Expected Diabetic Control in Childhood and Psychosocial Functioning in Early Adult Life

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This study examined relationships between the extent to which doctors seek to achieve good (i.e., tight) diabetic control during childhood and the frequency of psychosocial problems in later life. A sample of 225 young adults with insulin-dependent diabetes mellitus was studied by use of a systematic interview. A measure of the level of control the doctor was attempting to achieve was developed from questionnaires administered to the doctors who provided most of the patient's care during childhood. The results were compared with scores on three indices of psychosocial functioning based on responses given in structured interviews with the patients. Although potentially important psychosocial problems were found for 10–20%, there was no statistically significant relationship between any of these problems and the doctors' desired levels of control. Thus, efforts to achieve good control during childhood, whether successful or not, may not be followed by psychosocial problems in later life. This finding should help support clinicians' attempts to obtain the levels of control during childhood judged to be essential in preventing serious organic complications.
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O ver the past two decades, much attention has been given to the care of children with chronic medical conditions (1,2). It is generally acknowledged that these children have a higher rate of emotional problems than children who are healthy (3). It is not certain, however, what accounts for this increased risk. One explanation in the case of disorders where it is necessary to impose a strict medical regimen on the child is that the pressures placed on the patient and his/her parents may ultimately manifest themselves as emotional disturbances.

Children with insulin-dependent diabetes mellitus (IDDM) were often thought to be particularly vulnerable to emotional difficulties, although many investigators believe that the risk for these children is no greater than that of any other chronic disorder of childhood.

Nonetheless, the goals in caring for these children are to ensure a normal lifespan, free from the late complications of the disease, while maintaining an acceptable quality of life. This goal requires careful attention to the control of blood glucose and other aspects of health along with equal concern for the child's psychological development. Whether both can be achieved equally well or whether one may have to be compromised to attain the other is a question that has not yet been answered adequately.

In the past this debate was complicated by persistent uncertainty about the ultimate value of strict control. In 1971, one authority in a seminal review, referring to attempts to achieve normoglycemia and aglycosuria, stated, "Major restrictions in the natural activities of the child are necessary in such an approach. The emotional trauma induced by this type of management is not acceptable without solid evidence that it is effective in improving the future health and happiness of the patient." To this, the writer added the commonly held view that "the prevention of vascular disease, an objective of all, is not an achievable goal by specifically identifiable therapeutic approaches at this time. . . . The concept that the late vascular abnormalities are a consequence of the biochemical changes is widely accepted but scientifically unsubstantiated" (4).

Accordingly, during the period when most of the patients in this study were growing up (the 1960s), one school of thought advocated relatively loose control of blood glucose in an effort to improve the quality of life. It held that maintaining normoglycemia was not essential. In fact, some reasoned that because hypoglycemia is an immediate hazard, the goal should be modest glycosuria at all times.

The other school of thought, striving to prevent or delay organic complications despite inconclusive evidence, placed greater emphasis on tight control. It relied on careful education of the child and the help of mental-health services to limit whatever adverse emotional consequences such control may inflict (5). More recent results from animal studies (6,7) and research involving humans (8–10) offer much stronger support for this school of thought. Although the medical indications for tight control seem convincing, it is still reasonable to ask whether an emotional price is paid to achieve this goal.

We assess the level of control the doctor wanted the child to achieve rather than the control actually achieved. The distinction between what is expected of the patient and whether this was possible for most children in light of the technology available at the time is an important one. This study was not intended to answer questions about the obtained level of control and eventual adjustment for three reasons. 1) Our goal was to determine whether expecting much from children, at a time when it was far from certain whether such expectations were essential or feasible, was warranted in the light of possible emotional complications. 2) Throughout the patients' childhood, there were no measures such as glycosylated hemoglobin to assess control with precision. 3) Although the relation with actual control may differ, the expectations of physicians are the exclusive focus of this study, because these expectations may prove to be as important as actual physiologic control.

The terms *loose* and *tight* control are used largely for semantic convenience. These are potentially misleading concepts because they imply a clear dichotomy that rarely exists among most physicians. Instead they are viewed as a continuum, indicating a tendency toward one position. This study compares the psychosocial adjustment of young adults with IDDM treated under regimens of differing strictness during childhood. It serves as a model for examining related issues in the care of children with other chronic illnesses where physicians are faced with the choice between imposing difficult therapeutic demands for the sake of presumed physical benefits versus modifying those demands when it is feared they may provoke serious emotional problems.

MATERIALS AND METHODS

Patients. The population selected consisted of 431 young adults with IDDM who were >18 yr of age and who had previously been campers at the Quebec Camp for Diabetic Children. An attempt was made to interview

by telephone all those still living within reasonable calling distance. At least two successive letters were sent to the most recent known address of the patient or parents. Twenty-one patients were outside the province, 77 could not be traced, and 98 failed to reply or could not be located. Only 3 patients refused interviews; 7 others had died—3 in car accidents, 1 after being taken off insulin by a faith healer, and 3 at ages 15, 28, and 33 of causes related to diabetes.

A total of 225 subjects (70% of those eligible) were successfully interviewed. Their demographic and socioeconomic characteristics are shown in Table 1. The patients had a mean age of 22 yr. The distribution by socioeconomic status (based on father's occupation) and by educational accomplishments suggests a small over-representation of the upper end of the social-class spectrum.

Ninety-seven respondents (43%) were interviewed in English and the remainder in French. The patients were representative of young people in the province with respect to education. At the time of interview, 30% were still in school and 8% were university graduates.

The sample also appears reasonably typical of young diabetic patients with respect to the clinical features shown in Table 2. Less than 25% had been hospitalized for diabetes within the preceding year, and 20% reported episodes of hypoglycemia requiring glucagon or treatment by a doctor. However, most admitted to having mild reactions weekly—an indication of how closely they were attempting to control their glucose levels. Nine percent reported episodes of ketosis in the last 3 yr, and 1% required hospital admission. Most stated they tested their urine regularly, i.e., at least once daily. All patients

TABLE 1
Sociodemographic characteristics of patients and their families

	Percent
Age (yr)*	
25–34	33
20–24	36
18–19	31
Sex	
Male	49
Female	51
Socioeconomic status (father's job status)	
Professional	36
Nonmanual	21
Manual	42
Language	
English	43
French	57
Education completed	
<High school	15
High school	35
>High school	48

Values are adjusted percentages.
*Mean ± SD 23.3 ± 4.1 yr.

TABLE 2
Clinical characteristics of 225 patients

	Percent
Age at onset (yr)*	
0–5	28
6–10	34
11–17	37
Hospital admissions (last 3 yr)†	
0	73
1–2	20
≥3	7
Severe hypoglycemic reactions (last 1 yr)‡	
0	80
1–2	14
≥3	6
Mild hypoglycemic reactions (avg/wk)§	
0	18
1–2	23
≥3	59
General health	
Very good or good	89
Fair or poor	11
Complications	
Hypertension	8
Kidney	8
Neurological	5

Values are adjusted percentages. Means ± SD *8.5 ± 3.9 yr, †0.6 ±
1.4 admissions, ‡0.5 ± 1.3 reactions, §3.3 ± 1.3 reactions.

used insulin daily, and 10% used two or more injections daily. Thirty-three percent of the patients judged that they followed a diet closely. Less than 10% reported experiencing any of a list of 10 complications of IDDM.
Doctors. Subjects identified the doctor responsible for most of their diabetic care before the age of 18 yr. Of the 62 doctors involved, most had 1 or 2 patients each; 3 had >20 patients; and 1, a diabetologist, had 95 patients.

After an explanatory letter, at least three attempts were made to interview the doctors living in Canada. This interview consisted of structured questions about details of management and philosophy of care for the period when the patients were under their care. If doctors were unavailable for interview by telephone, two waves of postal questionnaires were sent. Interviews were completed with 54 physicians; only 4 refused or failed to comply, giving a response rate of 91%.
Methods of measurement. Information was obtained from patients with a structured telephone questionnaire administered in French or English by trained interviewers. The questionnaire included questions about education, work, social and family life, diabetic care during childhood, and social and emotional adjustment. Questions in the latter category were drawn from an early version of the Psychiatric Epidemiology Research Interview (PERI; 11) and from Piper's adaptation of the Structured Scaled Interview to Assess Maladjustment (SSIAM; 12,13).

The items selected from PERI were drawn chiefly from the self-esteem scale and included questions with 5-point Likert-type responses. These items are similar to those used by Langner (14). The most recent version is intended to identify "nonspecific psychological distress" and appears to have excellent psychometric properties (15). The SSIAM was designed as an outcome measure for studies of psychotherapy and is intended for administration by a trained interviewer. It includes 45 items to assess "deviant behavior, friction with others, and subjective distress" with a view to measuring social maladjustment (12,13). The measure has high intraclass correlation coefficients (.78–.97) and acceptable indices of concurrent validity. All responses are rated on 11-point Likert scales.

The questions chosen from each measure were those most pertinent to the global construct of maladjustment. Questions not used were judged to be irrelevant or to be excessively embarrassing when administered in a telephone interview.

A principal-component factor analysis, with orthogonal rotations according to Kaiser's criteria, was performed on the responses to the 23 questions dealing with adjustment. This resulted in three major factors: socioemotional functioning, work-study performance, and family-friend relationships. These factors involved 10, 3, and 5 items, respectively, scored to ensure equal weighting. The cutoff points used to judge abnormality were the same as those used in the original versions. This judgment was made after the individual index scores were weighted by the factor loadings and then normalized by a Z transformation. Those with a total average score in the top decile were judged abnormal.

The other principal measure, the degree of expected diabetic control (EDC), used information obtained from the interview with the doctor. The interview included 23 questions covering attitudes and practices regarding the control of diabetes when the child was under their care. Doctors were asked specifically about insulin dosage, diet, and urine testing and about their general philosophy as follows: "In summary, would you say your goal in caring for diabetics was to aim for: 1) no glycosuria, 2) one or two tests with a trace or more of sugar per day, or 3) simply to prevent ketonuria, regardless of glycosuria?" Responses were then judged by a panel of four physicians and given a score based on consensus about the extent to which each response was indicative of loose, intermediate, or tight control. All scores were given equal weights, and a mean EDC was derived.

Correlations between EDC and the patient's own rating of the doctor's overall strictness, insulin dosage, diet, and urine testing instructions were all highly significant. The doctors' EDC scores placed 72% of them in the strict category, and 61% of the patients classified the doctors identically.

The patient's judgment of what the doctor's expected level of control was may have been compromised by failure to recall this accurately in view of the average age of onset of IDDM. This judgment, however, was not crucial, and was simply intended to corroborate the EDC

based on the doctor's self-report. The mean EDC score was 2.0 (SD 0.23) with a range from 1.3 to 2.7. Loose control was defined as scores <1.8; intermediate control, scores between 1.8 and 2.2; and tight control, scores >2.2. Accordingly, 19 (8.4%) patients were classified as having doctors practicing loose control, 50 (20%) were in the intermediate control group, and 156 (72%) were in the tight control group.

To analyze the statistical relationship between EDC and adjustment, analysis of covariance (ANCOVA) was used with covariance adjustment for age, sex, and the other potentially confounding variables as listed in each of the tables. Although this procedure does not exclude the possibility that significant covariate-variable differences account for the results, it does diminish the possibility of such an effect.

RESULTS

Fourteen percent of the subjects had findings indicative of emotional problems. However, there were no statistically significant relationships between EDC and emotional functioning. As shown in Table 3, the main effect of EDC on work-study performance was not significant. Although men tended to have worse scores, as did those with fathers employed in manual jobs, after adjustment for the effects of sex and job status, the small linear relationship seen was not statistically significant.

EDC, language, and marital status each had significant effects on the family-friend relationship adjustment score; the largest was that of marital status, with those who were married having better scores. Likewise, English-speaking respondents had better scores than French-

TABLE 3
Relationship between psychosocial functioning and level of expected diabetic control

	n	Adjusted mean	F	P
Work-study performance*			0.3	NS
Loose	14	8.8		
Intermediate	29	9.0		
Tight	88	9.5		
Family-friend relationships†			2.4	.09
Loose	19	28.1		
Intermediate	42	26.9		
Tight	155	28.0		
Socioemotional functioning‡			0.2	NS
Loose	19	4.6		
Intermediate	42	4.5		
Tight	151	4.6		

Loose, intermediate, and tight control are defined as expected diabetic control scores <1.8, 1.8–2.2, and >2.2, respectively. For explanation of scores, see MATERIALS AND METHODS.
*Means are adjusted for effects of sex and job status.
†Means are adjusted for effects of language and marital status.
‡Means are adjusted for effects of sex, social class, and health.

speaking respondents. Again, however, after adjusting the EDC scores for the effects of these confounding variables, no statistically significant relationship was found.

EDC, social class, or sex, taken alone, did not significantly affect the scores on the socioemotional functioning factor; however, the response to a general question on health was significantly associated with it. After adjusting for the effects of sex, social class, and the general health question, EDC was not found to be significantly related to socioemotional functioning.

DISCUSSION

There is considerable evidence that children with diabetes, as well as children or adolescents with chronic disorders, may have more emotional disturbance than their healthy peers (16–18). Although some recent studies of IDDM conclude otherwise (19–21), the general assumption of increased risk for maladjustment is reasonable and remains to be disproven. Simonds (22) observes that because children with diabetes become dependent on diet, medications, and physicians, the psychological effects are easy to understand. Other investigators suggest that the adjustment problems seen in many teenage diabetic patients may be intensified by debates with parents when the demands of care are stringent (23).

Our investigation was prompted by a concern that some of these problems reflect the nature of medical care itself. In particular, we examined the hypothesis that there is a causal relationship between efforts to obtain tight control and emotional disturbances. This relationship has been characterized as "iatrogenic management reactions" resulting from "over-zealous physicians" (24). The question is of crucial interest because without such information, conscientious doctors will continue to worry about such effects when they press for good control.

Few suggest that emotional problems are important in the etiology of IDDM but rather that they are a frequent consequence of it and, when present, may make management more difficult (22). Although several studies suggest that good control is associated with better psychological functioning, it is not yet certain in what manner they are related (25,26). Most studies are cross-sectional, and therefore no firm conclusions about the direction of the effects can be drawn.

In contrast, the design of our investigation allows stronger inferences. It appears that the effort to obtain good control, contrary to what has been hypothesized, does not entail any measurable undesirable psychosocial consequences over the 15 yr from the average age of onset. We emphasize, however, that this conclusion should not be regarded as proven. Indeed, in the absence of a prospective study of considerable magnitude, conclusive evidence of no difference is very difficult to establish.

The measure of emotional disturbance used in this

study is based on two well-standardized and validated procedures (11,15). The original measures were modified because several scales (e.g., sexuality) were judged too sensitive to administer in a telephone interview. In view of this, the results must be interpreted with caution. Note, however, that this measure yields a rate of disturbance (~14%, representing those with scores in the most deviant decile) that is identical to that found in a major community-based study of mental health among noninstitutionalized adults in the United States (27). Thus, the items selected appear sufficiently sensitive to detect clinically important levels of emotional disturbance.

We are also reasonably confident that the measure of diabetic control expected by the doctor, based on statements about procedures and practices regarding the care of diabetes, is an adequate index of the expectations placed on the child and family. Although the physicians' recollections of their past care may be imperfect, the manner in which these were probed, beginning with questions about current practices and whether these differ from the past, makes it unlikely that selective recall would bias the responses. In view of the fact that the trend has been toward tighter control, however, those wanting to give more socially desirable responses may have been more inclined to categorize their past approach as tight. The misclassification that would result would yield results that favor rejection of the hypothesis. However, there is little reason to believe this occurred to any large extent. In fact, as the patient graduated from pediatric care, the physicians most recently involved would probably strive for tight control in keeping with the growing evidence in support of its value. This would exaggerate any adverse effects of earlier strict care.

The fact that all the subjects were drawn from a camp for diabetic children may further influence the conclusions. Camp attendance may help in the adjustment to diabetes, possibly through increasing the child's mastery of the illness (28,29). If true, this selection factor may mask the possibly negative effects of tight control. Similarly, the peer group at camp may have a buffering effect through a shared commitment to good control.

As had been stated, the principal focus of this study is the possible association between the level of control the doctor was trying to achieve and the patient's emotional adjustment, not on the actual control achieved. The ability to assess actual control more precisely (i.e., via HbA_{1c} levels) would enable further exploration of the relationship with maladjustment. Self-monitoring of blood glucose may also influence these results because it enables the patient to achieve better control with greater ease and certainty. However, because compliance can now be measured more accurately, there may be less latitude for the patient to escape from the demands of the regimen, which may have the opposite effect in terms of psychosocial functioning.

Although there is clear evidence of maladjustment in our sample of young adults with diabetes, it does not seem to be related to the philosophy of care to which they were subjected during childhood. Understandably,

when a doctor tells a child he/she must take medicine regularly or follow a strict diet with the implicit or explicit message that failure to do so will seriously impair his/her health, the child may become anxious and worried. The stress increases if it is difficult to comply with these instructions or when parents reinforce the doctor's demands, especially during adolescence. However, other factors may have a mitigating effect; children's reactions necessarily vary depending on their developmental level and individual background, and diabetes-care teams can, and often do, obtain psychological consultation as the need arises.

In light of articles questioning the desirability and feasibility of good control published over the last two decades (9,30), combined with the weak evidence then available linking tight control to the prevention of complications, it is not surprising that many physicians in the 1960s agreed with the conclusion that further attempts to gain rigorous control of blood glucose levels might be psychologically harmful (31).

The most powerful counterargument to this view is based on studies that suggest that self-monitoring of blood glucose results in a striking decrease in depression scores concurrent with lowering of HbA_{1c} levels (32). Before the availability of self-monitoring, the expectations placed on these patients were often unrealistic (33). It appears, however, that insulin infusions lead to improved glucose control (34,35); that implantable pumps are generally acceptable (36); and that the improvements from these measures may be maintained for years with the result that some of the features associated with microangiopathy may be arrested or even reversed (37,38).

Given these findings, which taken together offer strong support for working toward tighter control, it is somewhat surprising that in a recent survey of practices of pediatric diabetologists, only 58% recommended normal diet for age (39). Furthermore, self-monitoring was being used exclusively by <25% of patients in most clinics, and only 70% of clinics recommended twice-daily injections. Clarke et al. (39) suggest that their observations raise "significant questions concerning the reasoning behind current diabetes practices." The findings we report may help reconcile these disparities by diminishing concerns about the emotional implications of tight control.

ACKNOWLEDGMENTS

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