Brief Report: Normative Data on a Structured Interview for Diabetes Adherence in Childhood

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Objective This study provides normative data, divided by age and gender, for the Diabetes Self-Management Profile (DSMP), an empirically supported structured interview that assesses adherence with the type 1 diabetes treatment regimen. Despite wide use, normative data on the DSMP have yet to be reported. **Methods** The sample included 444 parents and 275 youth with type 1 diabetes. The DSMP was administered by a trained clinician. **Results** For both child and parent ratings of adherence, means and standard deviations for the overall sample and subdivision by gender and three age groups are presented for normative comparisons. Subscale data (e.g., glucose monitoring, diet, exercise) are similarly presented. Lower adherence scores were reported among older adolescents relative to preadolescents. **Conclusions** The literature has lacked normative data on pediatric diabetes adherence. These data present means and standard deviations for parent and child ratings of regimen adherence from a relatively large sample of youth with diabetes that can be utilized for normative comparisons for clinical and research purposes.

Key words adherence; children; diabetes; diabetes self-management profile normative data; DSMP; norms; type 1.

Poor adherence with the prescribed treatment regimen is commonplace among youth with type 1 diabetes (Kovacs, Goldston, Obrosky, & Iyengar, 1992; Wysocki, Hough, Ward, & Green, 1992) and has been linked to poor health outcomes (Hanson, Henggeler, & Burghen, 1987; Harris et al., 2000; Jacobson et al., 1990; Johnson et al., 1992; Lewin et al., 2006) and skyrocketing healthcare costs (ADA 2003; Dougherty, Schiffrin, White, Soderstrm, & Sufrategui, 1999; Ellis et al., 2005; Icks, Holl, & Giani, 2007). Consequently, assessment of adherence has become a central aspect of maximizing health status among youth with chronic illnesses, such as diabetes, which require a complex behavioral regimen. Although there are many methods for assessing adherence (e.g., 24-hour recall, daily diaries, electronic monitors, permanent product counts; Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008), patient- and parent-reports and structured interviews are among the most commonly employed (Johnson, 1992). Unfortunately, there are only a limited number of empirically validated instruments for assessing diabetes adherence behaviors among youth (Quittner et al., 2008). Moreover, the literature lacks normative data derived from adherence measures that allow comparison by age and gender. Normative data are required to compare an individual's adherence score with an objective value, rather than making a subjective inference (e.g., high/low; good/poor). In other words, quantitative markers such as *Z*-scores or percentiles can be calculated to describe, specifically, how an individual's score compares with a sample population.

The Diabetes Self-Management Profile (DSMP; Harris et al., 2000) is a structured interview to assess adherence to the diabetes regimen. Harris and colleagues (2000) refined and updated the Self-Care Adherence Inventory (SCAI; Hanson, Henggeler, & Burghen, 1987) to develop the DSMP. Strong psychometric properties including

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strong internal consistency, high test-retest and inter-rater reliability, good construct validity/high relations with Hemoglobin A1c (HbA1c), and other measures of diabetes regimen adherence have been consistently demonstrated by three independent research teams (Harris et al., 2000; Iannotti et al., 2006; Lewin et al., 2005). Thus, the DSMP is consistent with criteria outlined by Quittner et al. (2008) and Chambless and Ollendick (2001) for a well-established assessment measure. Even though administration requires a trained interviewer, the DSMP assesses a variety of regimens including the insulin pump (DirecNet 2005; Iannotti et al., 2006; Wysocki, Greco, & Buckloh, 2003) and has been utilized as a primary outcome in several treatment studies (e.g., Heidgerken et al., 2006; Wysocki et al., 2006).

The authors of the DSMP initially published means and standard deviations for a sample of 105 youth with type 1 diabetes, broken down by age (6.1–10.4 years, 10.4–13.4 years, and 13.4–15.8 years; Harris et al., 2000). However, this study focused on initial validation of the DSMP rather than on the provision of normative data. Consequently, the aim of this present research was to, as a research program independent of the instrument's authors, extend the promising research by Harris and colleagues (Harris et al., 2000; DirecNet, 2005) by providing more extensive normative data for the DSMP. Specifically, we aimed to: (a) provide data from a large subject pool to allow presentation of DSMP scores by age and gender, (b) to complement findings by Harris et al. (2000) by including older adolescents in our sample, and (c) to provide parent–child comparisons via independent administration across all age groups.

Consequently, in this research, we report means and standard deviations for both youth and parent administrations of the DSMP so that normative comparisons of overall adherence scores and adherence with individual regimen components can be calculated based on age and gender. Relationships between DSMP scores and age, gender, and HbA1c are also examined. Consistent with extant studies, we expect that adherence will become less optimal with age.

Methods

Participants were 275 youth (56% female) with type 1 diabetes and 444 parents (the term parent is used to refer to either parent or adult legal guardian). Youth were 77% Caucasian, 14% African American, 5% Hispanic, and 4% other ethnicities. Of the 444 parents, 275 parents completed study measures along with their child (one parent per child); the remaining 169 parents completed study measures (in a parent-only study) but their child did not. If two parents attended the appointment, the interviewer asked the adult who assumed primary responsibility for day-to-day diabetes care to participate. Parental participants were predominantly mothers (78%). The median family income was $36,000 (median family income for the county in which the study was conducted was $37,300 in 2007). Mean HbA1c was 7.9 ($SD = 2.0$; range = 4.7–14.9). Child's mean age was 13.3 years ($SD = 2.7$) and mean duration with diabetes was 2.9 years ($SD = 4.6$). Approximately 41% of youth were on intensive regimens—29% basal-bolus and 12% continuous subcutaneous insulin infusion (CSII; i.e., the insulin pump).

Participants were enrolled in overarching studies examining family functioning and/or peer relations among youth with type 1 diabetes occurring in the University of Florida-based pediatric endocrinology clinic over approximately 3 years. All participants used in this sample were unique—if a subject completed multiple studies, only data from the study in which they were initially enrolled were included. Recruitment of all participants was essentially identical, regardless of the specific study: during routine visits to a university based pediatric diabetes specialty clinic, families were asked if they were willing to complete a brief series of questionnaires regarding, ''what it is like being a [or having a] child with diabetes.'' Sample demographic characteristics, HbA1c, DSMP scores, and participation rate (approximately 92%) did not differ appreciably across studies. Thus, to obtain a large sample suitable for division by age and gender, DSMP data were pooled from studies with nearly identical methodology—in terms of recruitment criteria and study tasks.[1]

Study measures included the DSMP, a 23-item structured interview with an administration time of approximately 20–30 min. The DSMP has strong psychometric properties as discussed above. Items assessed exercise (3 items), diet (9 items), management of hypoglycemia (3 items), insulin administration (4 items), and blood-glucose monitoring (4 items) and were responded to in an open-ended manner and interviews were conducted by study authors (each with extensive training and several years experience with the DSMP). All items

[1]It is noteworthy that psychometric properties of the DSMP as well as relations with demographic, psychosocial and health-related correlates may be presented in subsets of the present sample in other publications (e.g., Duke et al., 2008; Lehmkuhl et al., 2009; Lewin et al., 2006; Lewin et al., in press; Lewin et al., 2005; Storch et al., 2006).

were summed to produce a total adherence score with higher scores suggesting more optimal adherence (scores range from 0 to 79). The DSMP for flexible regimens (DirecNet, 2005) was used given its applicability to intensive regimens, CSII, and non-intensive regimens. Identical parent and child administrations were conducted privately; youth were told parents and the healthcare team would not be told their responses. Acceptable internal consistency was found for both parent ($\alpha = .78$) and child ($\alpha = .75$) administrations in our sample. An estimate of glycemic control over the previous 2–3 months (HbA1c) was also collected via a routine blood sample as part of the patient's routine medical care. Child assent and parental consent was obtained for all participants in accordance with the Human Subjects Review Board for the affiliated health science center and academic institution.

Data Analysis

In order to provide means and standard deviations for normative comparison, the sample was divided into three groups based on rationally derived cutoffs: children (age 8–11 years), younger adolescents (age 12–14 years), and older adolescents (age 15–18 years). These data allow for *Z*-scores to be calculated for comparative purposes with this sample. Analysis of variance (ANOVA) with Bonferroni corrected *post hoc* tests were used to examine group differences in age and gender. Pearson product moment correlations were used to examine relationships among parent–child and adherence-HbA1c, and *t*-tests were used to compare DSMP scores between intensive and non-intensive regimens.

Results

Means and standard deviations are presented for the DSMP child and parent administrations in Tables I and II, respectively. Within this large sample of youth with type 1 diabetes, scores on the DSMP and subscales showed normal distributions.

DSMP child total scores were subjected to a 3 (age group) x 2 (gender) ANOVA. The main effect of age group (controlling for time since diagnosis) was significant, $F(3, 269) = 3.6$, $p < .01$, but the main effect for gender and the age × gender interaction was non-significant. Tests of the *a priori* hypothesis that adherence worsens with increased age were conducted using Bonferroni *post hoc* tests; higher DSMP total scores were found among children ($M = 59.2$; $SD = 8.3$) in comparison to older adolescents ($M = 54.9$; $SD = 11.7$). No other group differences were identified. Similarly, we found a significant main effect for age group among DSMP parent total scores $F(2, 438) = 14.5$, $p < .001$, but not for gender. Based on parent scores, *post hoc* analysis indicated that children ($M = 62.0$; $SD = 8.7$) were rated as having more optimal adherence (by parents) than young adolescents ($M = 59.9$; $SD = 10.8$) or older adolescents ($M = 54.6$; $SD = 11.6$). DSMP child and parent total scores had strong, inverse correlations with metabolic control (HbA1c), $r = -.49$ and $r = -.43$ ($p < .001$), respectively. Among 273 cases where parents and children were both (but separately) administered the DSMP, scores were highly correlated ($r = .52$; $p < .001$).

Age differences in HbA1c were also evaluated using ANOVA. The main effect of age group was significant,

Table I. DSMP-Child Means and Standard Deviations by Child Age and Gender

		Children (8–11 years)			Young adolescents (12–14)			Older adolescents (15–18)			Total sample		
	N	Total 75	Males 23	Females 52	Total 103	Males 48	Females 55	Total 97	Males 48	Females 49	Total 275	Males 119	Females 156
Total DSMP	*M*	59.2	59.5	59.1	56.8	58.2	55.6	54.9	55.9	54.0	56.8	57.5	56.3
	SD	8.3	8.2	8.4	10.2	9.0	11.2	11.4	11.1	11.7	10.3	9.8	10.6
Exercise	*M*	6.3	6.4	6.3	6.4	6.9	5.9	6.6	7.2	6.0	6.4	6.9	6.1
	SD	2.8	3.0	2.9	3.2	2.9	3.4	3.8	3.8	3.8	3.3	3.3	3.3
Hypoglycemia	*M*	5.2	5.0	5.3	4.8	4.5	5.1	4.6	4.6	4.7	4.9	4.6	5.0
	SD	1.6	1.7	1.6	1.6	1.7	1.6	1.6	1.7	1.5	1.6	1.7	1.6
Diet	*M*	21.9	22.5	21.6	19.8	20.2	19.4	19.5	19.8	19.3	20.2	20.5	20.1
	SD	4.3	3.8	4.5	5.3	4.3	6.1	5.4	5.5	5.3	5.2	4.8	5.4
Blood glucose	*M*	12.8	12.4	13.0	12.6	12.9	12.3	11.5	11.6	11.4	12.2	12.3	12.2
	SD	2.1	2.0	2.1	2.4	2.4	2.3	2.8	2.4	3.2	2.5	2.4	2.6
Insulin	*M*	13.1	13.3	13.0	13.3	13.6	12.9	12.7	12.8	12.7	13.0	13.2	12.9
	SD	2.6	2.2	2.8	2.6	2.3	2.7	2.8	2.7	2.8	2.7	2.5	2.8
HbA1c	*M*	7.7	–	–	8.2	–	–	9.0	–	–	7.9	–	–
	SD	1.5	–	–	1.9	–	–	2.1	–	–	2.0	–	–

Table II. DSMP-Parent Means and Standard Deviations by Child Age and Gender

		Children (8–11 years)			Young adolescents (12–14)			Older adolescents (15–18)			Total sample		
		Total	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females
	N	129	41	88	168	76	92	147	64	83	444	181	263
Total DSMP	*M*	62.0	60.7	62.6	56.9	59.7	54.7	54.6	54.9	54.3	57.6	58.2	57.2
	SD	8.7	9.4	8.4	10.8	9.0	11.7	11.6	11.3	11.9	10.9	10.2	11.4
Exercise	*M*	8.2	8.1	8.2	7.2	8.0	6.5	7.0	7.8	6.5	7.4	7.9	7.1
	SD	2.9	2.7	3.0	3.1	2.9	3.2	3.7	3.6	3.7	3.3	3.1	3.4
Hypoglycemia	*M*	5.4	5.2	5.4	4.9	5.2	4.7	4.5	4.2	4.7	4.9	4.8	4.9
	SD	1.6	1.8	1.6	1.8	1.9	1.7	1.6	1.8	1.5	1.7	1.9	1.6
Diet	*M*	21.7	21.1	22.0	19.3	20.3	18.5	18.5	18.1	18.8	19.7	19.7	19.8
	SD	4.2	4.1	4.3	5.6	5.0	6.0	5.7	5.9	5.6	5.4	5.3	5.5
Blood Glucose	*M*	13.6	13.5	13.6	12.6	13.0	12.2	11.9	11.8	11.9	12.7	12.7	12.6
	SD	1.9	1.9	1.9	2.3	2.2	2.4	2.5	2.4	2.7	2.4	2.3	2.4
Insulin	*M*	13.4	13.0	13.7	13.1	13.5	12.7	12.6	12.9	12.4	13.0	13.2	12.9
	SD	2.8	2.9	2.7	2.9	2.6	3.1	3.3	2.8	3.7	3.0	2.8	3.2

$F(2, 453) = 6.7$, $p = .001$. *Post hoc* tests indicated that worse metabolic control was found among older adolescents ($M = 9.0$; $SD = 2.1$) in comparison to children ($M = 7.7$; $SD = 1.5$) ($p < .001$). No other group differences were identified. No HbA1c-gender differences were found ($t = -1.4$; $p = .18$). Accordingly, means and standard deviations for HbA1c by age group are presented in Table I. DSMP child ($t = -1.6$; $p = .11$) and parent ($t = -1.9$; $p = .09$) total scores did not differ significantly on the basis of regimen (intensive vs. conventional).

Discussion

Utilizing pooled data from the DSMP, an empirically validated structured interview, this research presents a relatively large set of both youth- and parent-reported adherence data suitable for normative comparison. Although there are numerous methods for assessing adherence behaviors, empirical support is limited (Quittner et al., 2008). Moreover, even when means and standard deviations have been reported, sample sizes rarely approach those necessary for subdivision by age group and/or gender. Based on data provided in the present research, *Z*-scores can be calculated based on overall and subscale DSMP scores for both youth and parent administrations. Examinations of central tendency indices suggest that the distributions are roughly normal and that the percentages of cases under the curve match those of a normal distribution (e.g., 13.6% beyond 1 *SD* for a normal distribution, 14% in our DSMP child report, and 13.8% in our DSMP parent report).

Our data are consistent with previous studies suggesting that adherence becomes less optimal with age (Johnson, 1992). Similarly, we found that DSMP scores relate to metabolic control and that parent and youth reports of adherence are highly correlated, a finding consistent with others (e.g., Harris et al., 2000; Iannotti et al., 2006).

Normative data for the DSMP contribute information about patterns of adherence by age and gender and consequently are relevant to clinical practice. For example, given that (on average) youth in our sample were in fairly good metabolic control (compared to large-scale population studies, e.g., Danne et al., 2001; Mortensen et al., 1997; Svoren et al., 2007), results reported in this research suggest potential adherence levels that children need to maintain to achieve favorable HbA1c levels. Thus, data from this study can inform researchers and clinicians about target DSMP levels (based on the averages for age and gender). Moreover, consistent with prior research, our data suggest that adherence decreases with age (through adolescence). Overall, these data provide comparative adherence scores that clinicians and researchers can use for individual or group comparisons.

Although the DSMP requires 20–30 minutes to administer by a trained individual, clinicians familiar with diabetes treatment gain proficiency within a few administrations. Additionally, although the DSMP is relatively staff and patient intensive (during time-limited clinic visits), most of the information is routinely assessed by the clinic staff in some capacity—the DSMP provides a standard and validated method for assessing this routine information. Accordingly, Lewin et al. (in press) found that the DSMP predicated additional variance in metabolic control above and beyond more simplistic self- and parent-report measures of adherence. The upfront cost of

staff training (to use the DSMP) may be offset by the provision of a consistent and efficient assessment protocol that can be made available to the treating clinician when s/he enters the room (allowing for visits to be more streamlined and provider time to be used for effectively).

These data should be considered in the context of a number of methodological limitations. Although the methodology for recruitment was roughly identical for each of the parent studies, these data are pooled from samples of convenience. Additionally, cell sizes for certain age and gender divisions within the Child DSMP are relatively small. Nevertheless, no differences in DSMP scores or demographic information were identified between samples. Further, to our knowledge, these data are larger than any groupings of adherence ratings available in the extant literature. The median family income is relatively low and the sample income is concordant with the median income for the surrounding area, suggesting generalizability. Additionally, data were collected from a single site and may not generalize geographically. Finally, individual regimens may vary considerably, complicating interpretation of group averages. However, within these limitations, this study provides an extensive database that can be used for comparative purposes in both clinical and research applications.

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