Discordance Between Physician and Adolescent Assessments of Adherence to Treatment

Influence of HbA_{1c} level

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OBJECTIVE — To compare the subjective assessments (perceptions) of physicians and adolescent diabetic patients on the adolescents' adherence to treatment and to test the hypothesis that the HbA_{1c} level influences physicians' perceptions.

RESEARCH DESIGN AND METHODS — In a multicenter cross-sectional survey, 143 adolescents with diabetes (mean age 14.6 years) auto-assessed, while their pediatricians independently assessed, the level of adherence to treatment on a four-point scale. Scores of adherence given by a validated scale and metabolic control (HbA_{1c}) were compared according to those assessments.

RESULTS — Agreement between the adherence perceptions from adolescents and physicians was low ($\kappa = 0.23$), and adolescents scored significantly higher ($P < 0.001$). Mean adherence score to diabetes treatment was significantly higher when the adolescents' perception of their self-care behaviors was good than when it was poor ($P = 0.01$), but did not significantly differ according to physicians' perception. Mean HbA_{1c} level was significantly lower when the self-care behavior perception was good than when it was poor, both for the adolescents ($P = 0.02$) and for the physicians ($P < 0.001$). Multivariate analyses showed that only the adherence scale score was significantly associated with the adolescents' perception ($P = 0.015$), whereas only HbA_{1c} level was significantly associated with the physicians' perception ($P = 0.0008$).

CONCLUSIONS — By identifying the possible discrepancy between their own assessment of adherence and that of adolescents, and by avoiding the systematic attribution of poor metabolic control to poor adherence, physicians could generate a more confident and collaborative relationship with diabetic adolescents and therefore facilitate adolescents' self-management.

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Patient education is a basis for diabetes care (1) that aims at providing the patients with the means and ability to adopt the multiple self-care behaviors required in obtaining optimal glycemic control. A crucial step in the development of educational programs is the assessment of patient therapeutic behaviors. Indeed, to be effective, an educational approach must be based on the specific needs of the patient (2). Measuring patients' self-care behaviors is likewise necessary for evaluating critical outcomes of education. Reliable and valid tools are needed for this purpose. Although scales have been developed, their use in the evaluation of adherence to diabetes treatment raises several methodological (3,4) as well as clinical problems for the medical team, as they are time-consuming and complex to use. However, a subjective assessment is already made by physicians and by patients themselves. Little is known about the agreement between the physician's and the patient's perceptions of the patient's adherence to diabetes regimen (5). How do health care providers, especially physicians, estimate patients' self-care behaviors? What help could they obtain by asking the patient to estimate his/her own adherence? What is the situation during the critical period of adolescence, when adherence to diabetes regimen is commonly reported as deteriorating (6)?

The specific aims of the study were as follows:

- To compare adolescents' and physicians' perceptions of adolescents' adherence to treatment of diabetes,
- To compare the adolescents' and physicians' perceptions with a reference measurement of adherence as provided by a validated scale,
- To assess the influence of the level of metabolic control on these perceptions.

Our central hypothesis was that the degree of glycemic control largely influences the physician's assessment of patient adherence, but not that of the adolescent.

RESEARCH DESIGN AND METHODS

Procedure

A multicenter cross-sectional survey was conducted in six university-based pediatric departments in France. It was part of a longitudinal study evaluating the associations between psychosocial variables and adherence, for which a diabetic children's cohort was constituted (7). Standardized questionnaires were filled in independently by adolescents and by their usual physicians

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Abbreviations: SMBG, self-monitoring of blood glucose.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

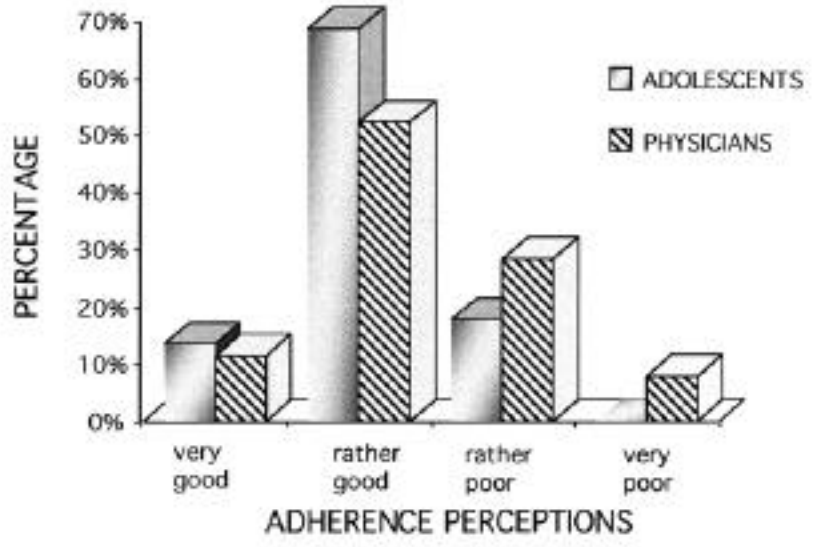

Figure 1—*Comparison of global adherence perceptions between diabetic adolescents and their physicians* (n = *135*).

during regular scheduled visits at the clinic. Blood samples were taken for HbA_{1c} measurement by micropuncture. Adolescent questionnaires were self-administered. Families participating in the study gave informed written consent.

Patients

At the time of the study the cohort comprised 143 adolescents (among 165 from the initial cohort). Adolescents included in the study did not differ in demographic and social characteristics from those of the initial sample. Mean age was 14.6 ± 1.9 years (range 10.6–18.2) and duration of diabetes was 7.4 ± 2.5 years (3.7–15.1). Of the adolescents, 55% were girls. Most of the adolescents (65%) were receiving 2 daily injections of insulin; the others were treated by ≥3 injections per day. Mean number of adolescent visits at the clinics was 4 ± 1.7 per year.

Methods

Adolescent questionnaires. Self-administered questionnaires were completed by adolescents according to the following sequence:

Adolescent perception of adherence to diabetes regimen. The first question was "Presently, how do you manage to stick to your diabetes treatment?" Adolescents rated their global adherence using a response frame: very well, rather well, rather poor, very poor (illustrated by different facial expressions: smile to sadness). The participation rate was 98%. Subsequent questions were focused on four specific areas of diabetes management: diet, self-monitoring of blood glucose (SMBG), hypoglycemia and insulin therapy, using the same question formulation and responsive frame.

Adherence to diabetes regimen. The scale developed by Hanson et al. (8) has been previously adapted and validated for linguistic and psychometric criteria in French (9). Four areas of diabetes regimen adherence (diet, insulin therapy, hypoglycemia, and SMBG) were measured. The multiple-choice test included 18 items, which were summed across the 4 areas, to yield a maximal score of 38. Results were expressed as the percentage of the maximal score. Internal consistency (Cronbach's α) in this sample was 0.60 (n = 133).

Diabetes knowledge. A shortened version of the Test of Diabetes Knowledge (TDK) has been previously validated in French (10). The multiple-choice test included 20 items measuring general information and 13 items measuring problem-solving skills. Internal consistency (Cronbach's α) in this sample was 0.82 (n = 140).

Physician questionnaire. Just after the visit, physicians completed a standardized medical questionnaire including assessment of adherence of the adolescent. Physicians first rated the global adherence using a response frame of very good, rather good, rather poor, and very poor. Participation rate was 96.5%. Physicians subsequently rated the patients' adherence to four specific areas of diabetes management: diet, SMBG, hypoglycemia, and insulin therapy, according to the same question formulation and response frame.

Results of HbA_{1c} measurement were not immediately available, so that when physicians answered the questionnaire they were unaware of the current results. It should be noted that, however, as they regularly followed the patient, they were aware of any prior HbA_{1c}.

HbA_{1c} level. HbA_{1c} was measured in a single laboratory by high-performance liquid chromatography (reference value: 5.1 ± 0.6%, mean ± 2 SD).

Statistical analysis

The adolescents were divided into two groups: those who reported a very good or a rather good adherence (perception of good adherence) and those who reported a rather poor or very poor adherence (perception of poor adherence). Similarly, the physicians were divided into two groups: those who reported a very good or a rather good adherence (perception of good adherence) and those who reported a rather poor or very poor adherence (perception of poor adherence). The overall and specific adherence perceptions of adolescents and physicians were compared using a K coefficient.

Analyses were then carried out separately for adolescents and for physicians and limited to overall adherence perceptions. Adherence scores from the scale were compared according to the perceptions by using a Student's t test and a χ^2 test. HbA_{1c} levels were compared with perceptions using the Student's t test. Logistic regression analysis was performed using two models, in which the dependent variable was either adolescents' assessment or physicians' assessment of adherence using the following explanatory variables: age, sex, diabetes duration, score of diabetes knowledge, HbA_{1c} level, and adherence score. All factors were entered into the analysis simultaneously.

Results are expressed as means ± SD. All tests were used at a 5% level. Analyses were performed using SPSS statistical software.

RESULTS

Comparison of adherence assessments between adolescents and physicians

The overall assessment of adherence from both adolescents and physicians, according to the same rating, are given in Fig. 1. The adolescents rated their adherence as "rather good" more frequently than did the physicians. About 10% of both physicians and adolescents estimated adherence as "very good." Few physicians but no ado-

Table 1—*Comparison of adherence scale scores according to the perceptions of adherence by diabetic adolescents and physicians*

	Perception of adherence			
	Adolescents		Physicians	
	Good	Poor	Good	Poor
n	106	24	81	47
Adherence score				
Mean ± SD (%)	73.3 ± 11.4	66.5 ± 11.6*	72.6 ± 11.7	70.5 ± 12.4†
<25th percentile (% of patients)	19.8	50‡	23.4	32†

Scores are expressed as the percentage of the maximal score of the scale. *P = 0.01 for poor vs. good perceptions of adolescents; †NS for poor vs. good perceptions of physicians; ‡$P < 0.01$ for poor vs. good perceptions of adolescents.

lescents rated adherence as "very poor." Subsequent analyses were conducted as a dichotomous variable: perceptions of good or poor adherence.

Comparison of adolescents' and physicians' assessments of self-care behaviors was conducted in the 135 cases where data were available for both groups. Agreement between the two global perceptions was low (κ coefficient = 0.23). A concordance was found in 92 cases (perception of good adherence in 77 cases, perception of poor adherence in 15 cases). Assessments were discordant in 43 cases (32%). The adolescents had significantly higher levels of perception of their global adherence than did their physicians: 34 adolescents perceived their adherence as good while physicians perceived it as poor. Only 9 adolescents perceived their adherence as poor while physicians perceived it as good ($P < 0.001$). When comparing adolescents' and physicians' assessments of self-care behaviors for the specific four areas of diabetes management, agreement was low (κ coefficients varied from 0.02 to 0.19). Adolescents had significantly more positive perceptions of their specific adherence than did their physicians in all areas except glucose monitoring, which was not significant.

Comparison of adherence scores according to the assessments

Among the adolescents, mean adherence score to diabetes treatment was 71.9 ± 11.9% (range 39.5–92.1%). Mean HbA_{1c} for the group was 9.1 ± 1.4% (range 6.1–12.5%). Adherence scores were significantly and negatively correlated with HbA_{1c} levels: $r = -0.23$, $P = 0.007$.

Mean adherence score to diabetes regimen was significantly higher when adolescents' perception of overall self-care behaviors was "good" than when it was "poor" (Table 1). Conversely, mean adherence score did not differ according to the perception of the physicians. When studying the proportion of adolescents that fell below the 25th percentile for the distribution of adherence scores in the sample, we found that this proportion was significantly higher when adolescents perceived their adherence as "poor" than when they perceived it as "good" (Table 1). Conversely, this proportion did not differ according to the physicians' perception of adherence.

Comparison of HbA_{1c} levels according to perceptions

Mean HbA_{1c} level was significantly lower when global adherence perception was good than when it was poor, both for the adolescents and for the physicians (Fig. 2).

Multiple regression analyses

The results of logistic regression indicated that among adolescents (Table 2), adherence score to diabetes regimen was the only factor significantly associated with the perception of adherence (P = 0.015). An odds ratio analysis showed that increasing the value of the adherence score by 10% decreased the probability that the adolescent rated his/her adherence as "poor" rather than "good" by a factor of 0.56 (95% CI 0.35–0.89).

Among physicians (Table 3), HbA_{1c} level was the only factor significantly associated with the perception of adherence (P = 0.0008). Odds ratio analysis showed that increasing the value of HbA_{1c} by 1% increased the probability that the physician rated the adolescents' adherence as "poor" rather than "good" by a factor of 1.78 (95% CI 1.27–2.49).

CONCLUSIONS — By comparing the assessments of adherence in a large group of diabetic adolescents and their physicians, we have shown that those assessments were discordant. Furthermore, adolescents' and physicians' perceptions were linked to distinct factors. The level of HbA_{1c} was the most important factor that influenced physicians' assessment of adolescents' adherence to diabetes regimen, and their perception was not related to the

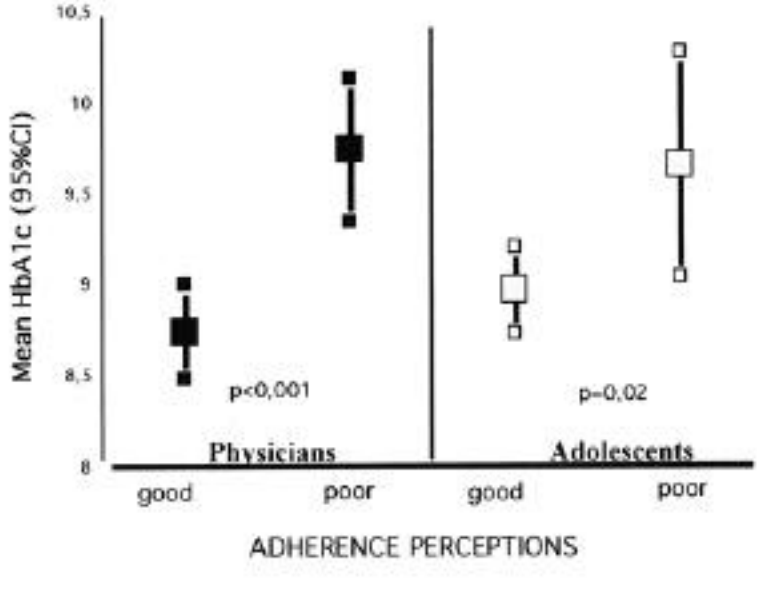

Figure 2—*Comparison of HbA_{1c} levels according to the perceptions of adherence by physicians* (n = *138) and diabetic adolescents* (n = *140).*

Table 2—*Logistic regression analysis on perception of adherence by adolescents*

	β	β/SEM	*P*	OR (95% CI)
Adherence score	−0.0576	−2.42	0.015	0.94 (0.90–0.99)
Sex	−0.2249	−0.43	0.66	0.79 (0.29–2.22)
Diabetes knowledge	0.1246	1.50	0.13	1.13 (0.96–1.33)
HbA_{1c}	0.1177	0.62	0.53	1.12 (0.77–1.63)
Age	0.0168	0.10	0.92	1.02 (0.74–1.40)
Duration of diabetes	0.0364	0.37	0.71	1.04 (0.86–1.25)

n = 126 adolescents.

measurement of adherence obtained by a validated scale. The adolescents' perceptions of adherence were concordant (means and frequencies) with the reference measurement given by the adherence scale. The HbA_{1c} level did not influence the adolescents' perception of adherence. However, patients had access to daily glucose monitoring, and the extent to which glycemic control influenced their assessments of adherence remains unknown.

The adolescents rated their adherence as "rather good" more frequently than did the physicians, as found in other reports of compliance with diabetes regimens (11–14). A tendency to overestimate adherence by adolescents could refer to their ability to psychologically adapt to chronic illness. Other psychological factors, such as self-efficacy or depression, not analyzed in our study have been shown to be important to the adolescents' self-reports of adherence (15).

A better understanding of the physicians' perception of adherence was suggested by the results of the multivariate analysis. Potential confounding factors such as age, sex, duration of diabetes, and diabetes knowledge were not found to influence their perceptions. The only factor significantly associated with the physicians' perception of adherence was the HbA_{1c} level, a factor weakly correlated to the adherence scale measurements in our study population. It must be underlined that the physicians' perception of adherence was independent of the scores of adherence measured by a validated and reliable scale. This suggests confirmation of our hypothesis that the degree of glycemic control influences the physicians' appreciation of patient adherence. The recognition that physicians tend to regard patients' adherence and metabolic control as interchangeable constructs has already been underlined (3). In this study, physicians alone were questioned and it would have been interesting to analyze adherence perceptions from other members of the medical team. Recommendations from McNabb (4) have recently emphasized the need for health care providers to "recognize that metabolic control may not be a valid measure of adherence, as adherence and metabolic control are not directly correlated." Many factors other than patients' behavior influence the level of metabolic control. The confusion between metabolic and behavioral parameters may reflect the positive belief of physicians that good adherence to the treatment program that they have prescribed will systematically lead to good metabolic control, without taking into account physiological and/or other factors influencing HbA_{1c} level (7).

Our results illustrate the difficulties in assessing self-care behavior levels in clinical practice. It could be possible that the reference of compliance for physicians was mainly based on the self-monitoring of blood glucose, as they always look at glucose monitoring results during visits. Unless a systematic assessment approach is followed (3), others items of compliance are usually less frequently assessed, inasmuch as they refer to several fields, are numerous in each therapeutic regimen area, and are necessarily time-consuming. Moreover, the responses of adolescents are highly dependent on the way questions are asked. In this study the two questionnaires were self-administered and anonymous. This method, well accepted by adolescents, allows a high rate of participation and reduces the influence of social desirability on the response set. In a routine care perspective, as well as in a more fundamental research approach to patients' adherence, valid and reliable measurements of adherence are needed. The lack of a "gold standard" of adherence (4,16) is critical for clinicians, who refer more easily to their medical standard, the level of glycemic control. Efforts must be made to provide clinicians with measurement methods that can be used systematically in clinical practice.

In conclusion, these data highlight an important problem in the treatment of diabetic patients: the difficulty of separating physiological (HbA_{1c}) from behavioral parameters (adherence to treatment regimen). Our study focused on physicians, but other health care providers are also frequently confused about the distinction between behavioral and metabolic outcomes. The fact that numerous factors other than patient behaviors influence the level of metabolic control must be integrated more comprehensively into patient care. A confident and collaborative communication between physicians and their patients has been shown to positively influence patients' health behaviors (17,18). As differences between the perceptions of physicians and adolescents may constitute barriers to patient–physician communication and interaction, it is important for the physician to keep in mind that his/her assessment of adherence is perhaps overinfluenced by the level of metabolic control. Our data emphasize the need for development of more collaborative relationships with diabetic adolescents and, within these relationships, a more valid approach to assessing patient adherence.

Table 3—*Logistic regression analysis on perception of adherence by physicians*

	β	β/SEM	*P*	OR (95% CI)
Adherence score	0.0041	0.21	0.83	1.00 (0.97–1.04)
Sex	0.2617	0.60	0.55	1.30 (0.55–3.04)
Diabetes knowledge	−0.0166	−0.31	0.75	0.98 (0.89–1.08)
HbA_{1c}	0.5761	3.36	0.0008	1.78 (1.27–2.49)
Age	0.1737	1.36	0.17	1.19 (0.93–1.53)
Duration of diabetes	−0.0147	−0.18	0.86	0.98 (0.84–1.16)

n = 124 physicians.

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APPENDIX

Members of the PEDIAB Collaborative Group

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References

1. Assal JP, Mülhauser I, Pernet A, Gfeller R, Jörgens V, Berger M: Patient education as the basis for diabetes care in clinical practice and research. *Diabetologia* 28:602–613, 1985
2. American Diabetes Association: Quality recognition for diabetes: review criteria for national standards from the American Diabetes Association. *Diabetes Care* 9:XXXVI–XLIII, 1986
3. Johnson SB: Methodological issues in diabetes research: measuring adherence. *Diabetes Care* 15:1658–1667, 1992
4. McNabb WL: Adherence in diabetes: can we define it and can we measure it? *Diabetes Care* 20:215–218, 1997
5. Boyer BA, Lerman C, Shipley TE Jr, McBreartry J, Quint A, Goren E: Discordance between physician and patient perceptions in the treatment of diabetes mellitus: a pilot study of the relationship to adherence and glycemic control. *Diabetes Educ* 22:493–499, 1996
6. Weissberg-Benchell J, Glasgow AM, Tynan WD, Wirtz P, Turek J, Ward J: Adolescent diabetes management and mismanagement. *Diabetes Care* 18:77–82, 1995
7. Tubiana-Rufi N, Moret L, Czernichow P, Chwalow J, the PEDIAB Collaborative Group: Risk factors for poor glycemic control in diabetic children in France: immigrant versus non-immigrant mothers. *Diabetes Care* 18:1479–1482, 1995
8. Hanson CL, Henggeler SW, Burghen GA: Model of association between psychosocial variables and health outcome measures of adolescents with IDDM. *Diabetes Care* 10: 752–758, 1987
9. Moret L, Tubiana-Rufi N, Chwalow J, Czernichow P: Validation en langue française d'une échelle mesurant l'adhésion au traitement des enfants diabétiques. *Rev Epidemiol Sante Publique* 43:361–370, 1995
10. Tubiana-Rufi N, Bean K, Moret L, Czernichow P, Chwalow AJ: Validation en langue française d'une échelle d'évaluation des connaissances (TDK), destinée aux enfants diabétiques insulinodépendants: méthodologie et intérêts pour la recherche et la pratique clinique. *Rev Epidemiol Sante Publique* 40:191–200, 1992
11. Mazze RS, Lucido D, Shamoon H: Psychological and social correlates of glycemic control. *Diabetes Care* 7:360–366, 1984
12. Most RS, Gross AM, Davidson PC, Richardson R: The accuracy of glucose monitoring by diabetic individuals in their home setting. *Diabetes Educ* 12:24–27, 1986
13. Wilson W, Ary DV, Biglan A, Glasgow RE, Toobert DJ, Campbell DR: Psychosocial predictors of self-care behaviors (compliance) and glycemic control in non-insulin dependent diabetes mellitus. *Diabetes Care* 9:614–622, 1986
14. Gonder-Frederick LA, Julian DM, Cox DJ, Clarke WL, Carter WR: Self-measurement of blood glucose: accuracy of self-reported data and adherence to recommended regimen. *Diabetes Care* 11:579–585, 1988
15. Littlefield CH, Craven JL, Rodin GM, Daneman D, Murray MA, Rydall AC: Relationship of self-efficacy and binging to adherence to diabetes regimen among adolescents. *Diabetes Care* 15:90–94, 1992
16. Tubiana-Rufi N, Du Pasquier-Fediaevsky L: The concept of compliance with diabetes treatment revisited. *Diabetes Metab* 25:172–176, 1999
17. Lorenz RA, Bubb J, Davis D, Jacobson A, Jannasch K, Kramer J, Lipps J, Schlundt D: Changing behavior: practical lessons from the Diabetes Control and Complications Trial. *Diabetes Care* 19:648–652, 1996
18. Golin CE, DiMatteo M, Gelberg L: The role of patient participation in the doctor visit: implications for adherence to diabetes care. *Diabetes Care* 19:1153–1164, 1996