Published in final edited form as:
Diabet Med. 2011 September ; 28(9): 1113–1117. doi:10.1111/j.1464-5491.2011.03321.x.

Validation of an abbreviated adherence measure for young people with Type 1 diabetes

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Abstract

Aims—Adherence to diabetes-related tasks is an important construct. The Diabetes Self-Management Profile is a validated, semi-structured interview assessing adherence in paediatric patients with Type 1 diabetes. We created and validated a brief questionnaire version of the Diabetes Self-Management Profile called the Diabetes Self-Management Questionnaire.

Methods—Young people with Type 1 diabetes, ages 9–15 years (n = 338) and their parents provided data from chart review, interview and questionnaires.

Results—Diabetes Self-Management Questionnaire scores correlated significantly with Diabetes Self-Management Profile scores, HbA_{1c}, blood glucose monitoring frequency and other measures associated with adherence and/or glycaemic control ($P \leq 0.01$ for all). Young people and parent scores were correlated ($r = 0.55$, $P < 0.0001$). The Diabetes Self-Management Questionnaire demonstrated modest internal consistency (Cronbach's $\alpha = 0.59$), adequate for a brief measure of multidimensional adherence. In addition, factor analysis confirmed one factor.

Conclusions—This brief adherence questionnaire demonstrated construct validity in young people 9–15 years old and their parents and may have utility in clinical and research settings.

Keywords

adherence; paediatrics; Type 1 diabetes

Introduction

Adherence to diabetes-related tasks is an important construct, as it predicts glycaemic control and health outcomes [1–3]. The Diabetes Self-Management Profile is a validated, semi-structured interview that measures adherence to diabetes management tasks over the previous 3 months [4–6]. It requires 30–40 min for a trained interviewer to administer the

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[+]The Young people and parent versions of the Diabetes Self-Management Questionnaire is available on request from the corresponding author.

Competing interests Nothing to declare.

Diabetes Self-Management Profile to a young person and parent sequentially. Because of the time and resources required to administer the Diabetes Self-Management Profile, its use in clinical care may be impractical. An abbreviated, self-administered version of the Diabetes Self-Management Profile may benefit both the clinical and research communities. Our aim was to determine the usefulness and validity of a brief self-report questionnaire (the Diabetes Self-Management Questionnaire), adapted from the Diabetes Self-Management Profile, in a sample of young people with Type 1 diabetes and their parents.

Patients and methods

Participants were young people with duration of Type 1 diabetes ≥ 1 year, aged 9– 15 years, and their parents. Written informed consent/assent was obtained from participants. Study procedures were approved by the Institutional Review Boards at the participating institutions.

Data were obtained uniformly across sites by interview, chart review and questionnaires across four clinical sites (Children's Memorial Hospital, Chicago, IL; Texas Children's Hospital, Houston, TX; Nemours Children's Clinic, Jacksonville, FL; Joslin Diabetes Center, Boston, MA). Diabetes Self-Management Profile interviews were conducted by staff from a central location who were all trained in administration of the Diabetes Self-Management Profile. These interviewers were completely independent from clinical research and clinical care staff. Other questionnaires (including the Diabetes Self-Management Questionnaire) were administered by well-trained research staff at all sites. Internal consistency and construct validity of the Diabetes Self-Management Questionnaire were examined.

Measures

Diabetes Self-Management Profile (DSMP)—The Diabetes Self-Management Profile is a 25-item, validated, semi-structured interview that measures adherence to diabetes management tasks in young people ages ≥ 11 years [4]. There are parallel young people and parent versions of the Diabetes Self-Management Profile, as well as separate versions for flexible and conventional insulin regimens. Higher scores indicate greater adherence.

Diabetes Self-Management Questionnaire (DSMQ)—A multidisciplinary team (paediatric endocrinologists, paediatric psychologists, certified diabetes educators) adapted a subset of Diabetes Self-Management Profile items for inclusion in the Diabetes Self-Management Questionnaire. Items were chosen by examining item-to-total correlations, as well as the clinical relevance of each question. Items were worded to be applicable to either conventional or flexible regimens. The time frame assessed was decreased to the previous month (rather than previous 3 months as used by the Diabetes Self-Management Profile) because patient responses to adherence questions tend to be more highly influenced by recent behaviour. While the Diabetes Self-Management Profile was designed for young people, ages 11 years and older, in our shortened, self-administered version, we elected to evaluate the utility of the Diabetes Self-Management Questionnaire across a wider age range, including younger patients, ages 9 years and older, who were already completing other self-administered surveys on diabetes family involvement, diabetes-specific family conflict and quality of life. Given the importance of assessing adherence for both research and clinical purposes, we wanted to determine whether this questionnaire could be used in younger children. The resulting Diabetes Self-Management Questionnaire, then, is a brief, 9-item self-report questionnaire for young people ages ≥ 9 years, encompassing all insulin regimens. There is a parallel parent version and completion time is under 10 min. Scores can range from 0–35, with higher scores indicating greater adherence (see Young people and

parent versions of the Diabetes Self-Management Questionnaire, for survey and scoring. Available on request from authors).

Blood Glucose-Monitoring Communication Questionnaire (BGMC)—The Blood Glucose-Monitoring Communication Questionnaire is an 8-item, validated questionnaire that assesses negative affect related to blood glucose monitoring, completed by young people and parents [7]. Higher scores indicate greater negative affect surrounding blood glucose monitoring.

Diabetes Family Conflict Scale (DFCS)—The Diabetes Family Conflict Scale, completed by young people and parents, is a 19- item, validated measure of diabetes-specific family conflict [8]. Higher scores indicate greater diabetes-specific conflict.

Pediatric Quality of Life Inventory—Generic Core Scales (PedsQL)—The 23-item Pediatric Quality of Life Inventory—Generic Core Scale, completed by young people and parents, is a validated measure of the child's general quality of life [9,10]. Higher scores indicate higher quality of life.

Glycaemic control

HbA_{1c} was measured in a central laboratory (reference range 4.0–6.0%; Tosoh 2.2, Tosoh Corp., South San Francisco, CA, USA).

Statistical analysis

Data are presented as means ± SD or percentages. Statistical analyses employed SAS version 9.2 for Windows (SAS Institute, Cary, NC, USA) and included Pearson and Spearman correlations, paired and unpaired *t*-tests and Wilcoxon rank-sum tests. Cronbach's α was used to assess internal consistency, that is the degree to which the items measure a unitary construct. To evaluate the psychometric properties of the Diabetes Self-Management Questionnaire across the sample age span, we performed stratified analyses by age.

Results

The sample consisted of 338 young people (49% male, 22% ethnic/racial minority) with Type 1 diabetes and their parents. Mean participant age was 12.5 ± 1.7 years, duration of diabetes was 5.4 ± 3.1 years and HbA_{1c} was 8.5 ± 1.1% (69 mmol/mol). Mean daily insulin dose was 1.0 ± 0.3 units/kg per day and participants checked blood glucose levels 4.5 ± 2.0 times per day, assessed by meter download (median = 4.2 times/day; range < 1 to 10.5 times/day; averaged over the preceding 2 weeks). Most participants were receiving multiple daily injections (63%); 37% used insulin pump therapy. Background data for the four sites were consistent, with previously reported pilot data representing the distribution across the four sites [11].

Diabetes Self-Management Questionnaire psychometrics

The original Diabetes Self-Management Questionnaire was composed of 10 items. Factor analysis indicated a single factor best fitted the data; however, one item did not load onto the factor (correlation with the factor was very low) for either parent or child version and was eliminated [How often have you (child version)/your child (parent version) eaten sweets and fatty foods like cookies, cakes, ice cream, chips, pizza, french fries, hot dogs, or others?]. Parent and child Diabetes Self-Management Questionnaire scores were correlated ($r = 0.56$, $P < 0.0001$). Independent of regimen, parent Diabetes Self-Management Questionnaire scores were higher than child scores ($P < 0.0001$). The final 9-item Diabetes Self-

Management Questionnaire demonstrated modest internal consistency (Cronbach's α = 0.59 for young people; 0.57 for parents); factor analysis confirmed a one-factor structure.

Construct validity

The Diabetes Self-Management Questionnaire demonstrated construct validity through significant correlation with the Diabetes Self-Management Profile (young people: $r = 0.64$, $P < 0.0001$; parents: $r = 0.62$, $P < 0.0001$). The Diabetes Self-Management Questionnaire correlated significantly with other measures associated with adherence and/or glycaemic control. Greater adherence was associated with greater frequency of blood glucose monitoring and greater quality of life, lower HbA_{1c}, less negative affect related to blood glucose monitoring and less diabetes-specific family conflict; correlations of variables assessing construct validity with the Diabetes Self-Management Questionnaire were similar to correlations with the Diabetes Self-Management Profile (see Table 1). Diabetes Self-Management Questionnaire scores also differed significantly by treatment regimen with young people on pump therapy scoring higher on the Diabetes Self-Management Questionnaire (pump vs. injections; young people: $P = 0.0002$; parents: $P = 0.001$). Diabetes Self-Management Profile scores did not differ significantly by treatment regimen.

Diabetes Self-Management Questionnaire psychometrics stratified by age

The internal consistency in the 9-item Diabetes Self-Management Questionnaire was similar in both the < 11 and ≥ 11 years age ranges, with Cronbach's α = 0.56 for those ages < 11 years ($n = 76$) and Cronbach's α = 0.60 for those ages ≥ 11 ($n = 255$). Total scores were also similar between age groups as reported by young people and parents. However, relations with relevant constructs differed by age group (Table 2). In the older group and not the younger group, Diabetes Self-Management Questionnaire correlated significantly with HbA_{1c}, negative affect related to blood glucose monitoring, diabetes-specific family conflict and quality of life. In both age groups, however, the Diabetes Self-Management Questionnaire was significantly correlated with frequency of blood glucose monitoring. Interestingly, in the younger cohort, the Diabetes Self-Management Questionnaire was significantly correlated with family responsibility for sharing diabetes tasks, while this correlation was not significant in the older cohort. Because there was a much smaller number of participants in the younger age group, we performed a gender- and duration-matched analysis with 79 randomly selected older participants. The results were similar to that of the complete older group (data not shown).

Discussion

The Diabetes Self-Management Questionnaire is a 9-item, self-report questionnaire that measures adherence to diabetes self-management tasks. The Questionnaire demonstrated acceptable psychometric properties and construct validity. Diabetes Self-Management Questionnaire scores were highly correlated with Diabetes Self-Management Profile scores, as well as frequency of blood glucose monitoring. Diabetes Self-Management Questionnaire scores were also correlated with HbA_{1c} and other measures associated with adherence to and/or glycaemic control. While the Diabetes Self-Management Questionnaire demonstrated questionable internal consistency, we would not necessary expect internal consistency to be high for a brief measure of adherence that taps multiple domains, including blood glucose monitoring, diet, exercise and insulin administration, which are not always correlated. Reported internal consistency for the Diabetes Self-Management Profile is higher (0.76; [4]); however, the Diabetes Self-Management Questionnaire is much shorter, which may negatively impact on its internal consistency. While the creation of the Diabetes Self-Management Questionnaire was underway, a new validation of the Self-Care Inventory was published [12]. The Self-Care Inventory is a 14-item self-report measure that assesses

diabetes adherence. Both the Self-Care Inventory and the Diabetes Self-Management Questionnaire were validated against the Diabetes Self-Management Profile and demonstrated good construct validity. While the Self-Care Inventory was validated with young people ages 11–18 years, the Diabetes Self-Management Questionnaire was validated in a younger population, ages 9–15 years. (The Self-Care Inventory was not included in the current study.)

There are a number of limitations to this study. First, the Diabetes Self-Management Questionnaire was adapted from the Diabetes Self-Management Profile, which included two versions based upon treatment regimen. We created a single version of the Diabetes Self-Management Questionnaire for use with all insulin regimens as a trade-off for ease of administration, with the potential loss of some regimen-specific adherence information. However, the correlations between the Diabetes Self-Management Questionnaire and the regimen-specific Diabetes Self-Management Profile versions were similar (Table 1). While the item wording used is consistent with that used in the Diabetes Self-Management Profile, some items may appear confusing or redundant to the respondent. Finally, we have assessed the utility of the Diabetes Self-Management Questionnaire in a younger population, including 9- to 11- year-olds, whereas the Diabetes Self-Management Profile was only validated among those of 11 years and older.

While the Diabetes Self-Management Questionnaire performed differently in those < 11 years and in those ≥ 11 years of age, it may have utility in both groups to identify problems with adherence. We hope that future studies and possible improvements to the questionnaire can confirm or refute its usefulness, readability and comprehension across this wider age range of young people.

The Diabetes Self-Management Questionnaire can be completed in less than 10 min, with both parents and young people able to complete the measure simultaneously, with few staff resources required. In addition, while HbA_{1c} tells us how adherent a patient is in general, the Diabetes Self-Management Questionnaire can help identify specific difficulties for a patient. Because this sample was geographically, ethnically and racially diverse, it is likely representative of young people with Type 1 diabetes. This brief self-report questionnaire may have utility for periodic use with paediatric patients/parents in clinical and research settings in order to measure adherence to diabetes self-management.

Acknowledgments

This research was supported in part by the intramural research program of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The following investigators and institutions made up the steering committee of the Family Management of Childhood Diabetes multi-site trial: Jill Weissberg-Benchell PhD, Grayson Holmbeck PhD (Children's Memorial Hospital, Chicago, Contract N01-HD-4-3363); Barbara Anderson PhD (Texas Children's Hospital, Houston, Contract N01-HD-4-3362); Tim Wysocki PhD, Amanda Lochrie PhD (Nemours Children's Clinic, Jacksonville, FL, Contract N01-HD-4-3361); Lori Laffel MD MPH, Deborah Butler MSW, Lisa Volkening MA (Joslin Diabetes Center, Boston, Contract N01-HD-4-3364); Tonja Nansel PhD, Ronald Iannotti PhD (NICHD, Bethesda, MD); Cheryl McDonnell PhD, MaryAnn D'Elio (James Bell Associates, Arlington, VA, Contract N01- HD-3-3360). This work was also supported in part by NIH Training Grant No. T32 DK007260, a grant from the National Institute of Diabetes and Digestive and Kidney Diseases (DK-46887), the Charles H. Hood Foundation, the Maria Griffin Drury Pediatric Fund and the Katherine Adler Astrove Young People Education Fund.

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Table 1

Diabetes Self-Management Questionnaire scores and construct validity

	Young people (*n* = 338)		**Parent (*n* = 334)**	
DSMQ [mean ± SD (range)]	23.0 ± 5.2 (7–35)		24.6 ± 5.0 (6–35)*	
DSMQ injection-treated (*n* = 212)	22.2 ± 5.1 (7–33)		23.9 ± 4.7 (9–34)*	
DSMQ pump-treated (*n* = 126)	24.3 ± 5.0 (10–35)		25.8 ± 5.3 (6–35)*	
DSMP [mean ± SD (range)]	59.9 ± 9.5 (34–82)		60.7 ± 9.5 (32.5–82)	
DSMP conventional	57.9 ± 9.9 (36–77)		59.2 ± 10.7 (32.5–82)	
DSMP flexible	60.6 ± 9.3 (34–82)		59.8 ± 9.7 (37.7–81.9)	
	Young people DSMQ	Parent DSMQ	Young people DSMP	Parent DSMP
Correlations with DSMQ score†	*r*	*r*	*r*	*r*
DSMP	0.63*	0.61*		
DSMP conventional (*n* = 65)‡	0.56*	0.61*		
DSMP flexible (*n* = 181)	0.65*	0.63*		
HbA_{1c}	−0.17*	−0.30*	−0.30*	−0.35*
Blood glucose monitoring frequency	0.39*	0.51*	0.38*	0.35*
Insulin dose (U kg^{-1} day^{-1})	−0.09	−0.13*	0.005	−0.12*
Negative affect related to blood glucose monitoring (BGMC)	−0.18*	−0.13*	−0.20*	−0.23*
Diabetes-specific family conflict (DFCS)	−0.30*	−0.31*	−0.23*	−0.38*
Young people quality of life (PedsQL)	0.25*	0.19*	0.32*	0.24*

*$P < 0.05$

†Correlations reported are for young people questionnaires with young people DSMQ/DSMP and parent questionnaires with parent DSMQ/DSMP.

‡The DSMP was completed by young people ≥ 11 years.

BGMC, Blood Glucose-Monitoring Communication Questionnaire; DFCS, Diabetes Family Conflict Scale; DSMP, Diabetes Self-Management Profile; DSMQ, Diabetes Self-Management Questionnaire; PedsQL, Pediatric Quality of Life Inventory—Generic Core Scale.

Table 2

Correlations with Diabetes Self-Management Questionnaire stratified by age

	< 11 years (*n* = 79)	≥ 11 years (*n* = 259)
	r	r
HbA_{1c}	0.04	−0.22*
Blood glucose monitoring frequency	0.22*	0.44*
Insulin dose (U kg^{-1} day^{-1})	0.03	−0.11
Negative affect related to blood glucose monitoring (BGMC)	−0.14	−0.19*
Diabetes-specific family conflict (DFCS)	−0.15	−0.35*
Diabetes responsibility sharing (DFR)	0.27*	0.01
Young people quality of life (PedsQL)	0.20	0.27*

* $P < 0.05$.

BGMC, Blood Glucose-Monitoring Communication Questionnaire; DFCS, Diabetes Family Conflict Scale; DFR, Diabetes Family Responsibility Questionnaire; PedsQL, Pediatric Quality of Life Inventory—Generic Core Scale.