

Employment Patterns among Parents of Children
with Insulin-Dependent Diabetes Mellitus

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Abstract

Employment Patterns among Parents of Children with Insulin-Dependent Diabetes Mellitus (IDDM)

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Keywords: employment, absenteeism, work stoppage

Objective: To examine the influence of diabetes on the employment patterns of parents of children living with diabetes.

Study Design: A case-control study of 197 families with an IDDM child and 142 control families without IDDM children was conducted. Case families were identified from a population-based diabetes registry. Brothers and sisters of the parents in the IDDM families were asked to participate as controls. Employment rates, absenteeism related to child care, and changes in work status were assessed by questionnaire. Surveys were obtained from 85% of the families (172 case: 118 control).

Results: No difference was found between the IDDM and control families in the overall rate of employment and changes in work patterns. IDDM families, though, were more likely to report absences from work related to child care (58% vs. 45%, $p < 0.05$). This impact was greatest for the working mothers. The greatest impact of IDDM on employment may be faced by single parents, who reported lower rates of employment and higher rates of absenteeism and changes in work patterns.

Conclusions: Families face decisions regarding employment and the appropriate level of care for children with diabetes. These data illustrate that most families with an IDDM child have employment experiences similar to those of families without diabetic children. Larger sample sizes of single parent families are necessary to confirm these findings.

Introduction

Insulin-dependent diabetes mellitus (IDDM) is a significant chronic disease developing in childhood. The impact of diabetes on persons and families living with the disease is wide ranging. In addition to the expected costs of raising a child, parents of children with diabetes must also cope with the economic and social costs of caring for a child with a chronic disease.

Employment issues in diabetes remain a leading social concern for persons with IDDM and their families. Job refusal and employment discrimination against individuals with diabetes have been noted in several reports (1-7). Increased absenteeism and/or disability among diabetic employees has also been reported (8-14). An earlier assessment of an IDDM cohort noted that diabetic individuals face a more difficult job application experience than the general population (15). Once employed, though, they have an employment experience similar to that of the general population, provided they have not developed a work-limiting disability. Disability in work activity, however, was markedly higher among individuals with diabetes.

These reports describe the employment experience for adults with diabetes, but the impact among children with IDDM and their families remains relatively undefined. Several factors related to diabetes suggest that parents of children with IDDM could have different employment patterns than parents of children without diabetes. For example, out-of-pocket, health care costs are higher for families with an IDDM child (16). The resources needed to manage IDDM on a daily basis,

particularly with intensive treatment, are extensive and costly. Management of diabetes requires regular and frequent blood glucose testing and insulin adjustments, as well as regular contact with health care professionals. The high cost of diabetes care may necessitate that a parent seeks employment to either pay for these costs or obtain insurance benefits. Conversely, the constant attention to diabetes treatment, nutrition, and exercise may require that a parent stay at home.

Second, children with diabetes use health care services more frequently and have higher rates of absenteeism than children without diabetes (17). Both characteristics may lead to greater burdens on families where parents must either leave work frequently to tend to the needs of their child, or spend time finding alternative arrangements.

Therefore, we sought to answer three questions in this study; a) Are parents of children with IDDM less likely to be currently employed?, b) Do working parents have to spend more time away from work in order to care for children with diabetes?, and c) Do the parents of children with IDDM experience more frequent changes in work patterns than do parents of children without diabetes?

Methods

The investigation was based on a case-control study of 339 families with and without IDDM children. Families with an IDDM child were identified from the Allegheny County IDDM Registry; a population-based listing of all newly diagnosed individuals with IDDM living in Allegheny County, PA at the time of diagnosis

from 1965 to 1985 (18). A comparison group of families with no diabetic children was identified from the family structure information of the IDDM families eligible for study.

The primary eligibility criteria for the IDDM 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 April 30, 1989. Patients were further excluded if they were participating in a clinical trial which 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). There were then 197 IDDM families eligible for study.

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

We initially identified all control families in a random manner. However, this selection process did not work well in practice because many case families had no eligible controls (n=49) 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 family requested it. As such, some degree of selection bias could have been introduced. Overall, 53.3% of the control families were selected in a randomized manner.

The use of first degree relatives as controls has strengths and weaknesses. The primary strength is that the controls were identified from a population that is similar to the population for the cases. Both the IDDM and control families are likely to have similar socio-economic levels since the parents were raised in similar environments. The underlying factors influencing their decisions regarding employment, health insurance and health care may also be similar. First degree relatives, though, may not be representative of the general population.

Initial contact was made with the IDDM families to describe the study and its requirements and to secure permission to contact the non-diabetic families. After enrollment, a questionnaire was mailed and the control families were contacted. A similar questionnaire was also sent to the control families who agreed to participate. Parents in each of the families were asked to complete and return the surveys. Topics covered in the questionnaire included the family's use of health care services, health insurance coverage for all family members, related health care costs, and parental work history. The specific questions related to employment dealt with the current employment status (yes/no) of each parent, the number of hours worked per week, absenteeism per year, and changes in employment patterns.

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

The demographic characteristics of the case and control families were very similar with respect to race, income, education, and family size. IDDM families, though, were slightly older than the control families (mean parental age in case families: 41.5 years \pm 5.8 (standard deviation), control families: 38.4 years \pm 5.9, $p < 0.01$) and case families were also more likely to be headed by a single parent than control families (22% vs. 9%, $p < 0.01$).

Data analysis in the study focused on the descriptive comparison of the responses from the 172 IDDM-affected families and the 118 control families from two perspectives. First, a family-based approach, where the employment experiences of the parent(s) in the families were aggregated and expressed collectively as the experience of the family. Second, an individual parent approach, where the experiences of each parent were considered as a distinct event.

Specific analyses were performed using the SPSS-PC statistical software package (19). Chi-square and t-test statistics were used to evaluate differences in employment and absenteeism patterns. Multiple logistic regression models were evaluated to consider the independent contributions of diabetes status to the respective employment issues. Where applicable, the data were adjusted by the direct method to consider the effect of the number of parents in the family on the results.

Results

1. Are parents of children with IDDM less likely to be employed?

Overall, in this study population, families with an IDDM child tended to have fewer parents working than control families ($p=0.03$) (Table 1). The large number of single parents in the case families, though, had some influence on this finding. Thus, single parent families and two parent families were analyzed individually.

Table 1

Number of Parents Working among Families with and without IDDM Children

	Number of Parents Working		
	0	1	2
IDDM Families	7.6%	37.6%	54.7%
Control Families	0.8%	40.7%	58.5%

Among the single parent families, the difference observed between the number of working parents (case: 73% working vs. control: 90%) was not statistically significant. The sample size of single parent families available for evaluation, though, was small. Among the two parent families, there also were no large differences in the number who worked. Seventy percent of the case families had two parents working compared to 64% of the control families. Similarly, 28% of the case and 36% of the control families reported one working parent.

Table 2 depicts the reported employment status of the families. For the families with one or more parents working, there was no difference in the number of hours

worked per week by case-control status. The distributions of full-time and part-time workers between the families were similar.

Gender was the largest factor related to "non-participation" in the labor force. After adjusting for the effects of age, single parent status, and diabetes status, females were 16 times more likely than males to be not working. These results would suggest that diabetes did not greatly influence the current employment patterns in the parents.

Table 2

Employment Status of Parents by Case-Control Status

	IDDM Families	Control Families
Labor Force Participation	84.5 %	83.2 %
Full-Time Work	64.4 %	66.8 %
Part-Time Work	18.5 %	15.9 %
Unemployed	2.0 %	1.3 %
Not in the Labor Force	15.5 %	16.8 %
Homemaker	17.8 %	16.8 %
Disabled	1.0 %	0.9 %

2.. Do working parents of IDDM children spend more time away from work?

Absenteeism from work for child care reasons was surveyed to evaluate the influence of diabetes on working parents. Mothers and fathers in both types of families were queried on the number of days in the last year in which they had to take time off from work in order to "take care of your children who may have been sick or needed to go to the doctor or hospital." In the family-based analysis, 58.1% of the eligible case families (those in which at least one parent was working) reported at least one day off associated with child care compared to 45.2% of the control families ($p < 0.05$). IDDM

families were two times more likely to report such an absence as the controls (odds ratio: 2.03, 95% CI: (1.13,3.65) when holding the effects of childrens age and number of parents working constant.

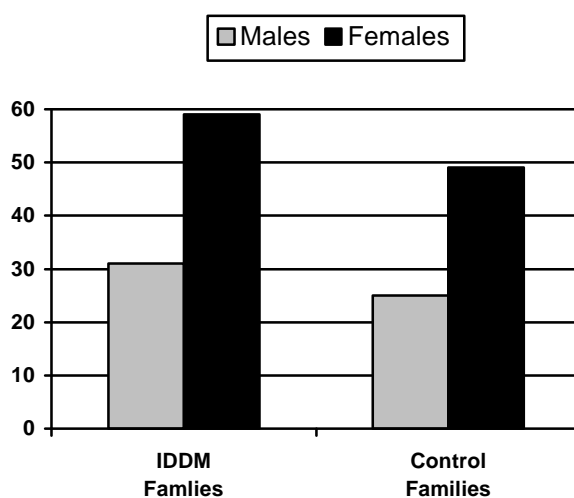
Absenteeism rates among the eligible families were not excessive. On average, the IDDM families reported about one more day off from work per year for child care than the control families (Table 3).

Table 3

Rate of Parental Absenteeism from Work for Childrens Care Among Families by Diabetes Status, Adjusted for Childrens Age and Number of Parents Working

	<u>Overall</u>		<u>Among Families with Absences</u>	
	IDDM Families	Control Families	IDDM Families	Control Families
Days Absent (per year)	2.46	1.63	4.16	3.88

The presentation above considered absenteeism from the perspective of the family. Analyses were also conducted from the standpoint of the individual parents. The most meaningful demographic traits related to absenteeism for all parents were gender, age, and single parent status. Mothers, young parents, and single parents were more likely to report as least one absence related to child care. Within the IDDM families, single parents were more likely to report such an absence than two parent families (73.1% vs. 55.0%). Figure 1 displays the percent of parents reporting absence by gender. As shown, mothers in both case and control families, were nearly two times more likely to report child care absences as their male counterparts.

Figure 1: Percent of Parents Absent from Work for Childrens Care by Gender

Childrens Absenteeism from School

One reason why parental absenteeism related to child care was higher for IDDM families may have been the higher rate of school absenteeism observed for IDDM children. Table 4 presents the age adjusted absenteeism rates for children with and without diabetes. Overall, IDDM children averaged 4-5 more absences from school than their siblings and the control children.

Table 4

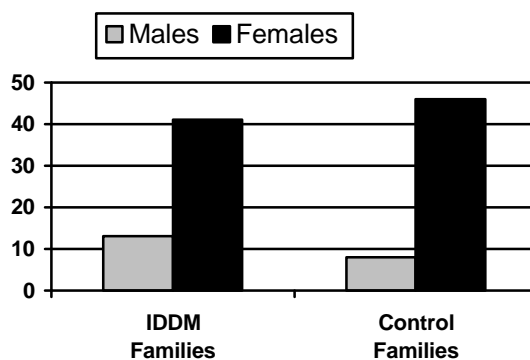
Absenteeism from School among Children by Diabetes Status-Adjusted for Age

	<u>IDDM Child</u>	<u>Sibling</u>	<u>Control Child</u>
Days absent per year	10.4	6.8	5.1

Do parents of IDDM children change their work patterns more frequently?

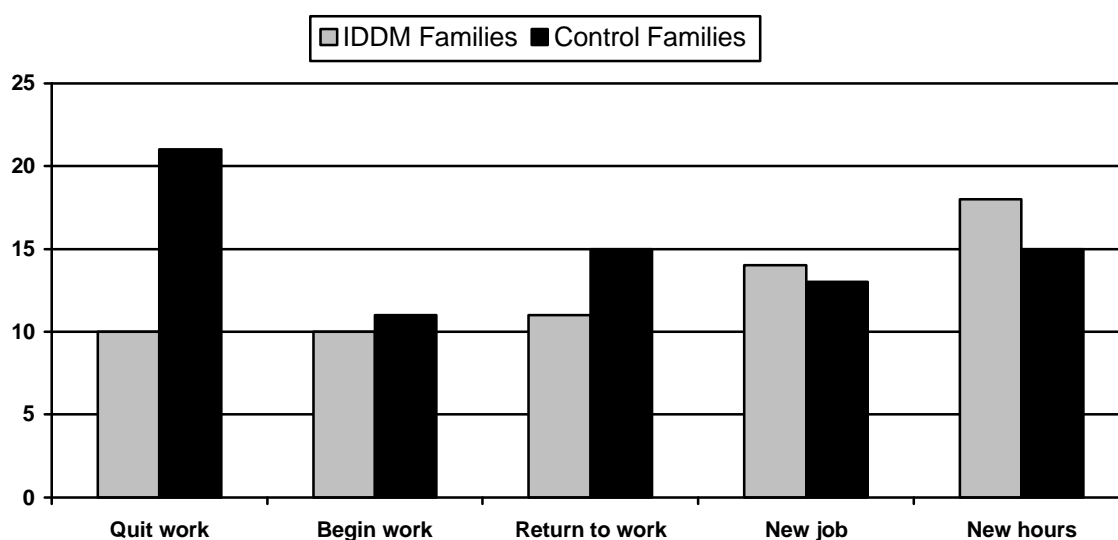
The last issue examined with respect to parental employment was reported changes in work patterns related to child care among the case and control families; including a) quitting work, b) beginning work, c) returning to work, d) changing jobs, and e) changing hours at the same job. In the family-based analysis, there was no difference between the IDDM and control families in the percentage reporting at least one work pattern change for the five areas listed (cases: 41.4% vs. controls: 45.6 %). Individually, the variable most often associated with changes in work patterns was gender. Figure 2 shows the percentage of parents reporting any work change by gender. Roughly, 45% of the mothers, both cases and controls, reported a change in work in one of the five areas compared to 10% of the fathers. In both the case and control families, those with lower incomes and single parents also tended to have a higher frequency of employment changes. Within the IDDM-affected families, 58.1% of the single parents reported a change in work patterns. Only 37.4% of the two parent families responded similarly.

Figure 2: Percent of Parents with a Change in Employment Related to Child Care by Diabetes Status and Gender



The frequency of reported changes among the families for each question surveyed are displayed in Figure 3. Overall, the number of families with reported changes in the specified areas was low (<20%). The frequency of reported changes was nearly identical between the IDDM and control families for the categories of starting work, returning to work, changing jobs, and changing work hours. More parents in the control families, though, reported quitting their jobs to take appropriate care of their children ($p=0.03$). This association, however, was not significant when evaluated multivariately to consider the competing influences of age, income, and number of parents in the family.

Figure 3: Percent of Families with a Change in Parental Employment Related to Child Care Reported by Either Parent by Type of Change



Discussion

Very little data are available on the role of child care in parental employment patterns in families affected by children with a chronic disease. A number of factors suggest that the parents of children with IDDM may have a different employment history than the general population. The high out-of-pocket costs associated with diabetes, the increased use of health care services, and the higher rate of school absenteeism for kids with diabetes, all, hint that the parents may have to make employment decisions more frequently than a control parent. The results of this study, though, suggest that the employment experiences of parents in families with an IDDM-affected child are not remarkably different from those in control families.

Overall, the IDDM families did report a higher absenteeism rate related to child care than the non-diabetic families. This increased rate was due to a higher probability of experiencing such an absence, rather than a higher number of absences. IDDM families were twice as likely to report at least one child care related absence than the control families. Absenteeism was particularly focused on the mothers in the IDDM families. Specific reasons for the absences reported by the case families were not surveyed. However, it is likely that the increased use of health care by the diabetic children and the increased school absenteeism rates may have had some role.

For the most part, though, the employment patterns of the parents were virtually identical. The number of parents currently employed was similar between

the case and control families, as well as the reported work changes, including quitting work, starting work, going back to work, changing jobs, or changing shifts. If changes did take place, it was more likely than not that the parent involved was the mother.

There was little evidence, then, to suggest that the high out-of-pocket, health care costs for IDDM families caused an appreciable number of parents to begin working or return to work. Nor was there support for a higher number of parents quitting work or changing shifts to be at home to provide care for their child with diabetes.

The burden of diabetes on employment may be most striking for the families with single parents. Our preliminary evidence suggests that fewer of these mothers may be working overall. Reported absenteeism among single parents who were working, and changes in work patterns, notably changes in the work hours undertaken, were both higher in these families. The sample size of single parent families available for evaluation, though, was small. The strength of these influences should be verified in future studies with larger numbers of single parent families.

Limitations in the study design may affect the interpretation of the results. Although the families surveyed are likely to represent a relatively stable experience of living with IDDM, the experiences associated with the diagnosis and adjustment to IDDM, and those of families with more than one child with diabetes, may not have been adequately captured. 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 differences seen between the families.

In summary, it appears that families with an IDDM-affected child have an employment experience that is similar to families with no diabetic children. Absenteeism related to child care, while higher in IDDM families, is not excessive. The largest burden of diabetes may lie on the single parents of an IDDM child.

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