

Adolescent Diabetes Management and Mismanagement

JILL WEISSBERG-BENCHELL, PHD
ALLEN M. GLASGOW, MD
W. DOUGLAS TYNAN, PHD

PHILIP WIRTZ, PHD
JANE TUREK, MSN, CDE
JOSEPH WARD, RN, CDE

OBJECTIVE — To document the existence and prevalence of adolescent-generated diabetes management techniques.

RESEARCH DESIGN AND METHODS — One hundred forty-four adolescents completed the confidential questionnaire developed for this study. Glycohemoglobin was also obtained for each individual.

RESULTS — Within the 10 days before their clinic visit, many adolescents admitted to engaging in various mismanagement behaviors, with 25% admitting to missing shots. Parents tend to underestimate adolescent mismanagement. Missing shots was significantly related to poor control ($P < 0.01$). Older adolescents engaged in more mismanagement than their younger cohorts ($P < 0.001$). The questionnaire factored into two subscales: blatant mismanagement and faking.

CONCLUSIONS — This study shows the importance of recognizing the prevalence of mismanagement among adolescents.

A major impediment to maintaining the health of individuals with diabetes is poor adherence to the prescribed regimen. The complex, multifaceted regimen makes nonadherence highly probable. Adolescents with insulin-dependent diabetes mellitus (IDDM) are less likely to adhere to their prescribed medical regimens than either their younger or older cohorts (1–4). Studies suggest that readmissions for diabetic ke-

toacidosis are primarily due to major deviations from recommended therapy, such as missing insulin shots (5–9). Nevertheless, the prevalence of poor adherence among adolescents and its contribution to poor control remain unclear. This may be true, in part, because none of the existing studies directly asked about missing shots or other major deviations from the regimen (3,10–16).

The first aim of the present study

was to document the existence and prevalence of adolescent-generated management techniques or diabetes mismanagement. We were particularly interested in two major behaviors: missing shots and making up results of/missing blood tests, although other regimen behaviors were deemed vital to the study. The second aim of the study was to evaluate the reasons given by adolescents for their mismanagement. Finally, the study was designed to assess the relationship between mismanagement and glycohemoglobin. Further explorations of these issues are of paramount importance, since adolescents may believe they are doing something adaptive, when in reality, mismanagement can have dangerous physiological implications.

RESEARCH DESIGN AND METHODS

Subjects

All IDDM patients between the ages of 11 and 19 at least 1 year post-diagnosis, literate, and without a major psychiatric diagnosis were considered eligible to participate in the study. Asked to participate were 156 adolescents (cared for by the same multidisciplinary diabetes team in an American Diabetes Association–approved education program) attending consecutive diabetes clinic outpatient appointments at our hospital; 144 adolescents agreed (mean age 14.6 years, SD = 2.3). The group was equally divided between males and females. Of those providing race information, 94 were white, 41 were black, and 5 were “other.” The range for duration of diabetes was 1–16 years (mean = 5.34, SD = 3.62).

Measures

The diabetes mismanagement questionnaire is a 10-item multiple-choice test (see APPENDIX). Items were derived from self-reports by patients seen in our clinic, in educational groups, and in therapy sessions. The questions addressed three ba-

From Children’s National Medical Center and George Washington University (P.W.), Washington, DC.

Address correspondence and reprint requests to Jill Weissberg-Benchell, Ph.D., Children’s National Medical Center, Department of Endocrinology, 111 Michigan Avenue NW, Washington, DC 20010.

Received for publication 22 June 1992 and accepted in revised form 18 August 1994.

IDDM, insulin-dependent diabetes mellitus.

Table 1—Admitted and perceived mismanagement in 10 days before clinic visit

	144 Youths (%)	55 Parents (%)	22 Doctors (%)	Range of Drs.' responses
Missed insulin injection	25	11	10	0–40
Missed injection and then took extra to cover	13	7	7	0–30
Made up blood test results because did not do test	29	24	26	5–50
Took extra insulin to cover inappropriate food	34	24	17	0–60
Ate inappropriate food	81	87	66	4–100
Missed meals and snacks	56	62	43	4–100
Fixed blood glucose monitor to give lower number	10	7	20	0–50
Changed test strip to give lower number	11	20	14	5–50
Made up blood test results because real ones were too high	29	18	23	5–50
Faked illness	13	26	12	2–50

Youths refers to teens who admit to engaging in that behavior at least once. Parents refers to those who believe their teens engage in that behavior. Doctors refers to mean and range of physicians' estimates of the percentage of youths in their practice who engage in that behavior.

sic areas of diabetes care: blood testing, insulin shots, and diet.

Subjects were asked how many times (within the past 10 days) they had engaged in the various behaviors. The questionnaire was scored on a likert-type scale, with answers ranging from 1 (never) to 5 (frequently). In keeping with our specific interest in missing shots and blood tests, two additional questions were posed. One asked for reasons why shots were missed, and the other asked for reasons why blood tests were missed. A list of possible answers were provided, as were blank spaces for adolescents to fill in additional answers.

Glycohemoglobin was measured by Quickstep column (Bio-Rad, Richmond, CA). This test was excluded in three patients known to have abnormal hemoglobin.

Procedure

The study's purpose was reviewed with each participant. Anonymity was ex-

plained and assured to each subject. After adolescents completed the questionnaire, a blood sample was obtained for an HbA_{1c}.

We were interested in comparing the admitted mismanagement practices of our adolescents with the expectations for mismanagement held by both parents and pediatric endocrinologists. Toward the end of our study, 55 consecutive parents who accompanied their adolescents to clinic were asked to respond to each item in the way they believed their teenager would. No one refused. In addition, 56 physicians who work with adolescents and are members of the Lawson-Wilkins Pediatric Endocrine Society were asked to estimate the frequency of each mismanagement behavior among the adolescents in their practice. These physicians do not work with the patients who participated in the present study. Twenty-two physicians completed and returned this questionnaire.

RESULTS— The mean HbA_{1c} for this population was 8.0, SD = 1.55 (normal range 4.9–6.1). The median was 7.6 and the mode was 7.4.

Adolescent mismanagement

Table 1 displays the admitted mismanagement practices of our adolescents within the 10 days before their most recent clinic visit. A relatively large number of adolescents admit to some mismanagement behaviors, with 25% admitting to missing their insulin shots at least once within the 10 days before their clinic visit.

Parent estimates of mismanagement

The agreement between parents and teens was assessed by comparing the answers of the 55 parents and their teenagers on each of the 10 questionnaire items. Initial analyses of the questionnaire data revealed that the distribution is skewed. Therefore, Fisher's exact probability tests were performed (Table 2). These analyses revealed significant differences between parents' perceptions and their teenagers' responses for missing shots and for taking extra insulin to cover eating inappropriate foods. Two other items approached significance: missing injections and then taking extra insulin to cover and making up blood test results because the real ones were too high. Parents underestimated the frequency with which teenagers engage in a variety of mismanagement behaviors.

Physician estimates of mismanagement

Only 22 of the 56 physicians surveyed completed and returned the questionnaire. Therefore, the following data must be viewed with caution (Table 1).

Reasons offered for missing shots/tests

Forgetting to take insulin shots or blood tests was the most commonly cited reason for missing these tasks (Table 3). With the exception of forgetting, however, the is-

Table 2—Numbers and percentages of youth-parent pairs admitting mismanagement

	Youth: No Parent:		Youth: Yes Parent:		Fisher's exact probability
	No	Yes	No	Yes	
Missed insulin injection					
<i>n</i>	40	2	9	4	0.02
%	95	5	69	31	
Missed injection and then took extra to cover					
<i>n</i>	47	2	4	2	0.06
%	96	4	67	33	
Made up blood test results because did not do test					
<i>n</i>	32	8	10	5	0.31
%	80	20	67	33	
Took extra insulin to cover inappropriate food					
<i>n</i>	35	6	7	7	0.01
%	85	15	50	50	
Ate inappropriate food					
<i>n</i>	3	8	4	38	0.15
%	27	73	10	90	
Missed meals and snacks					
<i>n</i>	14	14	7	20	0.10
%	50	50	26	74	
Fixed blood glucose monitor to give lower number					
<i>n</i>	46	4	5	0	1.00
%	92	8	100	0	
Changed test strip to give lower number					
<i>n</i>	39	9	4	2	0.59
%	81	19	67	33	
Made up blood test results because real ones were too high					
<i>n</i>	34	4	11	6	0.06
%	89	11	65	35	
Faked illness					
<i>n</i>	34	13	6	1	0.66
%	72	28	86	14	

sues around missing shots and missing blood tests appear to be different from each other. Adolescents missed shots because they did not believe they were needed, or to prevent lows. Missing blood tests seemed instead to be primarily due to a desire to appear to others to be in good control.

Relationship between HbA_{1c} and missing shots/tests

Given the skewed distribution of our data, a series of logistic regression analyses were performed in which the variables of missing shots and missing blood tests were regressed on the basis of patient age, sex, duration of diabetes, and HbA_{1c} level

(both individually and as a set). Results of these analyses reveal that individuals who admitted to missing shots were older and had higher HbA_{1c} levels than did those who denied ever missing shots (Table 4). No significant differences were found for missing blood tests.

Factor analysis

The 10 questionnaire items were subjected to a principal components analysis to determine if the individual items formed reliable subscales. Two factors were formed (Table 5). Conceptually, these factors were 1) blatant mismanagement and covering up and 2) faking illness and faking test results. The eigenvalue for blatant mismanagement was 2.09 and for faking was 1.32. This resulted in 25 and 18% of the total item variance explained by each of the two factors, respectively. The resulting two factors have acceptable internal consistency ($\alpha = 0.74$ and 0.60 , respectively).

Relationship among mismanagement, control, and demographics

A multiple regression was calculated for the relationship between glycohemoglobin and the demographic variables. Caucasian teens had lower HbA_{1c} levels than did non-Caucasians ($r^2 = 0.08$, $F[1,127] = 10.64$, $P = 0.001$). The associations among glycohemoglobin and demographics with the factor scores were also evaluated. The blatant mismanagement factor was significantly related to age ($r^2 = 0.05$, $F[1,125] = 7.18$, $P < 0.01$). Older adolescents engage in mismanagement more than their younger cohorts. No relationship between the factor scores and glycohemoglobin was found.

CONCLUSION— The purpose of our study was to document 1) the existence and prevalence of mismanagement, 2) the reasons for engaging in mismanagement, and 3) the impact of mismanagement on control.

Table 3—Reasons offered for missing shots and blood tests

Shots	
I just forgot	40
I was away from home and forgot to bring it with me	24
I didn't think the evening shot was necessary	12
I didn't plan on eating, so I missed the shot	10
I wanted to prevent a low reaction	8
I wanted to see what would happen	6
I wanted to lose weight	5
I didn't want to give a shot in front of friends	5
I wanted to get sick to get out of something	1
I never miss my shots	41
Blood tests	
I just forgot	35
Didn't test, wanted complete record, so made up	28
I wanted to show good results to doctor	24
I wanted to show good results to family	22
I'm fussed at when high, so made up lower number	22
I was away from home and forgot to bring it with me	20
It hurts to test	6
I didn't want to test in front of friends	3
I never made up blood tests	22

The percentages add up to more than 100 because respondents were permitted to choose more than one reason.

Prevalence

Adolescents admit to engaging in a wide variety of mismanagement behaviors, primarily around food. Not following the prescribed diet is one of the easiest and most tempting mismanagement behaviors. Food is involved in many peer-related activities and has social implications. Similarly, diet-related mismanagement behaviors were the ones physicians and parents cited as the most prevalent.

Of greater concern, however, is the prevalence of missing blood tests (29%), making up blood test results to give lower numbers (29%), and missing insulin shots (25%). Parents underestimated the prevalence of a variety of mismanagement behaviors among their adolescents.

Our 10-item scale factored into two subscales: blatant mismanagement and faking. These items did not fall into technique-related subscales such as shots,

blood tests, or diet. Instead, more conceptually based subscales were found. Perhaps youths who are uninterested in caring for their diabetes will not select specific diabetes care techniques to avoid, but instead will avoid most, if not all, of them. Similarly, youths who do not want others to know how well or poorly they control their diabetes will tend to misrepresent their behavior in all aspects of diabetes care.

Reasons for mismanagement

Understanding the reasons for mismanagement is a complex issue, and a questionnaire such as ours can only offer a simple first look. Our results suggest that forgetting shots and tests is common. In addition, many teens missed shots because they did not think the evening shot was necessary. Teens fabricated blood tests because of perceived pressure from family and physicians to produce good results.

Relationship between mismanagement and control

Finding a statistically significant relationship between mismanagement and control is often an elusive goal (17). Never-

Table 4— χ^2 analysis of missed shots and missed blood tests in relation to demographic variables, duration, and HbA_{1c}

	Shots		Blood tests	
	Single variable model	Multivariable model	Single variable model	Multivariable model
Age	5.26*	4.04*	0.00	0.51
Sex	0.67	0.02	0.00	0.19
Race	2.91	1.02	1.14	3.27
Duration	2.78	0.87	0.05	0.31
HbA _{1c}	4.39*	5.17*	1.35	2.20

*P < 0.05.

Table 5—Factor loadings

Factor	α
Mismanagement	
Missed insulin shots	(0.70)
Made up results for tests never done	(0.70)
Took extra insulin to cover food	(0.63)
Missed shots, took extra to cover	(0.56)
Ate inappropriate foods	(0.52)
Missed meals or snacks	(0.45)
Faking	
Faked test to read lower	(0.70)
Altered strips to lower reading	(0.45)
Altered monitor to lower reading	(0.45)
Faked illness	(0.45)

theless, we did find that the specific behavior of missing shots is related to control.

Summary

The results of the present study show that even in a diabetes program that offers a comprehensive multidisciplinary team, patients do struggle with adherence to their regimen. It is vital that health care professionals recognize the existence and prevalence of mismanagement so we can honestly discuss these behaviors with our patients and their families. Without such discussions, our ability to make effective decisions about treatment plans becomes moot. Concrete strategies for minimizing or avoiding mismanagement should become a standard part of diabetes education. Finally, parents' underestimations regarding the prevalence of a variety of mismanagement behaviors (missing shots, in particular) suggest that they are not monitoring their adolescents' diabetes regimens as closely as may be needed. The idea of encouraging parents to increase supervision of their adolescents has caused some controversy among health care professionals. Nevertheless,

increased parental supervision has been quite effective in decreasing general non-compliance (17) and has also been shown to be effective for teens with IDDM (18). Therefore, health care providers may need to encourage families to play a more active role in their adolescents' diabetes care than they have in the past.

Acknowledgments— This work was supported by a grant from the Gilbert and Jaylee Mead Family Foundation in Greenbelt, Maryland.

APPENDIX: DIABETES QUESTIONNAIRE

— Most people have difficulty taking care of their diabetes in the precise way their physician told them to. This questionnaire asks about different parts of your diabetes care. Do not spend much time on any one item. There are no right or wrong answers, as everyone takes care of their diabetes in different ways. We are interested in what you do. Please circle the answer that best fits the way things are for you.

1 = Never 2 = Once or Twice 3 = Three or Four Times 4 = More than Four Times 5 = Frequently

- | | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 1. In the past 10 days, how often did you fix your glucose monitor to give lower readings? |
| 1 | 2 | 3 | 4 | 5 | 2. In the past 10 days, how often did you miss shots? |
| 1 | 2 | 3 | 4 | 5 | 3. In the past 10 days, how often did you take extra insulin to cover something you should not have eaten? |
| 1 | 2 | 3 | 4 | 5 | 4. In the past 10 days, how often did you make up blood test results because the real ones were too high? |
| 1 | 2 | 3 | 4 | 5 | 5. In past 10 days, how often did you make up blood test results because you had not done them? |
| 1 | 2 | 3 | 4 | 5 | 6. In the past 10 days, how many snacks and meals did you miss? |
| 1 | 2 | 3 | 4 | 5 | 7. In the past 10 days, how often did you miss your shots and then take extra insulin to make up for it? |
| 1 | 2 | 3 | 4 | 5 | 8. In the past 10 days, how often did you change blood sugar test strips to give a different reading? |
| 1 | 2 | 3 | 4 | 5 | 9. In the past 10 days, how often did you fake a headache, stomachache, or other signs of high blood sugars to get out of doing what you didn't want to do? |
| 1 | 2 | 3 | 4 | 5 | 10. In the past 10 days, how often have you eaten something you know you really should not have eaten? |

References

- Jacobson AM, Hauser ST, Wolsdorf JL, Houlihan J, Milley JE, Herskowitz RD, Wertlieb D, Watt E: Psychologic predictors of compliance in children with recent onset of diabetes mellitus. *J Pediatr* 110: 805–811, 1987
- Christensen NK, Terry RD, Wyatt S, Pichert JW, Lorenz RA: Quantitative assessment of dietary adherence in patients with insulin-dependent diabetes mellitus. *Diabetes Care* 6:245–250, 1983
- Johnson SJ: Diabetes mellitus in childhood. In *Handbook of Pediatric Psychology*. Routh DK, Ed. New York, Guildford, 1988, p. 9–31
- Johnson SJ: Assessing daily management in childhood diabetes. *Health Psychol* 5:545–564, 1986
- Glasgow AM, Weissberg-Benchell JA, Tynan WD, Epstein SF, Driscoll C, Turek J, Beliveau E: Readmissions of children with diabetes mellitus to a children's hospital. *Pediatrics* 88:98–104, 1991
- White K, Kolman ML, Wexler P, Polin G, Winter RJ: Unstable diabetes and unstable families: a psychosocial evaluation of diabetic children with recurrent ketoacidosis. *Pediatrics* 73:749–755, 1984
- Golden MP, Herrold AJ, Orr DP: An approach to prevention of recurrent diabetic ketoacidosis in the pediatric population. *J Pediatr* 107:195–200, 1985
- Schade D, Drumm D, Duckworth W, Patton P: The etiology of incapacitating brittle diabetes. *Diabetes Care* 8:12–20, 1985
- Gray DK, Marreno DG, Godfrey C, Orr DP, Golden MP: Chronic poor metabolic control in the pediatric population: a stepwise intervention program. *Diabetes Educator* 14:516–520, 1988
- Schafer LC, Glasgow RE, McCaul KD, Dreher M: Adherence to IDDM regimens: relationship to psychosocial variables and metabolic control. *Diabetes Care* 6:493–498, 1983
- Glasgow RE, McCaul KD, Schafer LC: Self-care behaviors and glycemic control in type I diabetes. *J Chronic Dis* 40:399–412, 1987
- Hanson CL, Henggeler SW, Harris MA, Mitchell KA, Carle DL, Burghen GA: As-

- sociations between family members' perceptions of the health care system and the health of youths with insulin-dependent diabetes mellitus. *J Pediatr Psychol* 13: 543-554, 1988
13. Meldman L: Diabetes as experienced by adolescents. *Adolescence* 22:433-444, 1987
 14. Chase PH, Rainwater NG: Missed insulin injections, a common syndrome. *Pract Diabetol* 8:20-23, 1989
 15. Cox DJ, Irvine A, Gonder-Frederick L, Nowacek G, Butterfield J: Fear of hypoglycemia: quantification, validation, and utilization. *Diabetes Care* 10:617-621, 1987
 16. Wilson DP, Endres RK: Compliance with blood glucose monitoring in children with type 1 diabetes mellitus. *J Pediatr* 108:1022-1030, 1986
 17. Johnson SB, Kelly M, Henretta J, Cunningham W, Tomer A, Silverstein JH: A longitudinal analysis of adherence and health status in childhood diabetes. *J Pediatr Psychol* 17:537-554, 1992
 18. Patterson G: *A Social Learning Approach: Coercive Family Process*. Eugene, OR, Castalia, 1982
 19. Snyder J: Behavioral analysis and treatment of poor diabetic self-care and anti-social behavior: a single subject experimental study. *Behav Ther* 18:251-263, 1987