education, insulin, syringes, and blood glucose testing supplies, may not be fully covered (15–17).

These reports describe the insurance experience of adults with diabetes. The impact among children with IDDM and their families remains relatively undefined, although these observations suggest that out-of-pocket costs could be considerable. Health insurance coverage among children, in general, has been an important political issue over the past few years (18). Reports indicate that children are more often without insurance coverage than most adults in the U.S. population (8,19,20). Moreover, children without coverage are more likely to forego immunizations and outpatient health services in some situations where treatment is indicated (18,21). These experiences are not well understood among children with IDDM. To evaluate these issues, we examined the health insurance experience and the out-of-pocket costs of families with a child with IDDM and families with no diabetic children.

## RESEARCH DESIGN AND METHODS

— The investigation con-

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DCCT, Diabetes Control and Complications Trial; HMO, health maintenance organization.

ducted was based on a case-control study of the insurance and health care costs of 339 families with and without a child with IDDM. Families with a diabetic child were identified from the Allegheny County IDDM Registry, a population-based listing of all newly diagnosed individuals with IDDM living in Allegheny County at the time of diagnosis from 1965 to 1985 (22). A comparison group of families with no diabetic children was identified from the family structure information of the IDDM-affected families eligible for study.

The primary eligibility criteria for the IDDM-affected families in this study were that the child with IDDM was listed in the Allegheny County IDDM Registry, alive, and 18 years of age or younger on 30 April 1989. Since the latest date of diagnosis for this report was 1985, all IDDM-affected families were living with the disease for at least 3–4 years. As such, the families are likely to represent a relatively stable experience of living with IDDM. A total of 262 registrants fulfilled these criteria.

Patients were further excluded if they were participating in a clinical trial that offered free medical supplies ( $n = 26$ ), if they had a sibling or parent with IDDM ( $n = 29$ ), or if they were not living with either parent ( $n = 9$ ). One person with mental retardation was excluded as well. Families with more than one child with IDDM were not included because of their participation in other studies at our center. Families in which either parent had IDDM were excluded because of the associations of IDDM with insurance (14) and employment difficulties (23) among adults. That left 197 IDDM-affected families eligible for study.

A brother or sister of either parent in the IDDM-affected family (the aunt or uncle of the child with IDDM) and their families were asked to participate in the study as control subjects, provided that 1) permission was granted from the IDDM-affected family for contact, 2) no one in the immediate family had diabetes, and 3) they had at least one child 18 years of age or younger as of 30 April 1989. Overall, 142 comparison families met these eligibility criteria.

If more than one eligible comparison family existed, the comparison family of interest was initially selected in a random manner. However, this selection process did not work well in practice because it was discovered that a large number of case families ( $n = 49$ ) had no eligible control subjects and some families requested that we approach another brother or sister. It

became apparent that there would not be a large number of control families to enroll if we relied strictly on a randomized design. Thus, the selection of a control family outside of the random criteria was permitted if an IDDM-affected family requested it, with the aim of improving the sample size available for comparison. As such, some degree of selection bias could have been introduced. Overall, 53.3% of the control families were selected in a randomized manner.

After contact to describe the study, a consent form and questionnaire were mailed to the families. Parents in both the IDDM-affected and comparison families were asked to complete and return the materials. Topics covered in the questionnaire included health insurance coverage, health care use, health care costs, availability of insurance, barriers to health care, household income, and parental work history. Specific health insurance issues examined included whether the family had insurance coverage in the past year, which family members were covered, the source of the policy, the type of plan (group or individual), the cost of the plan (premium paid by the family), and reasons for not having any insurance. IDDM-affected families were also queried about the use and coverage for diabetes supplies.

Three measures of out-of-pocket health care costs are examined. The first is the measure of out-of-pocket costs defined in the survey as the money that families spent on health care services and supplies that was not reimbursed by insurance. Both case and control families were asked to categorize this amount of money in \$250 intervals ranging from \$0 to more than \$2,750 (in 1990 dollars).

The second measure combined reported out-of-pocket costs with the health insurance premiums paid by the family. This measure was examined because insurance premiums represent fixed costs, and there was some indication that premiums were slightly higher among the IDDM-affected families. In creating this measure, the ordinal data on out-of-pocket expenses were transformed into an average expenditure and summed with the reported premiums paid in the past year to yield an estimate of the total out-of-pocket expenses for the families. The transformation of the categorical data assumed that the expenses of the families would be evenly distributed through the dollar range reported. Estimated expenditures were then set equal to the midpoint of the interval indicated.

Reported expenses over \$2,750 were conservatively set equal to \$2,875, the midpoint of the \$2,750–\$3,000 interval.

A third measure examined out-of-pocket costs as a share of household income. In creating this measure, the ordinal data were again transformed into an average expenditure amount and divided by the midpoint of the household income interval. Household income was assessed in \$10,000 intervals ranging from \$0 to more than \$70,000. All three measures of out-of-pocket costs were highly correlated with each other (first:second measure,  $r = 0.70$ ; first:third measure,  $r = 0.49$ ; second:third measure,  $r = 0.67$ ).

Completed questionnaires were received between April 1989 and April 1990 from 172 (87.3%) of the IDDM-affected families and 118 (83.1%) of the eligible comparison families. Twenty families (14 case and 6 control) refused to participate in the study, and 16 IDDM-affected families refused permission to contact any control family. Five case families could not be located.

Data analysis in the study focused on the descriptive comparison of the responses from the 172 IDDM-affected families and 118 control families. Analyses were performed using the SPSS-PC statistical software package (24).  $\chi^2$  and  $t$  test statistics were used to evaluate the differences in health insurance (yes/no), insurance denial (yes/no), policy premiums, and the use of health services. Non-parametric statistics (the Mann-Whitney  $U$  test and the median test) were used to evaluate the difference in out-of-pocket costs between case and control families as the distribution of these costs was markedly skewed toward \$0. Median values are presented, rather than mean values, because of this distribution and the extreme costs incurred by some of the participants. Multiple logistic regression analysis was conducted to assess the independent association of diabetes status on health insurance coverage. Linear regression analysis was conducted to evaluate the independent relationship of diabetes status to out-of-pocket costs.

## RESULTS

### Demographic characteristics of respondents

The demographic characteristics of the IDDM-affected and comparison families are presented in Table 1. The attributes of the families were very similar with regard to race, household income, education, and

**Table 1—Demographic characteristics of case and control families**

Characteristic	Case families	Control families
n	172	118
Age		
Mean parental age	41.4 ± 5.8	38.4 ± 5.9
Mean age of children (years)		
0–5	4.1	22.9
6–12	30.2	44.1
>13	65.7	33.1
Race		
White	95.9	97.5
Black	4.1	2.5
Number of parents		
One	22.1	8.5
Two	77.9	91.5
Family income		
\$0–10,000	7.4	2.6
\$10,000–20,000	13.0	14.8
\$20,000–30,000	18.5	23.5
\$30,000–50,000	39.5	34.8
\$50,000+	21.6	24.3
Parental education		
No college degree	60.0	63.5
One college degree	26.5	17.4
Two college degrees	13.5	19.1
Family health status (other than diabetes)		
Chronic condition	30.4	33.1
Healthy	69.6	66.9
Mean family size	4.1 ± 1.1	4.2 ± 1.0
Duration of diabetes (years)	7.3 ± (3.1)	—

Data are n, means ± SD, or %. \* $P < 0.01$  among families across all categories combined.

family size. However, the case families were older than the control families. The mean ages of both the parents and the children were older. The IDDM-affected families were also more likely to be headed by a single parent than were the control families. Nearly 22% of the IDDM-affected families had single parents, compared with 9% of the controls ( $P < 0.01$ ). There were no differences between the demographic attributes of the single parents in the case families and those in the control families.

### Access to health insurance

Health insurance coverage for the families with a child with IDDM was fairly extensive and comparable with that reported by the control families (Table 2). About 90% of the case and control families reported full-year insurance coverage. Reasons reported

by the families (both case and control) for the lack of full-year coverage included the high cost of insurance, the presence of a pre-existing illness clause, the lack of coverage for a family member older than 21 years, unemployment, and no insurance benefits offered through the workplace.

Characteristics of the families without full-year insurance coverage for all members were examined by grouping families from the three categories (some members not covered, part-year coverage, and no coverage at all) together. Household income was the strongest factor related to the lack of full-year coverage in both case and control families. Families with reported incomes under \$10,000 and families with moderate and higher incomes (incomes over \$20,000) were more likely to be insured than those at income levels between \$10,000 and \$20,000. Within the IDDM-affected families, 91.7% with income levels under \$10,000 had full-year coverage, 52.4% earning between \$10,000–19,999 had coverage, and 93% reporting incomes over \$20,000 had insurance. A similar finding was evident in the control families. This relationship remained when examined in a multiple logistic regression model (not shown). Families with household incomes between \$10,000 and \$20,000 were ten times more likely to be uninsured than those reporting incomes under \$10,000 per year. Diabetes status was not a significant factor in the model.

### Availability of insurance

Diabetes, however, did appear to influence the availability of health insurance. IDDM-affected families more frequently reported being denied health insurance coverage than did the control families (8.4 vs. 1.7%,  $P = 0.03$ ). The presence of a child with diabetes was the primary reason stated for this refusal among the case families (reported by 93% of those refused insurance). The presence of a chronic disease in the family was the reason for refusal cited by both of the control families denied insurance previously. Twenty-six IDDM-affected families (16%) indicated that diabetes had influenced their insurance plan or coverage at some time. Nine of these families cited the presence of a pre-existing illness clause, which restricted the coverage of health services for the family member with diabetes.

### Health insurance coverage

Various aspects of the insurance policies were also examined. Overall, the source of

**Table 2—Health insurance coverage of case and control families**

	Case families	Control families
All members covered		
Full year	88.4	90.7
Part year	2.3	0.8
Some members not covered		
Full year	7.0	6.8
All members not covered		
Full year	2.3	1.7

Data are %.

insurance did not differ between the families. Coverage through Medicaid, CHAMPUS, Blue Cross/Blue Shield, commercial insurance companies, and health maintenance organizations (HMOs) appeared to be very similar. This relationship remained when the categories were grouped simply into public or private insurance plans. The type of policy (group or individual) and the type of third-party payment (fee for service or HMO) also appeared to be very similar among the families with private insurance coverage (Table 3). The IDDM-affected families, though, paid higher premiums than did the control families, but this difference was not statistically significant (\$763/year vs. \$521/year,  $P = 0.09$ ).

Payment for hospitalization, outpatient physician visits, insulin, and syringes appeared to be fairly extensive among the IDDM-affected families. Roughly 85–90% of the families with private plans had some type of coverage for these items. Somewhat smaller proportions of the families had coverage for lancets (64%), blood testing strips (70%), and blood testing meters (75%). These figures can be misleading, since many insurance plans require copayments or deductibles for these items before full reimbursement takes place. Over 60% of the families with private plans reported having to pay a deductible for either insulin, syringes, or blood testing strips. Over 85% reported that a copayment was required for these items.

### Out-of-pocket health care costs

Overall, IDDM-affected families reported significantly higher out-of-pocket medical expenses ( $P < 0.001$  by Mann-Whitney test) than did the control families. Figure 1 presents the distribution of the out-of-pocket expenses reported by the case and control families. Nearly one-third of the case

Table 3—Insurance characteristics among families with private health plans

	Case families		Control families	
	n	%	n	%
Type of policy				
Group plan	157	96.2	114	94.7
Individual plan	157	6.4	114	7.0
Type of payment				
FFS	153	76.5	111	74.8
HMO/PPO	153	20.3	111	15.3
Both	153	3.3	111	9.9
Premium				
Overall	151	\$763	108	\$521
Group plan	134	\$724	100	\$457
Individual plan	10	\$3,080	8	\$1,486

FFS, fee for service; PPO, preferred provider organization.

families spent more than \$1,000 of their own money on health care, compared with 16% of the control families. The majority (65%) of the control families reported out-of-pocket expenses under \$500, compared with 33% of the case families.

The second measure of health care costs examined was out-of-pocket payments plus out-of-pocket health insurance premiums. Overall, the median amount of money spent on health care and insurance premiums amounted to \$1,125 for the case families and \$625 for the control families ( $P = 0.03$  by median test). This difference between the case and control families was consistent across the basic demographic and insurance categories (Table 4). Among the IDDM-affected families, significantly higher expenses were reported by those with higher incomes and more health care visits. A similar trend was evident within the control families.

A multivariate model of the characteristics influencing out-of-pocket expenses was estimated to evaluate the independent contribution of diabetes status. In this model, the dependent variable, out-of-pocket expenses, was transformed into log units because of the skewed nature of the data. Diabetes status, household income, and the presence of a chronic health condition in the family were found to be significantly associated with out-of-pocket expenses. Total out-of-pocket expenses were 56% higher among the IDDM-affected families after statistical adjustment for the other listed factors. A similar pattern was found when the model was analyzed with health insurance premiums excluded and when the model was analyzed with the number of health care visits as an additional independent variable.

Limiting the evaluation of out-of-pocket expenses to the dollar amount spent by the families, however, may not reflect the true financial burden. Another measure of liability is the percentage of income spent on medical expenses (measured in terms of out-of-pocket costs plus the family share of the health insurance premium). The share of family income spent on health care was again significantly higher among the case families than the control families (mean, 5.6 vs. 3.1% of income; median, 3.3 vs. 1.9% of income;  $P = 0.004$ ). The distribution of the percentage of income devoted to health care among the case and control families is presented in Fig. 2. Over 30% of the IDDM-affected families had out-of-pocket expenses exceeding 5% of their reported income. About 17% of the case families had expenses that exceeded 10% of their income, compared with ~5% of the control families.

The burden of out-of-pocket medical expenses was the highest for the lowest-income IDDM-affected families. Overall, the average amount spent on health care by the low-income (under \$20,000/year) IDDM-affected families was 9.7% of household income, while the median amount was 5.3% of household income. If families with Medicaid coverage are excluded, these figures change to an average of 9.6% of household income and a median of 5.8%. The control families in this income group had a median amount of 2.5% of household income spent on health care.

**Catastrophic health care costs**

Out-of-pocket health care expenses of the magnitude seen for the low-income IDDM-affected families suggest that many may be incurring "catastrophic" health care costs. While the level at which health care costs become catastrophic is debatable (25), we examined the characteristics of all IDDM-affected families who had out-of-pocket expenses exceeding 10% of their income. A substantial percentage (17%,  $n = 24$ ) of IDDM-affected families had personal expenses exceeding this threshold. All but two of these families had insurance coverage through private sources.

Overall, case families with costs exceeding the 10% threshold were more likely to have had a family member hospitalized in the past year than case families with expenses below this level (Table 5). The family member hospitalized in most instances was the child with IDDM, accounting for 72% of the admissions in the families with catastrophic costs. Families reporting catastrophic costs were also

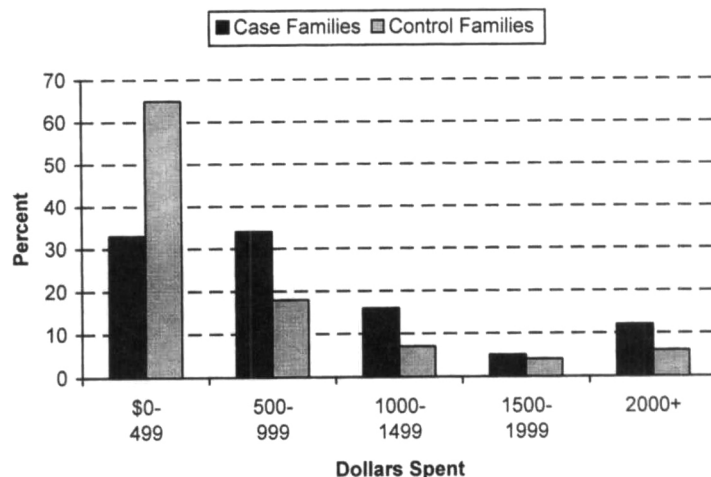


Figure 1—Distribution of out-of-pocket health care expenses.

**Table 4—Median out-of-pocket costs for health care and insurance premiums by family, insurance, and demographic characteristics**

	Case families		Control families	
	n	Median amount	n	Median amount
Overall	150	1,125	108	625
Insurance coverage all year				
Yes	134	1,072	100	625
No	16	1,266	8	750
Source of insurance				
Public	10	172	5	375
Private	134	1,125	100	675
Type of private plan				
FFS	102	1,125	74	712
HMO	26	760	17	440
Mean parental age (years)				
21–34	15	825	27	455
35–49	124	1,125	78	675
50–64	10	1,625	3	625
Family size				
2–3 individuals	41	875	24	548
4–5 individuals	94	1,175	76	737
6+ individuals	15	1,189	8	125
Single parent				
Yes	28	715	9	257
No	122	1,125	99	645
Income (in thousands)				
\$0–10	9	375	2	450
\$10–20	17	720	14	316
\$20+	115	1,200	90	737
Chronic health condition in family (other than diabetes)				
Yes	47	1,405	36	1,025
No	102	942	72	440
Family health care visits				
0–20	48	762	56	448
>20	83	1,295	50	875

Data are n or dollar amount. FFS, fee for service.

more likely to have lower household income levels and two or more chronic health conditions in the family (another condition in addition to diabetes). The use of diabetes-related health services and supplies at recommended levels for an individual with IDDM (26) was not related to catastrophic costs, nor was there an association between family size, parental age, and insurance and this high level of personal health care expenses (analysis not presented). Similar relationships were found when the two families with Medicaid coverage were excluded.

#### Health insurance, out-of-pocket costs, and the use of health services

Several previous reports suggest that limited access to care (21,27–29) and high

out-of-pocket health care costs may influence the use of health services. We examined this issue among the case families (Table 6), since limited use of health services may impact on the short- and long-term complications of IDDM. Overall, case families without full-year insurance coverage reported more problems in obtaining medical care than those with coverage ( $P < 0.001$ ). Regarding the use of specific services, the only link between the lack of coverage and a less frequent practice of diabetes care pertained to blood glucose monitoring. Children with no insurance were less likely to self-test their blood for glucose values. Reported median out-of-pocket costs did not differ between those who met the recommended standards of care and those who did not (3.6 vs. 3.1%

share of income). There also was no evidence that the families with high out-of-pocket expenses were less likely to use recommended diabetes services.

**CONCLUSIONS**— The results suggest that diabetes has a substantial economic impact on families with a diabetic child. Although the insurance coverage of the IDDM-affected families was roughly comparable with that of the control families, out-of-pocket health care expenses were 56% higher in IDDM-affected families than those in the control families after adjusting for the influence of other factors that could affect health care costs. Family health care expenses, as a percentage of annual household income, were nearly two times higher for case families than for control families. Seventeen percent of the IDDM-affected families had out-of-pocket expenses over 10% of their yearly income. The largest impact of out-of-pocket costs was on case families earning less than \$20,000 per year. Expenses for these families averaged close to 10% of their income.

This study is the one of the first reports to describe the personal health care costs associated with IDDM, and it is the first to do so for a representative cohort of families affected by IDDM. Overall, the results are comparable with the conclusions of earlier reports on diabetes. A paper based on data from the National Medical Care Expenditure Survey reported that the out-of-pocket expenses for a person with diabetes were 1.8 times higher than the expenses for a person without diabetes (30). Over 20% of an adult cohort with IDDM reported out-of-pocket expenses exceeding \$400 per year for basic diabetes and medical supplies in 1985 (31).

Why were the out-of-pocket expenses of the IDDM-affected families so much higher than those of the control families? The primary reason is the increased use of health care services and supplies by individuals with diabetes. Health insurance coverage did not differ largely between the case and control families in this report. Several national surveys indicate that individuals with diabetes use health services more frequently than the general population (30,32,33). Higher rates of hospital, physician, and emergency room use were also observed among the children with IDDM in this study, while the utilization patterns of the parents and siblings in the IDDM-affected families were similar to their respective counterparts in the control fam-

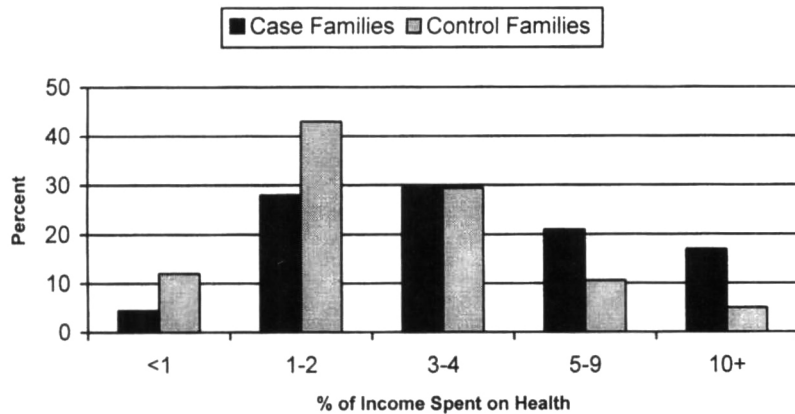


Figure 2—Distribution of the percentage of income spent on health care (premiums included).

ilies (34). In addition, children with diabetes use many devices that are unique to diabetes to manage their condition. Coverage for insulin, syringes, and blood testing strips was not always complete. Even for those with coverage, many families reported having to meet deductibles and copayments before reimbursement began.

The burden of out-of-pocket costs in this study was most striking for the IDDM-affected families with low incomes, most of which did not have Medicaid coverage. As a percentage of income, these families paid more of the costs of health care out of their own pockets than did those with higher incomes. This association is also found in the general U.S. population (25,35). Given the burden of the cost of health care, particularly in low-income families, it is possible that some families may have neglected expenditures on nonmedical needs, necessary medical services, or both because of their cost. This issue remains unresolved. We did not find evidence to link out-of-pocket costs with the nonuse of recommended levels of basic diabetes care, suggesting that expenditures could be affected in other areas. However, because of the indirect nature of our analysis, we cannot rule out that costs could have been an important barrier for some families.

No difference was found between the IDDM-affected and comparison families in the percentages with or without insurance. One reason behind this finding may be that most parents had obtained insurance through group plans at their place of employment. It is also possible that the parents of the diabetic child had the same job as when the diagnosis of diabetes was made. In this situation, they may not have faced diabetes-specific issues in applying for insurance.

Some limitations in the study design may affect the interpretation of the results. While the families surveyed are likely to represent a relatively stable experience of living with IDDM, the high expenses associated with the diagnosis and adjustment to IDDM and the expenses related to the presence of more than one person with diabetes in the family have been excluded from this report. In addition, the data largely represent the experience reported in one geographical region of the U.S. Sources and

types of health insurance coverage and factors behind health care use have been shown to differ greatly by geographical area (5). It is possible that insurance patterns and out-of-pocket costs related to IDDM could differ across the U.S.

Recall bias may be present in the study since the responses provided in the survey were not validated. To minimize the possibility for error, the questions used in this study were modeled from queries included in national surveys that have been verified. We have no evidence regarding the potential impact of any recall bias, but it remains feasible that the IDDM-affected families were better aware of the costs they faced since they used health care frequently.

Some bias may also have been introduced by the manner in which controls were included in this study. The random selection of control families was not complete, and this may influence the magnitude of the cost difference seen between the families. First-degree relatives of the case parents were also used as control subjects. The use of first-degree relatives as control subjects has strengths and weaknesses. The primary strength is that the control subjects were identified from a population that is similar to the population

Table 5—Factors associated with catastrophic out-of-pocket expenses in IDDM-affected families

	Families with catastrophic costs	Families without catastrophic costs	P value
n	24	117	
Hospitalization in the past year			
Any member of family	62.5	31.6	0.05
The child with IDDM	41.7	19.7	0.01
Emergency room visit in past year			
Any member of family	75.0	60.3	—
The child with IDDM	58.3	41.4	—
Attained recommended levels of diabetes care*	59.1	52.9	—
Family structure			
Single-parent	29.2	16.2	—
Two-parent	70.8	83.8	—
Income level			
\$0–20,000	37.5	14.5	—
\$20,000–40,000	50.0	39.3	—
\$40,000–60,000	8.3	30.8	0.01
\$60,000+	4.2	15.4	—
Chronic health condition present in family (other than diabetes)	54.2	26.5	0.05

Data are n, %, or P. \*Defined as at least four outpatient physician visits per year, one eye doctor visit per year in patients over 12 years old with diabetes for at least 5 years, and one self-blood glucose test per day.

**Table 6—Type of insurance coverage and the use of health services in families with a diabetic child**

	No insurance	Private plan	Public plan	P value
Problems getting medical care	35.0	3.5	0	<0.001
Hospital admission in the past year	20.0	23.1	46.7	—
Emergency room visit in the past year	40.0	41.8	73.3	0.06
Doctor visit in the past year	100	98.6	100	—
Testing blood glucose	85.0	97.2	100	0.028
Testing urine glucose	80.0	68.8	72.7	—
Recommended level of preventive care	66.6	52.3	54.5	—

Data are % or P. P values represent comparisons among all three categories.

of the case subjects. Both the IDDM-affected and control families are likely to have similar socioeconomic levels since the parents were raised in similar environments. The underlying factors influencing their decisions regarding health insurance and health care may also be similar. The families also are likely to live in the same geographical region. Health insurance coverage has been shown to differ by the part of the country in which one lives. First-degree relatives, though, may not be representative of the general population.

The out-of-pocket expenses reported by the IDDM-affected families, however, appear to be substantially higher than those reported for the general population in the literature. Estimates from earlier reports (35,36) indicate that 10–15% of the families in the U.S. with members under 65 years of age had spent \$1,000 or more on out-of-pocket health care expenses (premiums excluded). About 12% of the families in the U.S. reported out-of-pocket expenditures over 10% of family income, health insurance premiums included (35).

Many questions remain to be investigated. For one, do limited access to insurance, limited coverage, or high out-of-pocket costs have any long-term effect on the health of people with diabetes? Preliminary indications from this report suggest that the lack of insurance could be a barrier to the appropriate use of health services, particularly so for blood glucose monitoring. An earlier report (37) noted a similar finding among adults with diabetes, and a report from the follow-up of the Diabetes Control and Complications Trial (DCCT) cohort (38) suggested that glycemic control is poorer among those without insurance. Thus, there is some plausibility to the link between limited access to care and health outcomes.

One underlying indication, though, remains haunting. The insurance environment has become increasingly restrictive in recent years. Rapid increases in health care costs have led to higher premiums and copayments (2,5). All indications suggest that this trend will, in the absence of health care reform, continue to increase in the future. Thus, some uncertainty exists over the future affordability of health insurance and health care for individuals and families who use health services frequently.

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