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Re-examining a measure of diabetes-related burden in parents of young people with Type 1 diabetes: the Problem Areas in Diabetes Survey – Parent Revised version (PAID-PR)

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Abstract

Aims—In a pediatric patients, the burden of diabetes lies within the family. In the current era of intensive insulin therapy, perceived parental burden may affect the family's efforts at effective diabetes management. The aims of this study were to re-examine and revise a measure of perceived parental burden associated with caring for a child with diabetes in the current era.

Methods—A geographically diverse population of young people ($N = 376$) with Type 1 diabetes and their parents included participants in the Juvenile Diabetes Research Foundation continuous glucose monitoring study and patients from the Joslin Diabetes Center. Participants provided data on demographics, diabetes management, diabetes-specific family conflict, and quality of life at baseline and after 6 months of follow-up.

Results—Young people were 12.9 ± 2.7 years old with diabetes duration of 6.3 ± 3.5 years. Mean HbA_{1C} was $8.0 \pm 1.2\%$ (64 mmol/mol), 58% received insulin pump therapy, and young people monitored blood glucose 5.2 ± 2.3 times/day. Factor analysis yielded two factors, 'Immediate Burden' and 'Theoretical Burden'. The Problem Areas in Diabetes Survey – Parent Revised version (PAID-PR) demonstrated excellent internal consistency (Cronbach's $\alpha = 0.87$; factor 1 $\alpha = 0.78$; factor 2 $\alpha = 0.83$). Greater parental burden was associated with more frequent blood glucose monitoring, higher HbA_{1C} levels, greater diabetes-specific family conflict, and lower quality of life. Test-retest analysis was acceptable ($r = 0.62$).

Conclusions—The PAID-PR demonstrated excellent internal consistency, good test-retest reliability, and associations with diabetes-specific family conflict and quality of life. This brief measure may have both clinical and research utility in the management of young people with Type 1 diabetes.

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Competing interests

Nothing to declare

Supporting Information

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Keywords

adolescence; Type 1 diabetes

Introduction

The Problem Areas in Diabetes Survey (PAID) assesses diabetes-related burden in adults [1]. It has excellent psychometrics (Cronbach's $\alpha = 0.95$) and correlates with a number of emotional and diabetes-related variables [1]. In paediatrics, the burden of care lies with the patient and parent/guardian. For young patients, the burden lies with parents. Parental stress and burden in parents of children with Type 1 diabetes is common [2]. Parental burdens include daily diabetes-related tasks, financial burdens, managing blood glucose fluctuations, and, often, guilt and fear about future medical complications [3,4].

Family involvement is associated with increased adherence and improved glycaemic control [5,6]. If parents feel overly burdened, they may prematurely transfer responsibility for diabetes management to their child, which may lead to worsening control. Also, parental burden may promote diabetes-specific family conflict, which has an impact on glycaemic control [7]. Thus, parental burden is an important construct that may be amenable to intervention [4,5,7,8].

The Problem Areas in Diabetes – Parent version (PAID-P) assesses perceived parental burden associated with caring for a child with diabetes [9]. The original PAID-P had one general factor, excellent internal consistency (Cronbach's $\alpha = 0.92$) and validity in a conventionally treated sample of young people with Type 1 diabetes [9]. The aims of the current study were to re-examine and revise the PAID-P in parents of young people with Type 1 diabetes in the modern era of intensive insulin therapy.

Patients and methods

Participants were 376 young people with Type 1 diabetes (ages 8–18 years) and their parents. We combined data from a publicly-available dataset of nine centres (Juvenile Diabetes Research Foundation, JDRF [10], $n = 223$ and from the Joslin Diabetes Center, $n = 153$). Inclusion criteria were: Type 1 diabetes for ≥ 9 months, no major psychiatric/medical disorder, and fluency in English/Spanish.

Institutional Review Boards of participating institutions approved study procedures. Written informed consent/assent was obtained. Data were collected on age, duration of diabetes, height/weight, frequency of blood glucose monitoring, glycaemic control, diabetes-specific family conflict, quality of life, parent education and race/ethnicity.

Measures

Problem Areas in Diabetes – Parent Version (PAID-P [9])—Parents completed the 20-item PAID-P to assess perceived parental burden associated with caring for a child with diabetes.

Revised Diabetes Family Conflict Scale (DFCS-R [11], Joslin only)—Parents completed the 19-item DFCS-R to assess diabetes-specific family conflict.

Paediatric Quality of Life Inventory-Generic Scales and Diabetes Module (PedsQL [12,13])—Parents completed the 23-item PedsQL generic scales to measure parental perceptions of child's quality of life, including psychosocial and physical subscales.

Joslin participants completed the total scale while JDRF participants completed only the psychosocial subscale and 14 items of the diabetes module.

Glycaemic control—Haemoglobin A_{1C} was measured by automated, high-performance liquid chromatography (reference range 4.0–6.0%, Tosoh 2.2; Tosoh Corporation, South San Francisco, CA, USA) at the Joslin Diabetes Center and the University of Minnesota Laboratories.

Statistical analysis

Analyses were performed using SAS (v9.2 for Windows; SAS Institute Inc., Cary, NC). Data are presented as mean \pm SD or per cent. Statistics included Pearson/Spearman correlations for concurrent validity and test–retest reliability. For factor analysis, principal components analysis and Promax rotation were used. Internal consistency was assessed using Cronbach's α . A P-value of < 0.05 indicated significance.

Results

Participant characteristics

The total sample included 376 young people with Type 1 diabetes and their parents (Table 1). The two samples were similar in age, zBMI (age- and sex-adjusted BMI), duration of Type 1 diabetes, gender, and race/ethnicity; only frequency of blood glucose monitoring and HbA_{1C} differed. The distributions and mean scores of the PAID-P were nearly identical between samples; therefore, datasets were combined.

PAID-P factor analysis

Results of the Kaiser–Meyer–Olkin test [overall measures of sampling adequacy (MSA) = 0.85] and individual MSA statistics indicated the combined sample size was sufficient and the data acceptable for factor analysis on the 20-item PAID-P [14]. Factors were extracted using principal components analysis. Promax rotation was used because of the inherent relationship between many of the items. Factor analysis resulted in two factors (nine items in each) and two eliminated items with factor loadings < 0.40 with low face validity. One item with factor loading of 0.38 was retained for its construct value. Factor 1 represents the 'Concrete Burden' (see Appendix S1) of having a child with Type 1 diabetes and includes items focused on present, concrete burdens. Factor 2 represents 'Unpredictable Burden' (see Appendix S1) and includes items focused on negative emotions and worry about the future. The two factors were correlated ($r = 0.54$, $P < 0.0001$).

Psychometrics and concurrent validity

The 18-item Problem Areas in Diabetes Survey – Parent Revised version (PAID-PR) revised demonstrated excellent internal consistency (Cronbach's $\alpha = 0.87$), with good internal consistency within the two factors (factor 1: $\alpha = 0.78$; factor 2: $\alpha = 0.83$). Higher PAID-PR scores, indicating greater perceived parental burden, were correlated with more frequent blood glucose monitoring and higher HbA_{1C}.

Greater parental burden was associated with greater diabetes-specific family conflict. The PAID-PR was negatively correlated with parent-proxy report of quality of life. There were no associations between parental burden and child age, gender, zBMI (age- and sex-adjusted BMI) or duration of Type 1 diabetes (Table 1).

We then assessed diabetes characteristics and survey responses by factor (Table 2). The association between frequency of blood glucose monitoring and parental burden was explained by factor 2, while the association between HbA_{1C} and burden was explained by

factor 1. Parent report of diabetes-specific family conflict and parent-proxy report of quality of life were significantly correlated with factors 1 and 2. Significantly greater burden was reported by parents of pump users than by parents of non-pump users on factor 2 ($P=0.008$).

Test-retest analysis

Baseline and 6-month assessments of the PAID-PR in control participants ($n=97$) from the JDRF study demonstrated acceptable test-retest reliability ($r=0.62$; $P<0.0001$).

Discussion

The 18-item, two-factor, PAID-PR demonstrated excellent overall internal consistency, high factor internal consistency, and acceptable test-retest reliability. Factor analysis yielded two factors: 'Concrete Burden' and 'Unpredictable Burden' of having a child with Type 1 diabetes. Concrete burden focused on concrete, daily parental burdens; unpredictable burden included parental worries about the future and negative emotions experienced by parents.

Concurrent validity was measured with correlations between the PAID-PR and multiple constructs incurring parental burden, including blood glucose monitoring, HbA_{1C}, diabetes-specific family conflict, and parent-proxy report of quality of life. For example, blood glucose monitoring, as a recurring management task, can be a constant reminder of the permanence of diabetes. Haemoglobin A_{1C}, as a measure of glycaemic control, can create worries for parents regarding the child's overall health. Diabetes-specific family conflict and parent perception of child's quality of life can also create parental burdens related to diabetes.

Although frequency of blood glucose monitoring and HbA_{1C} were significantly correlated with one another ($r=-0.34$, $P<0.0001$), HbA_{1C} was weakly correlated with 'Concrete Burden' and blood glucose monitoring was weakly correlated with 'Unpredictable Burden'. For parents of young people with Type 1 diabetes, HbA_{1C} may represent a more unpredictable and immediate burden, as it reflects current glycaemic control. Blood glucose monitoring may represent a theoretical burden, as parents worry if their children will consistently check blood glucose levels when away from home and as they grow-up. Notably, parents of young people with diabetes have reported negative affect around blood glucose monitoring [15].

Parent report of diabetes-specific family conflict and parentproxy report of quality of life were moderately correlated with both 'Concrete Burden' and 'Unpredictable Burden'; greater conflict and lower child quality of life were associated with higher parental burden. While diabetes management tasks can add physical and time burdens to families, conflict and quality of life can add emotional burdens to parents.

In this contemporary cohort of paediatric patients with Type 1 diabetes from multiple sites treated with modern insulin therapy, parents provided responses regarding parental distress, diabetes-specific family conflict, and child quality of life. These three constructs are potentially modifiable factors. Approaches to Type 1 diabetes treatment aim to optimize glycaemia, minimize diabetes-specific family conflict and preserve quality of life. Family teamwork around diabetes management has been shown to improve adherence and glycaemic control, prevent increases in diabetes-specific family conflict and maintain quality of life; thus, teamwork is often targeted in the design and implementation of interventions [6,7,16,17]. In research, use of the PAID-PR can help assess efficacy of intervention trials. In clinical practice, it can be used as a screening tool to identify parents in need of greater support.

There are a number of limitations of this investigation. First, surveys were not completed by all participants; some measures were completed by only half and test-retest reliability was assessed in less than one-third. Although we had a large and varied study population, parents were highly educated, which may limit generalizability. However, a comparison between parents with a college degree/graduate education and those with less than a 4-year degree showed no difference in scores on the PAID-PR. The data were cross-sectional, limiting our ability to assess causation. Our study was also unable to assess construct validity of the PAID-PR; future studies should address this. Although we found significant correlations between the PAID-PR and other measures, the correlations were weak or moderate and may be attributed to the large sample size. In addition, this study focused solely on measuring parents' perceptions of burden. Future research should examine burden from the child/adolescent's perspective. Use of the new teen PAID measure [18] may yield insight to this query.

Although the two samples comprising the study population differed in diabetes management characteristics, there were no significant differences in PAID-PR scores. The variability in diabetes management characteristics and the diversity of our population strongly support the generalizability of our findings. Parents/guardians were able to complete the PAID-PR in less than 10 min, providing a brief, valid, and reliable measure of perceived burden related to having a child with diabetes. This tool may be useful in both clinical and research environments.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Participant characteristics and survey responses

	All (N = 376)	JDRF (n = 223)	Joslin (n = 153)
Age (years)	12.9 ± 2.7	12.9 ± 3.0	12.9 ± 2.3
Gender of youth (% female)	54%	52%	56%
Relationship to youth (% mothers)	80%	81%	78%
Racial/ethnic minority (%)	9%	8%	10%
zBMI (SDS)	0.7 ± 0.8	0.7 ± 0.8	0.8 ± 0.7
Diabetes duration (years)	6.3 ± 3.5	6.3 ± 3.4	6.3 ± 3.5
Regimen (% pump treated)	58%	82%	23% *
Frequency of blood glucose monitoring (times/day)	5.2 ± 2.3	6.3 ± 2.4	3.8 ± 1.2 *
HbA _{1C} (%), (mmol/mol)	8.0 ± 1.2% (64 mmol/mol)	7.6 ± 0.9% (60 mmol/mol)	8.4 ± 1.4% * (68 mmol/mol)
College/graduate degree (parents)	65%	73%	54%
Junior college/technical degree/some college (parents)	20%	14%	28%
Parent report surveys			
PAID-P	44.6 ± 15.0	45.1 ± 15.0	43.8 ± 15.1
PAID-PR	46.8 ± 16.7	47.8 ± 16.6	45.4 ± 16.8
Family conflict (diabetes-specific)	NA	NA	24.2 ± 3.7
Psychosocial quality of life	77.9 ± 13.5	76.9 ± 12.7	79.4 ± 14.4
Physical quality of life	NA	NA	84.1 ± 15.4
Diabetes-specific quality of life	NA	75.8 ± 13.2	NA

JDRF (Juvenile Diabetes Research Foundation) sample vs. Joslin sample; zBMI, age- and sex-adjusted BMI; PAID-P, Problem Areas in Diabetes–Parent version; PAID-PR, Problem Areas in Diabetes - Parent Revised version; SDS, standard deviation score.

* $P < 0.01$.

Table 2

Correlations with 18-item PAID-PR

	PAID-PR		Factor 1		Factor 2	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Age (years)	−0.04	0.46	−0.07	0.20	−0.01	0.93
zBMI (SDS)	−0.07	0.15	−0.09	0.08	−0.04	0.41
Diabetes duration (years)	0.005	0.92	0.06	0.23	−0.04	0.45
Frequency of blood glucose monitoring (times per day)	0.17	0.001	0.07	0.18	0.23	0.0001
HbA _{1c}	0.09	0.10	0.16	0.003	0.001	0.99
Parent report surveys						
Family conflict (diabetes-specific)	0.47	< 0.0001	0.39	< 0.0001	0.42	< 0.0001
Psychosocial quality of life	−0.48	< 0.0001	−0.43	< 0.0001	−0.42	< 0.0001
Physical quality of life	−0.37	< 0.0001	−0.31	< 0.0001	−0.35	< 0.0001
Diabetes-specific quality of life	−0.52	< 0.0001	−0.50	< 0.0001	−0.44	< 0.0001

zBMI, age- and sex-adjusted BMI; Problem Areas in Diabetes - Parent Revised version; SDS, standard deviation score.