Deviation From Developmentally Appropriate Self-Care Autonomy

Association with diabetes outcomes

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OBJECTIVE — Treatment of IDDM in youth emphasizes balancing children's self-care autonomy with their psychological maturity. However, few data exist to guide clinicians or parents, and little is known about correlates of deviations from this ideal.

RESEARCH DESIGN AND METHODS — In this cross-sectional study, IDDM self-care autonomy of 100 youth was assessed using two well-validated measures. Three measures of psychological maturity (cognitive function, social-cognitive development, and academic achievement) were also collected for each child. Composite indexes of self-care autonomy and of psychological maturity were formed, and the ratio of the self-care autonomy index to the psychological maturity index quantified each child's deviation from developmentally appropriate IDDM self-care autonomy. Based on these scores, participants were categorized as exhibiting constrained (lower tertile), appropriate (middle tertile), or excessive (higher tertile) self-care autonomy. Between-group differences in treatment adherence, diabetes knowledge, glycemic control, and hospitalization rates were explored.

RESULTS — Analysis of covariance controlling for age revealed that the excessive self-care autonomy group demonstrated less favorable treatment adherence, diabetes knowledge, hospitalization rates, and, marginally, glycemic control. Excessive self-care autonomy increased with age and was less common among intact two-parent families but was unrelated to other demographic factors.

CONCLUSIONS — The findings indicate caution about encouragement of maximal self-care autonomy among youth with IDDM and suggest that families who succeed in maintaining parental involvement in diabetes management may have better outcomes.

T reatment of youths with IDDM entails a complex medical and lifestyle regimen that is coordinated by health professionals but implemented, monitored, evaluated, and often adjusted largely by patients and their parents. The recent Diabetes Control and Complications Trial (DCCT) proved that maintenance of near-normoglycemia prevents the development and slows the progression of long-term complications of IDDM such as retinopathy, nephropathy, and neuropathy (1,2). Emphasis on aggressive self-management of IDDM by patients and families will likely increase in the aftermath of those findings. Hence, information about factors affecting the efficacy of diabetes self-management skills will increase in importance as IDDM therapy evolves in response to the DCCT findings.

Current therapy for childhood IDDM encourages developmentally appropriate self-care autonomy, but there are few data available to guide parents or health professionals. Several authors have argued that expectations for self-care autonomy exceeding the child's cognitive, affective, or behavioral capabilities may compromise adherence and diabetic control (3–5). Others have hypothesized that constraining the otherwise capable child from assuming developmentally appropriate treatment responsibility may convey a lack of confidence in the child, discouraging future initiative and responsibility (6).

Several authors have offered recommendations for age-appropriate self-care autonomy, but there is disagreement among them, and no recommendations have been validated empirically (7–12). Others have shown that diabetes knowledge and skill levels increase with age, but these studies have not yielded clinically practical guidelines (13–18). These studies revealed correlations between age and specific IDDM knowledge or skills ranging from 0.45 to 0.75, suggesting that age is an imperfect marker of IDDM self-care autonomy and that other dimensions of psychological maturity require consideration in clinical and educational management of childhood diabetes.

Previous studies by Wysocki and colleagues included surveys of 229 health care professionals (19) and 490 parents of youth with IDDM (20) concerning age-related changes in children's mastery of 38 IDDM self-care skills. Comparison of the results obtained with parental and professional versions of the Diabetes Independence Survey (DIS) (20) revealed that parents and professionals agreed closely about the sequence in which specific skills were mastered (Spearman's $p = 0.74$), but there was substantial disagreement about the ages at which individual skills were mastered. Parents rated young children as more skilled and adolescents

Table 1—*Characteristics of the enrolled sample*

n	100
Age (years)	12.3 ± 3.1
Duration of IDDM (years)	5.2 ± 3.1
Age at diagnosis (years)	7.1 ± 2.9
GHb (%)	11.1 ± 2.1
Hollingshead Four Factor Index of SES	41.1 ± 12.7
Sex (%)	
Female	59
Male	41
Family structure (%)	
Living with both biological parents	64
Living with one parent and one step-parent	25
Living with single parent	6
Living with other relatives	5
Race/ethnicity	
White	86
African-American	13
Other/biracial	1

Data are means ± 1 SD.

as less skilled than did the health professionals.

This study extends that work by examining the correlates of deviations between children's IDDM self-care autonomy and objective estimates of their psychological maturity. Two measures of IDDM self-care autonomy were combined into a composite index of that construct. Similarly, three sound measures of intellectual, social-cognitive, and academic maturity were entered into a composite index of psychological maturity for each youth. The ratio of the IDDM self-care autonomy index to the psychological maturity index (the autonomy-to-maturity ratio [AMR]) quantified each child's deviation from developmentally appropriate IDDM responsibility. This study examined the associations between the AMR and treatment adherence, diabetes knowledge, glycemic control, and frequency of diabetes-related hospitalizations among youths with IDDM.

RESEARCH DESIGN AND METHODS

Participants
A sample of 100 children and adolescents and 1 parent of each child participated in the study at three pediatric medical centers. Enrollment criteria required that the child had IDDM for at least 1 year, was at least 5 but not yet 18 years old at enrollment, had no other chronic diseases, was not thought to be mentally retarded by

the physician or parent, and had vision and hearing within normal limits.

Recruitment began by mailing an introductory letter signed by the physician and an investigator and a copy of an informed consent form to the parents of potential participants. The letter was followed by a telephone call from the research assistant about 2 weeks later. An enrollment rate of ~30% was achieved. At two of the participating centers, 23 parents of children who did not agree to participate in the study provided demographic information for the purpose of evaluating the representativeness of the enrolled sample. Characteristics of the enrolled participants are summarized in Table 1. Although representativeness of the sample cannot be assured, the distributions of age, socioeconomic status (SES), race/ethnicity, and previous glycohemoglobin levels were similar to those of the clinic populations at the participating sites and of participants in this group's previous research studies.

Setting
Participants were enrolled at one of three pediatric clinics: Nemours Children's Clinic in Jacksonville, FL (n = 66); Children's Hospital, Columbus, OH (n = 21); and Michigan State University, East Lansing, MI (n = 13). All patients received care for IDDM under the direction of subspecialty-certified pediatric endocrinologists. Details of the treatment regimens differed across centers, but all regimens

included two or more daily insulin injections, self-monitoring of blood glucose, a constant carbohydrate, low-fat diet, emphasis on self-management education of patients and families, and minimization of hypoglycemia, prolonged hyperglycemia, and ketonuria. Information collected for research purposes beyond that reported for this study indicated that the study sample had experienced severe hypoglycemic episodes less frequently (5.4 episodes per 100 patient-years) than was reported for adolescents in the DCCT conventional therapy group (2). The sample also demonstrated a normal distribution of scores on a measure of childhood behavioral problems (21).

Procedure and measures
Each child and parent completed a single evaluation session conducted by a research assistant with graduate training in clinical psychology, experience in psychological testing, and competence in administration of the study measures. Evaluations began with obtaining informed consent from parents and assent from patients. Participants had been instructed to bring snacks and blood glucose testing equipment. No youths complained of symptoms of hypoglycemia during the evaluations. Parents were instructed in completing certain of the questionnaires described below. Patients were then taken to a private examination room where the research assistant administered other measures that are described below. Evaluation sessions lasted about 3.5 h. The order of administration of the various measures was counterbalanced across participants.

Demographic information
Parents completed the General Information Form, which was used for collection of demographic information, pertinent medical and school histories, and calculation of the Hollingshead Four Factor Index of Social Status (A.B. Hollingshead, unpublished observations), a common measure of SES.

Measures of IDDM self-care autonomy
Two measures were collected for assessment of each child's degree of diabetes self-care autonomy. These measures provided, respectively, assessments of parent-child sharing of diabetes responsibilities and of parents' perceptions of their

children's IDDM self-management capabilities. The two measures correlated 0.82 with each other, and it was felt that the combined measures would provide a more reliable index of IDDM self-care autonomy than would either instrument alone.

The Diabetes Family Responsibility Questionnaire (DFRQ) measures family division of responsibility for 17 aspects of the IDDM regimen (23). Parents rate each treatment task on a three-point Likert scale as a parent, child, or shared responsibility. Higher scores indicate greater child responsibility. Internal consistency was 0.85 in a study of 121 families, and total scores correlated 0.74 with the child's age.

The DIS was developed by the first author for a multicenter survey of 490 parents of youth with IDDM (20). Parents were asked to indicate whether their child had achieved mastery of each of 38 diabetes skills and concepts, with mastery defined as the capacity to display the skill without parental assistance, prompting, or supervision. Total scores on the instrument correlated 0.71 with age, and a rank-order correlation of 0.74 was obtained with a parallel form completed by health professionals. Scores were not correlated significantly with duration of IDDM.

Diabetes Self-Care Autonomy Index
For each patient, a composite index of IDDM self-care autonomy was calculated by first summing raw scores from the DIS (20) and DFRQ (23) and transforming these sums into z-scores. A constant of 3.0 was added to z-score–transformed raw scores before statistical analyses to avoid data analysis problems entailed in the treatment of negative values.

Measures of psychological maturity
Three measures of children's intellectual, social-cognitive, and academic maturity were administered.

A prepublication version of a new test of cognitive processing, the Das-Naglieri Cognitive Assessment System (CAS), was used to measure intelligence as defined by the Planning, Attention, Simultaneous, Successive (PASS) theory (24,25). The PASS theory is based primarily on the neuropsychological work of A.R. Luria (26), which was used as a framework to develop and organize the 16 cognitive subtests into 4 factor-analytically de-

rived scales. This test battery, which is currently being standardized nationally with a large representative sample of children and adolescents, has been shown to provide reliable and valid measures of planning, attention, and simultaneous and successive processing (24,25). The CAS was selected over other intelligence tests because it is unique in providing measures of planning and attention, and it has been developed for administration to youths throughout the 5- to 18-year age range targeted in this study. It has been in development for more than 9 years and is supported by a large body of preliminary research (24).

The Interpersonal Negotiation Strategies Interview (INS) is a structured interview that assesses social-cognitive development in children older than age 4 (27,28). Psychometric properties of the INS have been well-documented (27,28). Children were presented verbally with a series of eight age-adjusted social dilemmas and guided by the interviewer to articulate the problem, specify why it is a conflict, identify possible solutions, and project the consequences of each solution. With consultation by one of the authors of this method (K.O.Y.), we constructed age-adjusted items consisting of IDDM-specific social dilemmas. Each patient was then interviewed using four general and four IDDM-specific social dilemmas. Interviews were audiotaped for later scoring, which yielded measures for each child for problem identification, generation of solutions, evaluation of solutions, and selection of a solution, as well as composite indexes of social-cognitive maturity for general, IDDM-specific, and all social dilemmas. The composite measure of social-cognitive maturity was correlated 0.65 with age. Since total scores that were derived from the general and IDDM-specific social dilemmas correlated 0.92, combined scores were used for all data analyses.

The Wide Range Achievement Test-Revised (WRAT-R) was used to assess children's academic maturity. The WRAT-R is a widely used screening test of academic achievement that can be administered to children as young as 5 years of age (29). Its advantages for the present study were its brief administration time and recent restandardization. The test has sound psychometric properties.

Psychological maturity index
As above, a composite index of psychological maturity was derived for each patient by transforming the sums of raw scores for the CAS (24), INS (27), and WRAT-R (29) into z-scores. The three component measures were all significantly positively correlated, with Pearson r values ranging from 0.38 for the correlation between the INS and WRAT-R to 0.64 for the correlation between the CAS and WRAT-R. As above, a constant of 3.0 was added to z-score–transformed raw scores before statistical analyses to avoid data analysis problems entailed in the treatment of negative values.

AMR
The ratio of the Self-Care Autonomy Index to the Psychological Maturity Index provided a measure of the extent to which each child exhibited developmentally appropriate self-care autonomy relative to objective assessments of that child's psychological maturity. Scores on this measure were divided into tertiles and patients were assigned to three groups as follows: constrained (scores ≤ 0.95; $n = 33$); appropriate (scores from 0.96 to 1.22; $n = 34$); and excessive (scores ≥ 1.23; $n = 33$).

Outcome measures
Information was collected regarding diabetes outcomes in terms of treatment adherence, diabetes knowledge, recent glycemic control, and frequency of diabetes-related hospitalizations for each child.

The Self Care Inventory (SCI) is a 14-item Likert-type scale used for the assessment of adherence with the IDDM regimen (30). It has adequate internal consistency and test-retest reliability, and it is well correlated with analogous measures derived from Johnson's 24-h recall interview method (31).

The Diabetes Information Survey for Children (DISC) is a 98-item structured interview administered in the same format for all ages (32). It yields a reliable measure of diabetes knowledge that has been validated with children as young as 5 years of age. The total score from the instrument correlates 0.76 with age, and it is not significantly correlated with duration of IDDM.

Results of the most recent GHb tests completed within the prior 6 months were retrieved from each child's medical chart as an index of average glycemic con-

trol over the preceding 2–3 months. Since the three centers used different methods and laboratories for these assays, the results for patients enrolled from each center were transformed into z-scores relative to that center's distribution of GHb results. The z-scores were used for all statistical analyses pertaining to this measure.

Data on each child's frequency of diabetes-related hospitalizations, excluding the hospitalization at the time of diagnosis, were obtained by parental report. Parents were asked to report the total number of IDDM-related hospitalizations since the child's diagnosis. Medical chart reviews were impractical because of the large number of hospitals involved, and it was felt that parents would have accurate recall of their children's hospitalizations because of their salience and low frequency.

RESULTS

Sampling

Participants did not differ from the sample of 23 families who declined enrollment in terms of age, race, duration of IDDM, SES, family size or composition, or history of special education placement. Girls were over-represented among participants (59%). There were no differences among the three centers with respect to the above demographic factors, hospitalization rates, GHb, or any of the psychometric measures collected for the study.

Statistical analysis

Mean ages of the three groups in years were as follows: constrained, 11.5; appropriate, 12.4; and excessive, 13.1. Age correlated 0.29 ($P < 0.001$) with the AMR. The groups did not differ with respect to age at diagnosis, duration of IDDM, sex distribution, SES, or family size. AMR scores for youths from intact, two-parent families were significantly lower than those from youths from alternative family structures [$F (3,96) = 5.87; P < 0.001$]. Previous studies have revealed significant associations between age and IDDM outcomes such as those measured in this study. Consequently, multivariate analysis of covariance (ANCOVA), with age as the covariate, was used to examine between-group differences in GHb concentrations, treatment adherence as measured by scores on the SCI, diabetes knowledge as measured by the DISC, and frequency of diabetes-related hospitaliza-
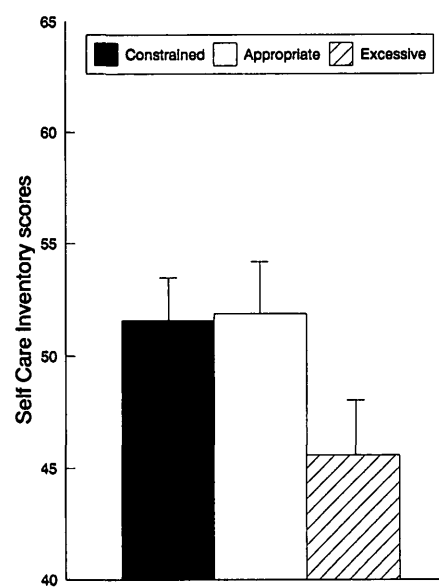

Figure 1—*Mean (+ 1 SE) scores on the SCI for the three groups. (Higher scores indicate better treatment adherence.)*

tions. A significant multivariate group effect was obtained [$F (3,96) = 2.98$, $P < 0.004$, and Wilks' $\lambda = 0.78$] and followed by univariate ANCOVA for each of the outcome measures. The covariate effect was significant for the analysis of group differences in diabetes knowledge but nonsignificant for the other analyses.

Figure 1 presents the mean scores for each group on the SCI (29). The values obtained were as follows: constrained, 51.6; appropriate, 51.9; and excessive, 45.6. These values indicate poorer treatment adherence with increasing IDDM self-care autonomy relative to psychological maturity. ANCOVA yielded a significant main effect for groups, with $F (3,96) = 4.47$ and $P < 0.01$. Effect size estimated by R^2 indicated that group membership accounted for 14% of the variance in treatment adherence. Post hoc analysis using the Tukey test indicated that scores for the excessive group differed significantly from those for the appropriate and constrained groups, but the latter groups did not differ significantly from one another.

Figure 2 presents each group's mean scores on the DISC (31). ANCOVA controlling for age yielded $F (3,96) = 4.56$ and $P < 0.01$. Post hoc analysis using the Tukey test revealed that scores for the appropriate group were significantly higher than were those for either of the other two groups.
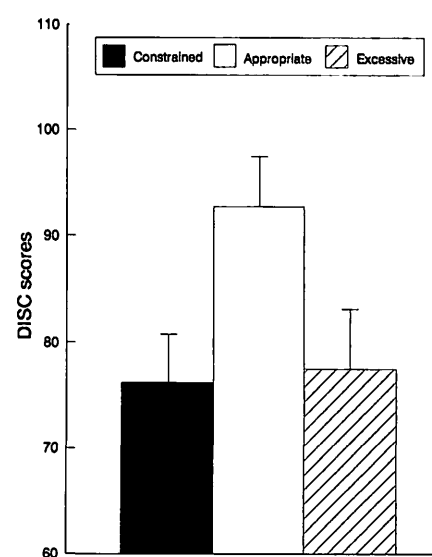
Mean GHb levels are shown in

Figure 2—*Mean (+ 1 SE) scores on the DISC for the three groups. (Higher scores indicate more diabetes knowledge.)*

Fig. 3. The main effect for groups achieved a marginal level of statistical significance with $F (3,95) = 2.48$ and $P = 0.06$.

Figure 4 displays the mean number of IDDM-related hospitalizations per 100 patients per year since IDDM onset, excluding the hospitalization at the time of diagnosis, as reported by parents. The mean numbers of hospitalizations per 100 patients per year since diagnosis of IDDM were as follows: constrained, 0.7; appropriate, 1.9; and excessive, 3.5. AN-COVA conducted as above yielded a sig-
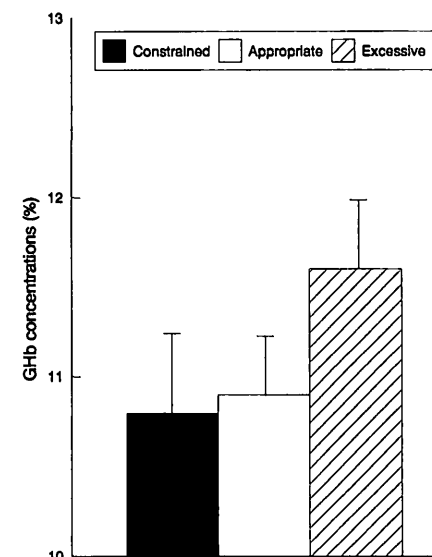

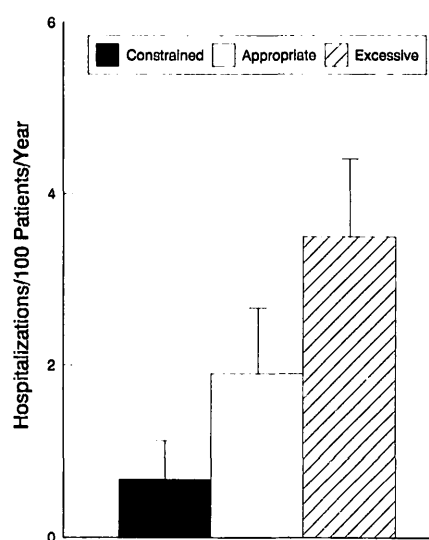**Figure 3**—*Mean (+ 1 SE) GHb concentrations for the three groups.*

Figure 4—*Mean number of hospitalizations (+ 1 SE) per 100 patients per year for the three groups.*

nificant between-group effect on these reported hospitalization rates with $F(3,96) = 5.06$ and $P < 0.008$ and on number of hospitalizations with $F(3,96) = 3.50$ and $P < 0.03$. Effect size estimated by R^2 indicated that group membership accounted for 13% of the variance in hospitalizations per year and 17% of the variance in number of hospitalizations. The mean number of hospitalizations reported for each group were as follows: constrained, 0.45; appropriate, 1.41; and excessive, 2.09. Median values for the three groups were as follows: constrained, 0; appropriate, 0; and excessive, 2. One patient in the constrained group and three patients in the appropriate group had more than two hospitalizations, while nine patients in the excessive group had more than two admissions. Post hoc analysis using the Tukey test indicated that all three groups differed significantly from one another.

CONCLUSIONS— The present results indicate that excessive IDDM self-care autonomy, as indexed by the AMR calculated in this study, was associated consistently with adverse outcomes in terms of treatment adherence, diabetes knowledge, and hospitalizations and a similar, albeit marginal, relationship with diabetic control. In contrast, constrained IDDM self-care autonomy was associated with more favorable outcomes in terms of treatment adherence and diabetic control compared with that reported for children

with both developmentally appropriate and excessive levels of self-care autonomy.

Children in the appropriate self-care autonomy group demonstrated greater diabetes knowledge than did those in the other two groups. This finding may be open to several interpretations. Lesser diabetes knowledge is perhaps to be expected among youths in the constrained group who were younger and whose parents were more involved in IDDM management. Less intuitively, youths in the excessive group experienced less parental involvement in diabetes care and, consequently, fewer opportunities for parental feedback and refinement of their knowledge of IDDM. It is also possible that assumption of developmentally appropriate levels of diabetes responsibility may facilitate children's mastery of knowledge and skills related to the disease. The apparently weaker diabetes knowledge of children in the constrained group may be of little clinical consequence since parents of these children are relatively more involved in their diabetes management. But, the lower knowledge demonstrated by the excessive group is more ominous clinically since it could predispose those children to dangerous treatment errors, possibly culminating in the poor diabetic control and increased frequency of hospitalizations documented among those children in this investigation.

This study also provides important methodological contributions. Our results substantiate the validity of the methodology introduced here for quantifying the degree of children's deviation from developmentally appropriate levels of self-care autonomy. These methods may be applicable to addressing other empirical questions about the determinants and the consequences of imbalances of IDDM self-care autonomy and psychological maturity.

Our findings lend support to the speculations of other authors who have identified possible deleterious effects of developmentally excessive self-care autonomy among youth with IDDM (3–5,8,32–35). The present results generally fail to support the speculation that parental involvement in diabetes management might entail adverse consequences (6), since only one outcome measure (diabetes knowledge) favored the appropriate group over the constrained group.

The positive association obtained between age and the AMR implies that

older children and adolescents are progressively more likely to exhibit excessive levels of self-care autonomy relative to their psychological maturity. Similar findings have been reported in several previous studies. Ingersoll et al. (33) reported that parents tend to relinquish higher-level diabetes self-management responsibilities to adolescents independently of the youths' cognitive maturity. Allen et al. (34) and La Greca et al. (35) observed that among older children, greater levels of child responsibility for IDDM management were associated with poorer diabetic control. Wysocki et al. (20) found that mastery of several types of IDDM self-management skills appeared to reach an asymptote during early to middle adolescence. These included IDDM tasks that were more cognitively complex (e.g., basic knowledge of insulin pharmacology), skills for which nonadherence typically yields delayed or uncertain negative consequences (e.g., adjustment of dietary intake in response to blood glucose fluctuation), and skills that are infrequently invoked for most patients and families (e.g., urine ketone testing). The present data bolster the implication of this collection of studies that families who succeed in maintaining parental involvement in IDDM management during adolescence are likely to achieve better diabetes outcomes. This study provides no information about the precise nature of that involvement, the characteristics of families who demonstrate it, or the role of clinical and educational practices in its cultivation.

The interpretation of these results and their clinical implications must be done with consideration of the cross-sectional nature of the present study. The direction of causality, if any, between the AMR and diabetes outcomes cannot be specified by this study, and the results do not necessarily implicate inadequate parenting or misguided clinical management as causal agents. It is entirely plausible, for instance, that youths with poor treatment adherence, deficient diabetes knowledge, chronic hyperglycemia, and frequent hospitalizations actively discourage adult involvement in their diabetes management. Alternatively, parents and clinicians whose diabetes management efforts have met with failure may resign themselves to accept suboptimal self-care by adolescents. The association between the AMR and hospitalization

rates may have been inflated because parental reports of hospitalizations may have been inaccurate, and no attempt was made to distinguish between recent and past hospitalizations.

Numerous reports have implicated family conflict in general (36–39) and parent-adolescent conflict and communication problems in particular (40–43) as correlates of ineffective diabetes management. Although the available research directs attention to these interaction patterns as possible mediators of adverse IDDM outcomes, this link can only be proven by a well-conceived longitudinal investigation. Similarly, the present study provides no information about the long-term sequelae of developmentally constrained or excessive IDDM self-care autonomy. Although little or no adverse effects of constrained diabetes responsibility were evident and excessive self-care autonomy was associated consistently with unacceptable outcomes, different effects of these patterns might be evident over the long term. Again, only a longitudinal study could clarify these issues.

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