Comparative Study of Diabetes Knowledge Among Juvenile Diabetics and Their Parents

Boy N. Collier, Jr., Ph.D., and Donnell D. Etzwiler, M.D., DeKalb and Minneapolis

SUMMARY

One hundred and twenty-nine children with diabetes from fifty-eight junior and senior high schools in the Minneapolis-St. Paul area and their parents were given a thirty-four-item test to evaluate their knowledge of diabetes and to determine if there were significant differences in understanding. Areas of deficiency were noted particularly involving understanding of diet, acidosis and alterations in management that occur with changes in activity or illness.

Descriptive material is presented indicating that there is high correlation of knowledge levels between diabetic children and their parents. DIABETES *20*:51-57, January, 1971.

The importance of understanding the basic nature of diabetes and its management procedures has consistently been stressed by medical authorities. All references on management and control of diabetes have reinforced the need for the adolescent with diabetes to have a working knowledge of his disease, its problems, and proper methods of control. One of the authors (D.D.E.) conducted a survey among seventy-four children with diabetes, ages six to seventeen years, who were attending a summer camp in Minnesota.[1] A fifteen-item multiple choice test covering basic concepts of diabetes was given to the campers. It was found that knowledge of diabetes appeared to increase with the age of the child, and there was a significant difference in knowledge possessed by six through eleven-year-olds and that of children over twelve years of age. This latter finding was interpreted to imply that there might be a critical age before which certain levels of understanding and comprehension are more limited. The level of the child's ability to read with understanding about his condition and its management appeared to be one of the keys to appropriate applied knowledge.

From the Diabetes Detection and Education Center, Minneapolis, Minnesota, and Northern Illinois University, DeKalb, Illinois.

Etzwiler and Sines further compared parental and child responses to the same fifteen-item test of diabetes knowledge.[2] On twelve of the fifteen items analyzed, a larger percentage of parents than of children responded correctly; on two items a larger percentage of the children answered correctly; and one item was discarded because of its ambiguity. The scope of the questions was purposely of a basic nature, and only a few critical items of management knowledge were measured. No conclusions could be made about the comparative knowledge of diabetes possessed by the child and his parents. No other studies could be located in which an attempt was made to evaluate the nature of the knowledge possessed by the adolescent diabetic.

Neither of the previously mentioned papers nor other investigational studies reviewed was conducted outside the atmosphere of a medical clinic, hospital or summer camp for children with diabetes. Each of these three environments serves a special clientele, and those utilizing the facilities of each might not be representative of the broad range of diabetic children.

During the fall of 1966, a broad study was made of children with diabetes enrolled in public secondary schools in the Minneapolis-St. Paul, Minnesota, area. This study was conducted with the cooperation of the Educational Research and Development Council of the Twin Cities Metropolitan Area, Inc., and the Twin Cities Diabetes Association, Inc. One objective of this study was to determine if there are significant differences between the adolescent with diabetes and his parents with respect to their level of knowledge of diabetes and diabetes management practices.

PROCEDURES

The study proposal was submitted to and approved by the Commission on the Exceptional Child and the Board of Directors of the Educational Research and Development Council. The research proposal was then forwarded to the superintendent of each Council-member school district requesting his cooperation and research participation. As soon as the participating districts in the Minneapolis-St. Paul area were identified, contacts were

initiated with administration representatives to identify the student personnel services staff member who would serve as school coordinator for the study. Personal contact was then arranged with the coordinators in the participating junior and senior high schools to clarify the study procedures and to obtain the name and grade level of each known diabetic student as well as the name of his second period teacher. The second period teacher served as the intermediary between the school coordinator and the diabetic child and his parents. Parents were sent letters describing the research study and requesting their permission for their child to participate in all aspects of the study. Parents were also asked to complete a test, self-administered at home, assessing their knowledge of diabetes and diabetes management procedures. Tests on diabetes similar to those given the parents were then administered by the school counselor to the students involved. Instrumentation was then forwarded to the project coordinator for compilation and analysis.

The questions in the diabetes test used in this aspect of the study are shown in table 1. This multiple-choice test was developed from materials previously used by one of the authors (D.D.E.). Physicians who worked closely with the Twin Cities Diabetes Association and its summer camping program reviewed the test for content and provided suggestions for item development. Changes in question format and expansion of certain areas were made by one of the authors (B.C.) to strengthen the items and broaden their content. The resulting Diabetes Knowledge Test consisted of thirty-four items intended to assess specific knowledge of the basic fundamentals of diabetes and certain aspects of its management. The areas covered were general concepts of diabetes, insulin effects, levels of control, symptoms, urine testing procedures, and nutrition components.

TABLE 1

Diabetes test for diabetics and their parents

1. The usual cause of diabetes is
   a. Eating too much sugar and other sweet foods.
   b. *Failure of the pancreas to make enough insulin.*
   c. Failure of the kidneys to control sugar in the urine.
   d. I do not know.
2. Insulin causes the amount of blood sugar in the system to
   a. Increase.
   b. *Decrease.*
   c. Insulin has no effect on blood sugar.
   d. I do not know.
3. In uncontrolled diabetes the amount of sugar in the blood is
   a. *Increased.*
   b. Decreased.
   c. Not affected.
   d. I do not know.
4. Which of the following complications is usually *NOT* associated with diabetes?
   a. Changes in vision.
   b. Changes in the kidney.
   c. *Changes in the lungs.*
   d. I do not know.
5. Which of the following symptoms is usually *NOT* associated with an insulin reaction?
   a. Weakness.
   b. Hunger.
   c. *Chest pain.*
   d. I do not know.
6. When a diabetic feels he is beginning to have an insulin reaction he should
   a. Immediately take some insulin.
   b. Immediately lie down and rest.
   c. *Immediately eat some sugar.*
   d. I do not know.
7. An insulin reaction or insulin shock is caused by having
   a. *Too much insulin in the system.*
   b. Too little insulin in the system.
   c. Too little exercise.
   d. I do not know.
8. Routine urine tests for sugar should be made
   a. *Just before meals.*
   b. One hour after meals.
   c. Each time a diabetic urinates.
   d. I do not know.
9. If a diabetic increases his daily physical activity after several months of relative inactivity, his daily insulin dosage will probably need to
   a. Be increased.
   b. *Be decreased.*
   c. Remain unchanged.
   d. I do not know.
10. 1/2 cc. of a U-80 insulin contains
    a. 20 units of insulin.
    b. *40 units of insulin.*
    c. 80 units of insulin.
    d. I do not know.
11. 1/2 cc. of a U-40 insulin contains
    a. *20 units of insulin.*
    b. 40 units of insulin.
    c. 80 units of insulin.
    d. I do not know.
12. The maximum effect of REGULAR insulin after being injected usually occurs
    a. *Rapidly, within 1 to 3 hours.*
    b. Moderately, within 8 to 12 hours.
    c. Slowly, within 15 to 20 hours.
    d. I do not know.
13. The maximum effect of Lente, PZI, and NPH insulins after being injected usually occurs
    a. Rapidly, within 1 to 3 hours.
    b. *Moderately, within 8 to 12 hours.*
    c. Slowly, within 15 to 20 hours.
    d. I do not know.
14. Diabetics should take especially good care of their feet because
    a. A number of years of injecting insulin into the legs may cause swelling of the feet.
    b. Flat feet are commonly associated with diabetes.
    c. *As diabetics become older they may have poor circulation of the blood in their feet.*

TABLE 1 *(cont'd.)*

d. I do not know.

15. When a diabetic who routinely uses insulin becomes ill and is unable to eat his prescribed diet
    a. He should immediately stop taking his insulin.
    b. *He should continue to take his insulin.*
    c. He should use the oral hypoglycemic pill instead of the insulin.
    d. I do not know.
16. When a diabetic who routinely uses insulin becomes ill, he frequently requires
    a. No insulin.
    b. Less insulin.
    c. *More insulin.*
    d. I do not know.
17. The presence of acetone in the urine of a diabetic indicates
    a. A need for less insulin.
    b. *A need for more insulin.*
    c. A normal insulin need.
    d. I do not know.
18. Which ONE of the following symptoms is usually *NOT* associated with acidosis?
    a. *Chest pain.*
    b. Rapid breathing.
    c. Nausea.
    d. I do not know.
19. Which ONE of the following factors is usually *NOT* associated with acidosis?
    a. Illness.
    b. Too little insulin.
    c. *Too much insulin.*
    d. I do not know.
20. Acetest* tablets or Ketostix* give the following color when acetone is present in the urine:
    a. Green.
    b. Blue.
    c. *Purple.*
    d. I do not know.
21. A diabetic who uses insulin and finds that his urine checks are constantly testing BLUE-GREEN with Tes-Tape† should
    a. Stop taking his insulin.
    b. Decrease his insulin dosage.
    c. *Increase his insulin dosage.*
    d. I do not know.
22. A diabetic who uses insulin and finds that his urine checks are constantly testing RED-ORANGE with Clinitest tablets should
    a. Stop taking his insulin.
    b. *Increase his insulin dosage.*
    c. Decrease his insulin dosage.
    d. I do not know.
23. When the urine is tested with Tes-Tape, a BLUE-GREEN color indicates
    a. *There is a large amount of sugar in the urine.*
    b. There is little or no sugar in the urine.
    c. Tes-Tape is not used to measure sugar in the urine.
    d. I do not know.
24. When urine is tested with Clinitest tablets, a BLUE color indicates
    a. There is a large amount of sugar in the urine.
    b. *There is little or no sugar in the urine.*
    c. Clinitest tablets are not used to measure sugar in the urine.
    d. I do not know.
25. A diabetic diet is normally
    a. A guide for planning only the carbohydrate or sugar content of a meal.
    b. *A well balanced diet that the whole family can use.*
    c. A carefully planned system of special foods and measured insulin.
    d. I do not know.
26. A diabetic diet prescription is NOT calculated for
    a. Carbohydrate.
    b. Protein.
    c. *Vitamins.*
    d. I do not know.
27. A diabetic should normally
    a. Have his food cooked separate from that of the family.
    b. Limit the variety of foods that he eats.
    c. *Vary his diet from the foods listed in a food exchange list.*
    d. I do not know.
28. The number of calories in most diabetic diets range
    a. From 200 to 800 calories.
    b. *From 1000 to 3500 calories.*
    c. From 4000 to 6000 calories.
    d. I do not know.
29. One whole milk exchange contains
    a. 100 calories.
    b. 140 calories.
    c. *170 calories.*
    d. I do not know.
30. Which *ONE* of the following statements is correct?
    a. One cup of milk can be exchanged for four ounces of cheese.
    b. One ounce of beef can be exchanged for one ounce of bacon.
    c. *One egg can be exchanged for one ounce of fish.*
    d. I do not know.
31. The bread exchange list contains many similar foods. One slice of bread may be exchanged for
    a. 3/4 cup of cornflakes.
    b. 4 graham crackers.
    c. *One small potato.*
    d. I do not know.
32. Some vegetables contain very little carbohydrate or sugar and may be eaten freely or as much as a cup at a time without significantly altering the diet. These vegetables belong to
    a. *Vegetable exchange list A (Asparagus, Celery, Lettuce, Spinach).*
    b. Vegetable exchange list B (Beets, Young Peas, Carrots).
    c. Vegetable exchange list C (Fresh Corn, Potatoes).
    d. I do not know.
33. Fruits contain mainly carbohydrates. One orange may be exchanged for
    a. 1 banana, medium size.
    b. 1 cup orange juice.
    c. *1 small apple.*
    d. I do not know.
34. One egg can be exchanged for
    a. 3 ounces of meat (90 gm.).
    b. *1 slice of cheese (30 gm.).*
    c. 4 tablespoons of peanut butter (60 gm.).
    d. I do not know.

*Ames
†Eli Lilly and Co.

RESULTS

Agreements to participate in the research study were received from twelve school districts with seventy junior and senior high schools. Twelve schools reported no known diabetic children enrolled. Three of these twelve schools openly stated that their health records were inadequate to identify students with health problems such as diabetes. Two additional schools implied that their records were not complete. The remaining fifty-eight participating junior and senior high schools provided the names of one hundred and sixty-nine children identified as having diabetes mellitus. Twelve of these children were either denied parental permission to participate in the study or research materials were not returned to the school. Two additional diabetic subjects withdrew from school, and five more were eliminated from participation because of limited cooperation by their teachers. In seven more cases the materials were not returned to the project coordinator in time to be included in the study. The remaining one hundred and forty-three children with diabetes participated, at least in part, in the study. From these subjects, one hundred and twenty-nine children and one hundred and forty-one parent completed Diabetes Knowledge Tests were received for analysis.

The objective of the present analysis was to determine if there was a difference between the proportion of adolescents with diabetes and their parents who respond correctly to items on a test of diabetes knowledge. Items of the diabetes test were divided into four categories of information: general knowledge and control information; insulin specific items; urine assay; and dietary items. Two items (28 and 31) were not included in this breakdown because of errors in item response choice content. Table 2 shows that as a category, the items relating to general knowledge were answered correctly with high frequency by both the diabetic children and parents. With the exception of Item 8, all twelve general items were answered correctly with greater frequency by the parents than by the children. On six of these twelve items, the differences in response proportions between the two groups were statistically significant. On Items 2, 3, 4 and 14 nearly 90 per cent of the children answered the questions correctly. Thus, the practical significance of the difference in response proportion is questionable, although it would be hoped that on Items 2 and 3 all diabetic children would respond knowledgeably. On the latter two items on which statistically significant differences in proportions were observed (items 18 and 19), only 54.3 per cent and 47.3 per cent of the children responded correctly while the parental responses were in the middle 70 per cent range. These two questions were related to symptoms and factors associated with conditions of acidosis.

Only one item (17) provided a difference in proportion between children and parents responding correctly to the insulin specific and urine assay items. It may be noted, however, that correct response percentages of both children and parents in these two areas generally border at the 70 per cent level. Since these areas are critical to proper diabetes management of the diabetic, it was assumed that they constitute a subject field in which both children with diabetes and parents need further education.

The eight items covering dietary management identified differences which reached statistical differences with the greatest frequency. The proportional differences reached significance on seven of the eight items. Reviewing physicians indicated the dietary items analyzed were knowledge-related items; however, these were not identified unanimously as critical items, since there are a number of points of view as to what comprises critical dietary knowledge.

DISCUSSION

Diabetes mellitus is a chronic disease whose management requires close cooperation between the patient and his physician. Since this disease affects not only the individual but also the living pattern of the entire family, effective diabetes management can be carried out only by an understanding patient and his family working together with a knowledgeable and interested physician. This is particularly true among juvenile diabetics who in general are much more labile than adults and still dependent on their parents and family for supervision and support. A vital part of medical care for patients with this chronic illness must include education of that patient and his family members in the basic nature of the disease as well as supervision of administration of insulin, oral hypoglycemics, diet and exercise. Unfortunately, members of the medical profession frequently have not provided the quality of medical care necessary in the area of education. This has been shown in several regional studies,[1-5] and more recently in the findings published in a National Health Survey.[6] Diabetes very dramatically demonstrates a need for patient education and involvement; however, this is equally vital in the management of many other long term illnesses.

The objective of this study was to correlate patient knowledge and that of his parents concerning the basic fundamentals of diabetes. We would be greatly remiss, however, if we failed to point out areas where lack of

TABLE 2

Percentages of correct response and values of z on proportional comparisons of diabetes knowledge test items between 129 diabetic children (C) and 141 parents of diabetic children (P)

Test Item	CORRECT RESPONSES				z
	Children		Parents		
	NC	Per cent	NP	Per cent	
	General knowledge and control information items				
1	126	97.7	140	99.3	1.089
2	114	88.4	136	96.4	2.532*
3	116	89.9	139	98.6	3.102*
4	107	82.9	135	95.7	3.445*
5	116	89.9	130	92.2	.656
6	127	98.4	139	98.6	.090
7	112	86.8	131	92.9	1.665
8	120	93.0	130	92.2	— .253
9	106	82.2	120	85.1	.841
14	110	85.3	139	98.6	4.060*
18	70	54.3	109	77.3	4.000*
19	61	47.3	102	72.3	4.203*
	Insulin specific items				
10	96	74.4	112	79.4	.978
11	96	74.4	116	82.2	1.568
12	93	72.1	101	71.6	— .084
13	64	49.6	72	51.1	.238
15	80	62.0	99	70.2	1.420
16	64	49.6	83	58.8	1.650
	Urine assay items				
17	84	65.1	114	80.8	2.883*
20	94	72.9	111	78.7	1.162
21	74	57.4	78	55.3	— .338
22	107	82.9	128	90.8	1.910
23	77	59.7	82	58.1	— .256
24	119	92.2	132	93.6	.439
	Dietary items				
25	61	47.3	71	50.3	.506
26	76	58.9	103	73.0	2.454*
27	93	72.1	121	85.8	3.051*
29	33	25.6	75	53.2	4.624*
30	68	52.7	106	75.2	3.851*
32	107	82.9	133	94.3	2.971*
33	78	60.5	110	78.0	3.131*
34	50	38.8	86	61.0	3.694*

*Significant at the 0.05 level

knowledge may not only affect control but may also actually endanger life. Responses to the items included under general knowledge which are critical in control of the disease, indicated failure to recognize symptoms associated with the development of acidosis. Diabetic acidosis is still a life-threatening situation for the diabetic and one with which patients and their families should be cognizant.

The difference between U-80 and U-40 insulin is not understood by many patients, and broad concepts of the various insulin time actions are not well comprehended. Answers to questions pertaining to testing for acetone also showed less than optimal knowledge. Some of the errors made under the urine assay items may be excusable since certain commercial products were involved and may not have been used by the specific family. Understanding and comprehension of dietary items in general were poor, particularly among these teenagers who are primarily responsible for their food intake away from home.

In comparing the children's responses to those of their parents (table 2), fourteen of the thirty-two items analyzed showed differences in proportion of correct responses which reached statistical significance. In twenty-eight of the test items the proportion of parents scoring correctly was higher than the proportion of

TABLE 3

Mean diabetes knowledge test scores of 116 diabetic adolescents categorized by family income

	Yearly family income in dollars					
	Less than 4,000	4-6,000	6-8,000	8-10,000	Greater than 10,000	Totals
Sum of Scores	103	262	651	821	774	2,611
N	5	13	29	36	33	116
Mean Score	20.60	20.15	22.45	22.81	23.46	22.51

children, indicating a clear trend favoring the parents. It could only be concluded, however, that in general, similar proportions of children with diabetes and parents of diabetic children respond correctly to diabetes knowledge items. Although fourteen proportion differences reached statistical significance, this constitutes slightly less than one-half of the possible items and indicated that there is not a significant difference in knowledge pertaining to diabetes between this group and their parents.

An additional review of the diabetes knowledge tests for the one hundred and twenty-nine children revealed that one hundred and twenty-five could be paired with their own parents for knowledge comparison. With the exception of only a few cases, the pairs of matched parents and children were similarly knowledgeable of the broad range of diabetes knowledge items to which they were exposed. Proportions correct were also analyzed for matched child-parent subjects and no changes of importance over the population analysis were noted. The question of effect of parental income level on the child knowledge was also investigated (table 3). An analysis of variance was conducted to determine if significant differences between subject test scores by income category were produced. Table 4 shows the negative results of this analysis. Grade level of the child, the duration of his diabetes and the education level of the child's mother were also analyzed to determine if they played a significant role in the amount of knowledge possessed by the child. No relationship between these variables and the amount of knowledge could be shown. The results did tend, however, to support the contention that when the mother has a higher level of education, both she and the daughter with diabetes will assimilate greater diabetes knowledge than when the mother has less formal education.

It was further thought that the presence in the family of parents or siblings who were diabetic might be an influencing factor on the knowledge scores. Of the one hundred and forty-one sets of parents participating, ten mothers and eight fathers reported themselves as having diabetes. In two cases, both the mother and the father were diabetic. The mean parental knowledge scores for sixteen cases was 24.50, only 0.77 lower than the all-parental mean. The mean child score, however, for the fourteen available related child subjects was 19.36, being a deficit of 3.00 below the all-child mean of 22.36. Such results would appear to be in the direction opposite to that which might be predicted. It might be, however, that when a parent is diabetic, assumptions of knowledge are made because of the parent's condition, and less interaction regarding education of the child is undertaken. A comparative check where siblings were diabetic was not made because only five instances were identified in which a brother or sister of a subject was also diabetic. In three of these cases, both were subjects for the study.

An additional question was raised concerning comparative knowledges as they related to the sources from which the subjects indicated they received most of their diabetic knowledge. To obtain some estimate of the perceived source of information, both parents and chil-

TABLE 4

Analysis of variance of diabetes knowledge test scores of 116 adolescent diabetics categorized by family income

Source of Variation	Sum of Squares	Degrees of Freedom	Mean Square	F.	$F_{.95}$
Between Means	123.09	4	30.77	1.005	2.46
Within Groups	3,397.90	111	30.61		
Total	3,520.99	115			

TABLE 5

Parent and child responses to primary source of diabetes information

Source	Parent N-140	Child N-138
Nurse	1	12
Books & pamphlets	32	36
Diabetes Association meetings & materials	10	19
Family physician or pediatrician	87	52
Other	*6*	*19*
No response	4	0

dren were asked the following question: "From what source have you learned *most* of your knowledge about diabetes?" Response to the multiple choice alternatives provided are summarized in table 5.

This summary shows the family physician or pediatrician is the primary source of information regarding diabetes. Although this is as was expected, it was a disappointing indication that the physician might not be engaging sufficiently in the educational relationship with the child, but concentrating on the parents. Regardless of this possibility, the ultimate relationship of knowledge to control still has not been explored.

Control of the diabetic is a difficult, if not an impossible concept to define, and ultimately must be reduced to the individual patient and individual physician involved. Medically, the goal is primarily to keep the patient within reasonable physiological bounds in reference to the blood glucose levels he exhibits throughout a twenty-four-hour period.

Patients, however, have entirely different objectives of which we must be cognizant. Primarily they want to be able to lead an enjoyable life while they endure this chronic disease and hope there will be minimal impairment or infringement upon their daily activities. Practically, the obvious goals of controlling the diabetic are to avoid hypoglycemia or diabetic acidosis. With juveniles, however, we must project what this child's health status will be in fifteen, twenty, or twenty-five years after the onset of his disease. Dr. Robert Bradley of the Joslin Clinic[7] has recently reported that they had found the life expectancy of the average juvenile diabetic is less than thirty years after the onset of his disease. Although this expectancy cannot be generalized to the onset case of today, the life style of those so affected has contraindications. The latter portion of this life-time may well be plagued with the problems of blindness, renal failure, or other vascular difficulties. The role of control in the prevention of these complications is still not well defined; however, certain studies do suggest that the optimal control of the diabetic patient may minimize the incidence of these complications. The most effective control for any individual juvenile diabetic can only be achieved by a well educated and properly motivated patient and his family cooperating with a knowledgeable and interested physician.

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