

Adjustment to Diabetes Mellitus in Preschoolers and Their Mothers

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Although preschool-aged children with diabetes might be at increased risk for both general and disease-specific psychological adjustment difficulties, this issue has not been investigated. We evaluated both general and diabetes-related adjustment of 20 preschool-aged children and their mothers. The mothers completed the Child Behavior Checklist, Parenting Stress Index, Parents' Diabetes Opinion Survey, and the Preschool Diabetes Behavior Checklist. The latter measure was constructed specifically for this study to measure the frequency of oppositional and avoidance behaviors of children regarding diabetes management tasks. Mothers reported that their children displayed significantly more internalizing behavior problems (anxiety, depression, withdrawal) and were a significantly greater source of parental stress compared with corresponding nondiabetic normative group samples. Also, certain maternal attitudes about diabetes and its treatment were correlated with the children's disease-specific behavior problems. The children's general psychological adjustment, however, was not predictive of these diabetes-specific behavior problems. *Diabetes Care* 12:524-29, 1989

Investigators who have focused on the behavior of children and adolescents with diabetes have noted a lack of information about interactions between the demands imposed by the disease and the developmental status of the patient (1-6). Although parents report that behavioral concerns represent a major problem in terms of the family coping with diabetes, there is little

information available to guide professionals in helping families with these difficulties (7,8).

In contrast to extensive recent literature regarding the adjustment of school-aged children and adolescents to insulin-dependent diabetes mellitus (IDDM) (6), there are no published studies of the psychological adjustment of preschool-aged children and their mothers to the disease. Among the reasons for this lack of research attention may be that IDDM occurs infrequently in this age group and the assumption that behavior problems in diabetic preschoolers are normal, transitory, and without clinical significance.

Several aspects of diabetes care are likely to present particular difficulties to preschool-aged children and their parents (9,10). First, both insulin injections and blood glucose testing require the parent to inflict pain on the child on a recurring basis. There is evidence that some children in this age range may infer hostile intent by adults who undertake such procedures (11). Also, the child's limited cognitive ability to cope with this stress may precipitate reliance on other coping strategies, such as aggression, noncompliance, or withdrawal, or it may increase the frequency of stress-induced symptoms, such as psychosomatic complaints, appetite disturbances, or anxiety. Also, the necessity of strict adherence to schedules and routines for eating, insulin injections, and glucose testing is unlikely to mesh well with such characteristics as unpredictability, emotional lability, and transient food preferences, which may typify many preschool-aged children (12). Furthermore, IDDM may represent an obstacle to mastering important developmental tasks, such as the resolution of separation anxiety and development of self-confidence, because parental anxiety about the child's physical safety may inhibit encouragement of appropriate autonomy. Finally, diabetes care responsibilities are

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assumed almost exclusively by parents, leading to the prospect of parental guilt, frustration, and fear when the child or the disease do not behave as expected.

Thus, preschool-aged children and their parents may be at considerable risk for developing general adjustment difficulties and may adjust poorly to the behavioral demands of IDDM. The purpose of this study is to investigate the general and disease-specific adjustments of 24- to 72-mo-old diabetic children and their mothers. We hypothesized that diabetic preschoolers and their mothers would show evidence of adverse behavioral and emotional adjustment to the disease and that general and diabetes-specific adjustment would be positively correlated. Mothers completed various standardized surveys and a checklist constructed for this study that measured the frequency and severity of various oppositional and avoidance behaviors among children concerning the treatment of diabetes.

RESEARCH DESIGN AND METHODS

Twenty-three children with IDDM of at least 3 mo duration, between 24 and 72 mo of age, were identified by review of hospital records or by their parents' response to advertisements published in newsletters of the Ohio Affiliate of the American Diabetes Association, the Central Ohio Diabetes Association, and a local support group affiliated with the Juvenile Diabetes Foundation. Area pediatricians were also informed of the study and encouraged to refer patients. After receiving a telephone call describing the investigation, all of the mothers expressed a willingness to participate.

After initial contact by one of the members of our study group, a packet containing one copy of each of the measures described below, along with a consent form and instructions for the completion of each questionnaire, was mailed to each mother. The participants were asked to return the completed forms in an enclosed self-addressed envelope and were informed that the project director would mail them each a check for \$10 on receipt of the completed questionnaires.

Every effort was made to enlist the participation of all eligible mothers. Despite these follow-up efforts, three mothers failed to complete the study. Thus, 20 of the 23 mothers (87%) of diabetic preschoolers completed the study requirements.

The study population was composed of 9 boys and 11 girls with a mean \pm SD age of 49.7 ± 13.9 mo and a mean duration of diabetes of 20.9 ± 14.5 mo. Age at diagnosis ranged from 4 to 64 mo (average 28.8 ± 14.2 mo). All children were living with their mothers at the time of the study. Socioeconomic status, as measured by Hollingshead's four factor index raw scores, ranged from 17 to 63 (mean 39.6 ± 10.9), indicating that the study sample represented a broad range of socioeconomic strata (A.B. Hollingshead, unpublished manuscript, 1975). The mean number of children per participating family was 2.3 ± 1.1 . Of the 20 partici-

pating mothers, 17 (85%) were married at the time of the study.

Each mother completed the questionnaires described below.

Four Factor Index. Socioeconomic status of the participating families was measured with the method of Hollingshead. This measure reflects the occupational category and educational level achieved by each parent. Possible scores range from 9 to 66, indicating very low to very high socioeconomic status, respectively.

Child Behavior Checklist (CBCL). Achenbach and Edelbrock (13) designed this questionnaire to assess the social competence and behavior problems of children. Separate standardized forms of the CBCL are available for 2- to 3-yr-old and 4- to 16-yr-old children. Both of these forms yield a standard score for total behavior problems (sum) and for internalizing and externalizing disorders. The internalizing behavior disorders include somatic complaints, social withdrawal, sleep problems, anxiety, and symptoms of depression. The externalizing behavior disorders include symptoms such as destructive, aggressive, and schizoid (acting out) characteristics. The current version of the CBCL for 4- to 16-yr-old children was standardized on a stratified sample of 1442 children residing in urban, suburban, and rural areas of the mid-Atlantic United States. A comparable standardization sample of 273 children served as the source of normative data for the corresponding CBCL form for 2- to 3-yr-old children. Mother-father reliabilities exceeded .98 for total behavior problem scores, whereas test-retest reliabilities were .95 and .84 at 1 and 12 wk, respectively. Construct validity was evident in a correlation of .91 between the total behavior problem score and scores from the Conners Parent Questionnaire (14).

Parenting Stress Index (PSI). The PSI was introduced by Abidin (15) to measure the relative magnitude of stress in a parent-child relationship and to identify the specific source(s) of the stress. Three major sources of stress are defined and measured: parent characteristics, child characteristics, and total stress. The parent rates their degree of agreement or disagreement with each of 120 statements about the parent-child relationship on a 5-point Likert scale. Form 6 of the PSI was used in this study. The standardization sample consisted of 534 mothers of children in the targeted age range residing in the eastern United States.

Test-retest reliability, assessed in four separate studies, ranged from .55 to .82 for the child domain, .69 to .91 for the parent domain, and .65 to .96 for total stress. Correlational and factor-analytic data indicated adequate internal consistency and content and factor validity have been demonstrated (15).

Parents' Diabetes Opinion Survey (PDOS). Introduced by S.B. Johnson (unpublished manuscript), the PDOS is an 86-item Likert-type questionnaire on which parents register their degree of agreement or disagreement with various attitudes about diabetes and its treatment. The survey yields scores for eight attitude factors, including stigma (the extent to which the parent per-

ceives the child and family as treated differently because of diabetes), manipulateness (the extent to which the child uses diabetes for personal gain), attitudes toward medical staff (the extent to which the parent negatively rates health-care professionals who treat the child), divine intervention (the extent to which the causes and outcomes of diabetes are viewed as controlled by supernatural forces), rule orientation (the rigidity with which the parent adheres to rules about diabetes and its treatment), family interruption (the extent to which the disease is seen as a source of family conflict or inconvenience), sweet consumption (the parent's concern about the child's intake of concentrated sweets), and observation/detection of insulin reactions (the extent to which the parent is sensitive to fluctuations in the child's blood glucose concentration as a critical determinant of the child's behavior or well-being). Lower scores on the PDOS scales indicate stronger endorsement of the measured attitudes and, presumably, less favorable parental adjustment to diabetes.

The fourth revision of the PDOS, which was used in this study, was standardized on a sample of 241 mothers of 6- to 19-yr-old children with diabetes. Its factor structure has survived three replications with different standardization samples. Interobserver reliability ranged from .70 to .84 for the various factor scores, whereas internal consistency, as measured by Cronbach's coefficient α , exceeded .79 for each factor.

Preschool Diabetes Behavior Checklist (PDBC). Because we constructed this scale specifically for this project, normative data collection is not yet complete. It is a 79-item questionnaire on which parents rate the frequencies of certain behavior problems that are either unique to IDDM or tend to be common in children in this age range. Items were derived from behavior-rating scales and direct observation procedures with established reliability and validity. Many of the diet items were derived from a protocol for observation and scoring of mealtime behavior described by Riordan et al. (16). Several items that measured avoidance behavior during blood glucose tests and insulin injections were adapted from behavioral observation codes used in previous studies of children's responses to painful or distressing medical procedures, such as dressing changes in a burn unit and bone marrow aspirations (17,18). Furthermore, items were reviewed for comprehensiveness of content and for clinical significance by an experienced pediatric endocrinologist and a diabetes nurse educator and were revised according to their suggestions. Responses are made on a 5-point Likert scale: 1, not at all a problem; 2, an infrequent or insignificant problem; 3, an occasional or minor problem; 4, a frequent or significant problem; and 5, a constant or major problem. The PDBC measures the child's behavior in the areas of general adjustment, glucose testing, diet, and insulin injections.

Internal consistency of the PDBC was assessed by calculating Cronbach's coefficient α and a homogeneity ratio for the entire scale, based on data collected in our

study (19,20). Cronbach's coefficient α of .96 indicates excellent scale reliability, but it may be inflated due to the many items relative to the number of study participants. The homogeneity ratio of .28 reflects moderately positive mean interitem correlations for the scale.

Data analysis. Data analysis included calculation of descriptive statistics for each measure, inferential statistical analyses of differences between the study sample and appropriate normative groups (Student's *t* tests), and correlational analyses of associations among the various measures that were collected during the study (Pearson *r*). Only total scores for the CBCL, PSI, and PDBC were included in the correlation analyses in an effort to reduce the number of comparisons made. Because the PDOS does not yield an interpretable total score, the individual factor scores for that instrument were used in the correlational analyses. Also, because many statistical comparisons were made relative to the number of mothers enrolled, we recommend cautious interpretation of any correlations that were significant between the .01 and .05 levels of confidence.

RESULTS

Statistical comparisons of results obtained for the study sample with corresponding scores from standardization samples on the CBCL, PSI, and PDOS appear in Table 1.

TABLE 1
Scores on Child Behavior Checklist, Parenting Stress Index, and Parents' Diabetes Opinion Survey compared with corresponding normative data

Measure	Study sample	Normative sample	P
Child Behavior Checklist			
Sum	50.55 \pm 10.68	50.0 \pm 10.0	NS
Externalizing	52.50 \pm 12.89	50.0 \pm 10.0	NS
Internalizing	55.35 \pm 8.27	50.0 \pm 10.0	<.01
Parenting Stress Index			
Total	249.1 \pm 56.19	221.1 \pm 38.9	<.05
Parent	135.8 \pm 36.16	122.7 \pm 24.6	NS
Child	113.4 \pm 23.22	98.4 \pm 19.2	<.01
Parents' Diabetes Opinion Survey			
Manipulativeness	32.9 \pm 5.82	29 \pm 9	<.01
Stigma	20.7 \pm 5.04	25 \pm 5	<.01
Rule orientation	27.4 \pm 5.81	30 \pm 7	NS
Divine intervention	17.9 \pm 5.09	17 \pm 6	NS
Observation/detection of insulin reactions	13.3 \pm 3.53	15 \pm 4	<.05
Family interruption	28.7 \pm 7.13	36 \pm 8	<.001
Sweet consumption	10.7 \pm 3.84	11 \pm 3	NS
Attitudes toward medical staff	17.5 \pm 4.09	17 \pm 6	NS

Values are means \pm SD.

Demographic factors. Demographic factors that were analyzed included the child's age, duration of diabetes, age at diagnosis, sex, socioeconomic status, and family size. Pearson product moment correlation coefficients were calculated for association between each of the measures and results from each of the surveys.

Neither the child's age, sex, nor age at diagnosis correlated significantly with scores on any of the survey tools. Duration of diabetes correlated significantly with scores on three of the PDOS scales: stigma ($r = .476$, $P < .034$), family interruption ($r = .48$, $P < .032$), and sweet consumption ($r = .479$, $P < .033$). Thus, mothers of children with shorter duration of diabetes perceived more differential treatment by others because of diabetes, reported more disruption of family life as a result of the disease, and expressed more concern about their children's concentrated sweet intake.

Family size also correlated significantly with two of the PDOS scale scores: rule orientation ($r = .464$, $P < .039$) and family interruption ($r = .465$, $P < .039$). Mothers with many children reported more flexible rules concerning diabetes management and less disruption of family life by the disease.

Socioeconomic status correlated significantly with the CBCL total ($r = -.53$, $P < .017$) and PSI total scores ($r = -.55$, $P < .013$). Thus, mothers with a lower socioeconomic status reported both more behavior problems in their diabetic children and higher levels of psychosocial stress. Socioeconomic status also correlated significantly with three PDOS factor scores: manipulateness ($r = .49$, $P < .027$), attitudes toward medical staff ($r = -.66$, $P < .002$), and family interruption ($r = .58$, $P < .008$). Mothers with a lower socioeconomic status described their diabetic children as more prone to use the illness for personal gain and more disruptive of family life. However, they also reported more positive and satisfying relationships with the health-care professionals who treated their children.

CBCL. Standard scores (mean \pm 1SD) obtained on each of the CBCL global behavior disorder scales were internalizing disorders, 55.35 ± 8.27 ; externalizing disorders, 52.5 ± 12.88 ; and sum, 50.55 ± 10.68 . Compared with the standardization sample mean of 50.0 ± 10.0 , the scores for internalizing disorders achieved statistical significance ($t[19] = 2.89$, $P < .01$). Standard scores for sum and externalizing disorders did not differ significantly from the normative group's scores.

In addition to the relationship between socioeconomic status and CBCL scores, many other significant correlations emerged. The CBCL sum correlated with the PSI total ($r = .54$, $P < .014$) and with scores on the PDOS manipulateness scale ($r = -.57$, $P < .009$). Thus, mothers who reported higher levels of parenting stress also reported higher rates of behavior problems in their children. Furthermore, diabetic children who displayed more behavior problems were rated as more manipulative. The CBCL sum score, however, was unrelated to mothers' ratings of their children's diabetes-

specific behavior problems, as measured by the PDBC. **PSI.** Scores on PSI domains (mean \pm 1SD) were parent, 135.8 ± 36.16 ; child, 113.4 ± 23.22 ; and total stress, 249.1 ± 56.19 . Compared with the standardization sample, a statistically significant difference was found for the child domain ($t[19] = 2.88$, $P < .01$) and the total stress domain ($t[19] = 2.23$, $P < .05$). The parent domain score was not statistically significant.

In addition to the correlational findings described previously, levels of maternal stress were significantly correlated with the PDBC ($r = .496$, $P < .02$) and various scales of the PDOS. For example, maternal stress was significantly correlated with four PDOS scales: manipulateness ($r = -.86$, $P < .0001$), stigma ($r = -.56$, $P < .01$), attitudes toward medical staff ($r = .52$, $P < .019$), and family interruption ($r = -.62$, $P < .004$). Mothers who reported higher current levels of stress rated their diabetic children as both more manipulative and more disruptive of the family. Higher maternal stress was also associated with more positive relationships with health-care professionals, but with a greater perception of differential social treatment because of the diabetes.

Maternal stress was significantly positively correlated with the PDBC total ($r = .50$, $P < .026$). Thus, higher maternal stress was associated with a higher incidence of behavior problems specific to diabetes.

PDOS. Scores (mean \pm 1SD) for each scale of the PDOS are shown in Table 1, including data for the comparison group of mothers of older children with IDDM. As indicated in Table 1, scores for the following scales were significantly below those of the standardization sample, indicating less favorable adjustment to diabetes among the participants in this study: stigma ($t = -3.86$, $P < .01$), observation/detection of insulin reactions ($t = -2.16$, $P < .05$), and family interruption ($t = -4.61$, $P < .001$). The participating mothers rated their children as less manipulative regarding diabetes compared with the normative group, because their scores for the PDOS manipulateness scale were significantly higher ($t = 2.96$, $P < .01$). The remaining factor scores, which included divine intervention, attitudes toward medical staff, sweet consumption, and rule orientation, did not differ significantly from those of the normative sample.

Several relationships emerged among scores for certain PDOS factors and PDBC total score. The PDBC total score was negatively correlated with both the PDOS family interruption ($r = -.57$, $P < .008$) and stigma scores ($r = -.48$, $P < .033$). Thus, diabetes-specific behavior problems were more common in children whose mothers perceived more differential treatment because of diabetes and more diabetes-related family disruption.

PDBC. Maximum possible scores for the PDBC scales were total, 395; general, 55; diet, 125; glucose testing, 115; and insulin injection, 100. Raw scores (mean \pm 1SD) obtained for the PDBC as a whole and for each subscale were total, 145.60 ± 47.43 ; general, 25.00 ± 7.21 ; diet, 41.65 ± 12.53 ; glucose testing, $42.00 \pm$

12.83; and insulin injection, 36.95 ± 16.32 . The mean score for individual PDBC items was 1.84 and the highest mean score for any item was 3.30. Thus, none of the listed behaviors was rated as more than an occasional or minor problem by the mothers as a group. However, each of the mothers rated at least one item from among the PDBC items as a 4 (frequent or significant problem) or a 5 (constant or major problem). The 10 items that received the highest mean scores among the mothers are listed in Table 2. Of the 5 PDBC items that received the highest mean scores, 4 items measured parental anxiety or uncertainty related to the impact of diabetes on various parenting responsibilities.

DISCUSSION

Overall, the results provided evidence of adjustment difficulties among preschool-aged children with IDDM and their mothers compared with normative sample groups. The significantly elevated mean for the present sample on the CBCL internalizing disorders scale suggests that mothers see their diabetic preschool-aged children as having more sleep problems, social withdrawal, somatic complaints, and depressionlike symptoms. However, interpretation of this finding should be viewed with caution. Despite a statistically significant difference between the normative mean and present sample mean, the sample mean was still within the normal range. Thus, mothers perceived more internalizing symptoms but did not rate their children in the clinically deviant range. It was somewhat surprising that elevations on the externalizing disorders scale were not observed. It was expected that

adherence to a set diet and the need for painful medical procedures, such as insulin injections and fingersticks to obtain blood, would lead to more acting out behaviors (e.g., tantrums, noncompliance, property destruction).

The mothers' PSI responses indicated a perception of more overall stress in families with preschool-aged diabetic children, with the child seen as the source of that stress. Correlational analyses showed that mothers who reported more stress rated their children as being both more manipulative and disruptive of the family unit, as measured by subscales of the PDOS. Whereas mothers who reported more stress reported more satisfying relationships with medical staff, they were also more likely to report that their children were treated differently because of diabetes.

Results of the PDOS also revealed that mothers of preschool-aged diabetic children perceived them as being more stigmatized by the disease compared with findings from a large sample of older children and adolescents with IDDM. Mothers reported more concerns about identifying insulin reactions in their children and rated the amount of family disruption to be generally higher than that found for the older sample. Interestingly, the preschool-aged children were rated as less manipulative in terms of using symptoms of IDDM to control others.

Despite the finding of adjustment difficulties in certain areas on the above measures, scores on the PDBC and CBCL were not related. This suggests that general adjustment problems are not predictive of diabetes-specific behavior problems. Demographic variables also were not predictive of diabetes-specific behavior problems. However, these problems were associated with certain maternal attitudes toward diabetes, as measured by the PDOS. Mothers who reported more differential treatment of their children because of diabetes and more family disruption also reported more diabetes-specific behavior problems.

The overall implications of these findings are that disease-specific behavior problems in the preschool-aged child with IDDM are associated with maternal stress but are not predicted based on the child's general adjustment or other demographic or disease variables. Behavioral adjustment in this sample differed from the healthy preschool-aged population only with respect to internalizing symptoms but not to an extent that can be classified as pathological. Another factor related to maternal perceptions of stress was the duration of the child's disease. Mothers of children with shorter duration of disease reported more differential treatment by others because of diabetes, more disruption in family life, and more concern about their children's concentrated sweet intake. That these concerns dissipate with increased disease duration suggests that these mothers develop effective methods for managing or coping with these problems.

The results of this study must be considered tentative for several reasons. First, the use of normed assessment

TABLE 2
Ten items from Preschool Diabetes Behavior Checklist with highest mean scores

Item	Mean score
I can't find a babysitter I can trust with my child	3.30
I am uncertain about the ability of day-care centers to care for my child	3.00
My child leaves the table during meals	2.95
I'm often uncertain about whether to punish my child because his/her behavior may be caused by high or low blood glucose levels	2.75
When my child's glucose test comes out high, I get upset	2.60
If told it's time to do an injection, my child won't come to me	2.60
Keeping a strict schedule and routine for my child has been very hard	2.55
My child shows a lot of fear and anxiety in new places and new situations	2.50
My child dawdles a long time before coming to the table for meals	2.50
My child is never satisfied with what is being offered at mealtime	2.50

surveys asks the question of comparability of the present sample with the samples used to establish the norms. Although a larger sample size would be desirable, only three of the identified eligible subjects did not participate in the study.

Second, correlational analyses cannot confirm the direction of cause-and-effect relationships. Whereas several associations among parental attitudes, parental stress, and child behavior were revealed, it is impossible to determine if any of these variables were causally related to the others.

Finally, evidence pertaining to the reliability and validity of the PDBC is quite limited. Because each of the participants rated at least one item as a frequent or constant problem (although the overall item averages were in the infrequent or occasional range) perhaps various problems exist related to IDDM in preschoolers that are not consistent across families.

Results of this study raise several questions that would best be addressed in longitudinal investigations. If adjustment difficulties begin in the preschool years, are these problems predictive of poor adjustment in later childhood and adolescence? More specifically, do early avoidance behaviors predict later noncompliance? And, is maternal and family stress predictive of long-term coping with the disease? A host of other variables not examined in this study could also be important in determining patient and family adjustment to IDDM in this population. These may include race and ethnicity, aspects of the diabetes management regimen, adequacy of diabetic control, and major life events affecting the family, such as death or divorce.

The apparent association between early diagnosis of diabetes and subsequent development of learning disabilities suggests that these children may already be at increased risk for academic and vocational difficulties later in life (21–23). The adjustment difficulties revealed in this study underscore the importance of early detection of and intervention for these problems so that these patients do not face a compounded risk of adverse psychological adjustment.

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