

Validation of a Structured Interview for the Assessment of Diabetes Self-Management

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OBJECTIVE — The authors developed and validated a semi-structured interview, the Diabetes Self-Management Profile (DSMP), to measure self-management of type 1 diabetes. The DSMP includes the following regimen components: exercise, management of hypoglycemia, diet, blood glucose testing, and insulin administration and dose adjustment.

RESEARCH DESIGN AND METHODS — Families of youths with type 1 diabetes ($n = 105$) who were entering a controlled trial of intensive therapy (IT) versus usual care (UC) were administered the DSMP. Analyses assessed the reliability and validity of the DSMP, including its associations with HbA_{1c} and quality of life.

RESULTS — The DSMP total score has adequate internal consistency (Cronbach's α 0.76), 3-month test-retest reliability (Pearson correlation, $r = 0.67$), inter-interviewer agreement ($r = 0.94$), and parent-adolescent agreement ($r = 0.61$). DSMP total scores ($r = -0.28$) and 3 subscales correlated significantly with HbA_{1c} (diet [$r = -0.27$], blood glucose testing [$r = -0.37$], and insulin administration and dose adjustment [$r = -0.25$]). Adolescents' reports of self-management did not differ from parental reports. Higher DSMP scores were associated with more favorable quality of life for mothers and youths.

CONCLUSIONS — The DSMP is a convenient measure that yields a reliable and valid assessment of diabetes self-management. Compared with extant similar measures, the DSMP is more strongly correlated with HbA_{1c}.

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Management of type 1 diabetes requires patients and their families to implement, monitor, and regulate a complex regimen. Many studies show that patients have difficulty consistently meeting the expectations of health care providers and fulfilling basic self-management responsibilities (1–5). Published estimates of non-adherence rates have ranged from 40 to 90% across studies and measures (1–5).

However, research on the determinants and consequences of effective self-management of diabetes has been fraught with conceptual and methodological impediments (4,5).

First, there are disagreements about semantics and terminology related to such constructs as compliance, adherence, and self-management that have implications for the development and validation of appropriate measures of these constructs (5–8).

Compliance and *adherence* have been used to indicate how a person's behavior coincides with medical advice, such as the percentage of insulin injections given on time (5). These terms are somewhat pejorative and assume a dichotomy between healthy and unhealthy behavior (5). Additionally, this terminology may evoke a negative emotional stance from the respondent, resulting in reactivity and inaccurate responding. In contrast, the term *self-management* encompasses the behaviors displayed by a patient or family members that are directed at the establishment, maintenance, and monitoring of diabetic control, as well as the prevention or correction of deviations from targeted blood glucose levels. *Self-management* therefore emphasizes the amount, precision, and regularity of these behaviors rather than the degree to which the patient's behavior conforms to prescribed ideals.

Second, the most reliable and valid measure of these behaviors would require unobtrusive and continuous recording of the patient's diabetes self-management behaviors by a totally accurate observer. Because this is impractical and unacceptable, all existing measures of diabetes self-management attempt to approximate this ideal using more convenient and acceptable methods while preserving accuracy of measurement (4,5,9). A variety of questionnaires (10–12) and structured interviews (4,9,13) have been developed and validated.

Third, existing research confirms that adherence with diabetes treatment is not a unitary behavioral trait. Instead, adherence with the various regimen components is often uncorrelated and differentially stable over time (4,9,14,15). Any sound measure of diabetes self-management must capture this complexity.

Finally, most studies with extant measures have failed to confirm a statistically significant association between treatment adherence and diabetic control (4,9,14,16). Although this is perplexing, many plausible factors could dilute this association, including 1) a lack of temporal congruity between the measures of diabetes self-management and of diabetic control, 2) unreliable assessment due to measurement bias, 3) the pos-

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Abbreviations: DQOL, Diabetes Quality of Life; DSMP, Diabetes Self-Management Profile; IT, intensive therapy; UC, usual care.

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

sibility that adherence and metabolic control are associated in a nonlinear fashion, and 4) the observation that poor adherence with 1 regimen component can be offset by good adherence with another (4–9). Much variance in diabetic control may be attributable to genetic, biologic, and demographic factors and characteristics of the insulin, diet, and exercise regimens (14). A sound measure of self-management might therefore account for only a modest proportion of variance in diabetic control.

With the evolution of diabetes care toward more intensified therapy, assessing self-management has become more complex (8,17). Extant measures of adherence may not account for recent advances (4,8,9), such as insulin pump therapy, the use of rapidly acting insulins, and the application of clinical algorithms for insulin dosage adjustment.

In the 1980s, Hanson et al. (13) developed and tested a semi-structured interview to assess diabetes self-management. The development of this tool represented a change in the evaluation of self-management by addressing the different prescriptions given by health care providers for individuals with diabetes and by providing response options that reflect these differences. Hanson et al. revised this tool in 1989; however, no additional changes have been made since that time.

The above considerations led us to attempt to validate a measure of diabetes self-management that is convenient to administer and score, minimizes self-report bias, measures adherence with each dimension of diabetes treatment, can accommodate flexible self-management as it occurs in intensive therapy, and reflects significant associations between diabetes self-management and glycemic control. In this study, we report the results of our efforts to refine the structured interview developed by Hanson et al. (13) and present data on the reliability and validity of the Diabetes Self-Management Profile (DSMP).

RESEARCH DESIGN AND METHODS

Participants

Study participants included the first 105 youths with type 1 diabetes and their parents or caregivers who entered a larger study on intensive diabetes management. All families were randomized to 18 months of treatment with intensive therapy (IT) or

usual care (UC). Families were approached at regularly scheduled clinic visits. Inclusion criteria were as follows: 6–15 years of age; type 1 diabetes for ≥ 2 years, or stimulated C-peptide level ≤ 0.5 pmol/ml; no other major diseases or cognitive impairments; living with legal guardian; and not incarcerated, in foster care, or administered residential treatment. Neither the parent or caregiver nor the adolescent could have been treated for major psychiatric problems within the previous 6 months. Families who met these criteria were given study information, and interested eligible families signed an approved informed consent form. After a comprehensive baseline evaluation assessing a number of constructs (e.g., diabetes knowledge, diabetes-specific family conflict, and sharing of diabetes responsibilities), the youths were stratified on baseline HbA_{1c} and age and randomized to either IT or UC. Except for data on test-retest reliability, the data reported here are from the baseline evaluations.

Characteristics of the 105 youths (means \pm SD) were as follows: age 11.6 ± 1.2 years (range 6.1–15.8), diabetes duration 4.9 ± 2.6 years, and HbA_{1c} $8.1 \pm 0.8\%$ (range 6.1–11.3). The Hollingshead Four-Factor Index (18) of socioeconomic status indicated that the majority of parents were in occupations as minor professionals and technically trained white-collar workers (mean 44.1 ± 8.9 ; range, 13 unskilled laborers to 66 CEOs, PhDs, MDs, JDs, etc.). Girls comprised 49% of the patients, and 12% were African-American subjects.

Procedures and measures

Participants completed a baseline evaluation of demographic and psychosocial measures. Included were the DSMP interview and collection of the measures described below, as well as additional measures that are not described here and are irrelevant to the data reported in this study.

DSMP. The DSMP is a semi-structured interview based on the work of Hanson et al. (13) and designed to assess diabetes self-management over the preceding 3 months. The DSMP includes 23 questions that assess diabetes self-management in 5 domains: exercise, management of hypoglycemia, diet, blood glucose testing, and insulin administration and dose adjustment. Content analysis was conducted by a team of 4 pediatric endocrinologists, 2 pediatric psychologists, 2 registered nurses/certified diabetes educators, and 2 dietitians. Higher scores indicate more

meticulous self-management. Administration time is ~ 15 –20 min. The DSMP was designed for administration to parents or other caregivers, to youths ≥ 11 years of age, or to parent-child dyads. The interview begins with a statement, read by the interviewer, to the effect that imperfect diabetes self-management is common and that few patients consistently do all that is asked of them. To minimize response bias and maximize accuracy, the sections were ordered so that management tasks for which nonadherence is more readily admitted (exercise, diet, and hypoglycemia) were followed by tasks for which nonadherence may be less readily admitted (blood glucose testing and insulin). Questions were adapted slightly to accommodate various insulin delivery methods. Interviewers were trained to refrain from judgmental verbal or nonverbal reaction to participant responses. For youths < 11 years of age, the DSMP was administered to the parent(s) or caregiver(s) and child together. For youths ≥ 11 years of age, 26 parents and adolescents were interviewed separately; for 27 families, only the adolescents were interviewed. Interviewing adolescents who knew their parents were not being interviewed enabled comparisons of parent and adolescent responses on the DSMP. The 32 families in the UC group who had been in the study for ≥ 3 months repeated the DSMP 3 months after the baseline evaluation for test-retest reliability analyses. Finally, 28 audiotaped interviews were scored independently by 2 raters, enabling assessment of inter-rater agreement.

HbA_{1c}. During the baseline evaluation, blood was collected from each youth for an HbA_{1c} assay using the DCA2000 device. The nondiabetic mean of HbA_{1c} is $\sim 4.8\%$, with an upper limit of 6.05%.

Diabetes quality of life scale. The pediatric version of the diabetes quality of life (DQOL) scale is a 50-item measure of the effects of diabetes on children's quality of life. It was completed by parents and by youths ≥ 11 years of age in this study (19).

Statistical methods. Cronbach's α was calculated to measure internal consistency, and Pearson correlations were used to estimate inter-rater, parent-adolescent, and test-retest reliability (20). Validity was determined by examining Pearson correlations between DSMP scores, HbA_{1c} levels, and DQOL scores. Additional comparisons were made between adolescents who were administered the DSMP either

with or without separate interviews of their parents.

RESULTS

Descriptive statistics

Table 1 summarizes DSMP total and subscale scores obtained from this sample. Scores are reported (means \pm SD) for the total sample and separately for youths in the youngest (<10 years of age), middle (10.4–13.4 years of age), and oldest (>13.4 years of age) thirds of the study sample. One-way analyses of variance confirmed statistically significant effects for age on the DSMP total score ($F = 6.97$; $P < 0.001$) and subscale scores for hypoglycemia ($F = 4.66$, $P < 0.012$), diet ($F = 6.02$, $P < 0.003$), blood glucose testing ($F = 3.87$, $P < 0.024$), and insulin administration and dose adjustment ($F = 3.10$; $P < 0.049$). Youths in the oldest third of the study sample demonstrated poorer adherence than 1 or both of the other age-groups.

Reliability

Internal consistency. Internal consistency of the DSMP total (Cronbach's α) was 0.76. α -Coefficients for the DSMP subscales were all < 0.50 , indicating that the subscales are unreliable when used separately. Correlations between the total and subscale scores were as follows: exercise, 0.55; hypoglycemia, 0.55; diet, 0.87; blood glucose testing, 0.62; and insulin administration and dose adjustment, 0.54.

Test-retest reliability. Test-retest reliability over 3 months was determined using data obtained from 32 families in the UC group for whom the diabetes management regimen was not changed after randomization. Pearson correlations between baseline and 3-month scores on the DSMP were as follows: total, 0.67; exercise, 0.47; hypoglycemia, 0.40; diet, 0.44; blood glucose testing, 0.45; and insulin administration and dose adjustment, 0.34.

Inter-rater agreement. Inter-rater agreement was determined by having 2 independent raters score DSMP interviews of 28 participants and by calculating Pearson correlations between their scores. Inter-rater agreement was 0.94 for the DSMP total score (range 0.85–0.97 for subscales).

Comparison of parent and adolescent reports. Among youths ≥ 11 years of age, 26 parent-adolescent dyads were interviewed separately from one another; for another 27 families, only the adolescents, and not parents, were interviewed. This

Table 1—DSMP total and subscale scores for the entire study sample and for youths in the older, middle, and younger thirds of the sample's age range

DSMP score	Younger (<10.4 years)	Middle (10.4–13.4 years)	Older (>13.4 years)	Entire sample
Total*	60.3 \pm 8.2	59.4 \pm 7.7	54.3 \pm 9.9	58.5 \pm 9.1
Exercise	4.9 \pm 2.9	4.6 \pm 2.8	4.8 \pm 2.7	4.8 \pm 2.8
Hypoglycemia	5.7 \pm 1.4	5.2 \pm 1.5	4.6 \pm 1.7	5.2 \pm 1.6
Diet*	23.2 \pm 4.1	22.7 \pm 3.8	19.9 \pm 5.1	22.0 \pm 4.5
Blood glucose testing*	13.6 \pm 1.8	13.5 \pm 1.6	12.4 \pm 2.2	13.2 \pm 1.9
Insulin*	13.8 \pm 2.1	13.4 \pm 2.2	12.6 \pm 2.9	13.3 \pm 2.5

Data are means \pm SD. *Analysis of variance main effect for age-group statistically significant at $P < 0.05$.

permitted analyses of parent-adolescent agreement and of whether interviewing adolescents separately from their parents yielded different results than interviewing the adolescent only.

There was no significant difference (using t tests for independent means) between the DSMP total scores of parents (60.4 \pm 8.5) and adolescents (59.8 \pm 8.3) interviewed separately. Adolescents reported significantly worse adherence on the hypoglycemia subscale (4.7 \pm 1.7) than parents (5.2 \pm 1.4), but their scores on the other 4 subscales did not differ significantly. Interviewing parents separately from adolescents did not appear to affect adolescent DSMP scores.

Validity

Concurrent validity. Concurrent validity was determined by correlating DSMP and DQOL scores. The DSMP scores were significantly correlated with the DQOL scores of mothers ($r = -0.27$) and adolescents ($r = -0.27$) but not with fathers.

Predictive validity. Predictive validity was determined by correlating DSMP and HbA_{1c} results. HbA_{1c} correlated significantly with the DSMP total ($r = -0.28$, $P < 0.01$) and 3 of the 5 DSMP subscales (blood glucose testing, $r = -0.37$; insulin, $r = -0.25$; and diet, $r = -0.27$).

CONCLUSIONS — The DSMP is a practical, convenient measure of diabetes self-management with several attractive psychometric properties. Reliability of the DSMP was evaluated using several methods. Cronbach's α coefficient was acceptable for the total score but not for any of the 5 subscale scores. Agreement between 2 independent raters was 0.94 for the total score and comparable for the 5 subscales. Parent-adolescent agreement was modest at 0.61, and there was no apparent evi-

dence that adolescents interviewed separately from their parents overreported their levels of self-management behaviors. Equivalent DSMP scores were obtained from adolescents who were interviewed alone compared with adolescents who knew that their parents were also being interviewed separately. These findings suggest that interviewing adolescents alone yields a sound measure of diabetes self-management. However, the stronger test of this conclusion would have been to assess adolescent DSMP responses with parent DSMP responses within, rather than between, families. Test-retest reliability over a 3-month interval was 0.67 for the total score and ranged from 0.34 to 0.47 for the subscales. These modest associations are probably adequate for a measure of labile behaviors such as diabetes self-management.

Validity of the DSMP was assessed using several methods. DSMP scores declined with the patient's age—a finding that has been reported in many studies (1–5). DSMP total scores correlated significantly with youths' and mothers' scores on the DQOL. More meticulous self-management was associated with more favorable diabetes-related quality of life.

Most importantly, DSMP total scores and subscale scores for diet, insulin administration and dose adjustment, and blood glucose testing all correlated significantly with HbA_{1c}. More careful self-management was associated with better glycemic control. Although the DSMP scores accounted for only 6–14% of the variance in HbA_{1c} values and 7% of the variance in DQOL scores, these correlations were statistically significant ($P < 0.01$) and in the expected directions. In addition, these associations were stronger than those reported previously for other similar instruments (8–14), which is possibly related to the restricted

inclusion of items, a time frame similar to HbA_{1c} values, introductions to interview sections that "normalized" nonadherence, and extensive training of interviewers in nonjudgmental interviewing techniques.

The DSMP is a convenient and easy-to-administer measure of diabetes self-management, with acceptable levels of reliability and validity. Additional follow-up studies in our study subjects who have been randomized to 18 months of IT or UC, and use of the DSMP in other centers, will permit a more thorough evaluation and will hopefully confirm these early promising results for the method.

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