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Short Report: Educational and Psychological Aspects Validation of the Diabetes Family Impact Scale: a new measure of diabetes-specific family impact

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Abstract

Aims—To develop and validate the Diabetes Family Impact Scale, a scale to measure the impact of diabetes on families.

Methods—The Diabetes Family Impact Scale was developed by an iterative process, with input from multidisciplinary diabetes providers and parents of children with Type 1 diabetes. The psychometric properties of the Diabetes Family Impact Scale were assessed in parents of children with Type 1 diabetes. This assessment included internal consistency, convergent validity and exploratory factor analysis.

Results—Parents ($n=148$) of children (mean $\pm$ SD age 12.9 ± 3.3 years) with Type 1 diabetes (mean $\pm$ SD duration 6.2 ± 3.6 years) completed the 15-item Diabetes Family Impact Scale. After eliminating one item, the 14-item measure demonstrated good internal consistency (Cronbach's $\alpha = 0.84$). Correlations between the Diabetes Family Impact Scale and measures of parent diabetes burden ($r=0.48$, $P<0.0001$), stressful life events ($r=0.28$, $P=0.0007$), and child's quality of life ($r=-0.52$ and -0.54 , $P<0.0001$ for generic and diabetes-specific quality of life, respectively) supported the convergent validity of the instrument. Factor analysis identified four factors corresponding to the four survey domains (school, work, finances and family well-being).

Conclusions—The Diabetes Family Impact Scale measures diabetes-specific family impacts with good internal consistency and convergent validity and may be a useful tool in clinical and research settings.

Introduction

Type 1 diabetes has a substantial impact on families [1,2]. Diabetes care may strain families' financial resources [1] and lead to increased burden [2–4] and high rates of stress, anxiety and depression for families [5,6]. For some children, attendance [7] and participation at school may be affected. The impact of Type 1 diabetes on families may differ from that of other diseases in that diabetes can induce parental worries about acute and chronic complications [8,9].

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Competing interests

None declared.

Diabetes family impact, that is, the effects of diabetes on family life, may be influenced by new diabetes therapies, policy decisions, family interventions and societal changes. Although well-established general measures of family impact exist [10,11], a scale measuring the distinct impact of diabetes on families is needed.

The aim of the present study was to evaluate the convergent validity and internal consistency and reliability of the new Diabetes Family Impact Scale (DFI-S). We hypothesized that the DFI-S would positively correlate with the child's HbA_{1c}, parent burden and family adverse life events and negatively correlate with the child's age and quality of life.

Patients and methods

Survey development

To ensure the DFI-S had strong content validity, we reviewed extant surveys [10–12] related to the impact of paediatric chronic illness on families in order to inform development of a diabetes-specific family impact measure. Members of a paediatric multidisciplinary team brainstormed the potential impacts of diabetes and developed questions. Next, multidisciplinary representatives (paediatric endocrinologists, diabetes nurse educators, psychologists, social workers and dieticians; ~12 individuals in total) reviewed and provided feedback. We then presented our survey to diabetes behavioural researchers (~25 individuals) for revision. We performed cognitive interviewing with parents of children with diabetes, assessing whether we had included relevant items and whether the items were understood.

The survey originally consisted of 15 items in four domains: school, work, finances and family well-being. Families chose the answer that best described how often the statement was true during the past year. Responses were recorded on a four-point Likert scale ('Almost never'=0; 'Sometimes'=1; 'Often'=2; and 'Almost always'=3). One item from the work domain was eliminated because of low item-to-total correlation (0.07). We considered responses of 'Not applicable' to be the same as unanswered items for two questions that had this option. The scores were then transformed to a 0–100 point scale, with higher scores indicating greater negative impact, normalizing the score for those who omitted questions. Scoring required the completion of 75% of survey questions.

Survey population

In this cross-sectional study, participants were parents/guardians of a child with Type 1 diabetes. One parent per child supplied information. The child had to have Type 1 diabetes for ≥6 months, and attend primary or secondary school (age 5–18 years). Institutional review board approval was obtained. Parents provided written, informed consent.

Data collection

Parents completed paper surveys including the DFI-S, the Problem Areas in Diabetes Survey-Parent Revised version (PAID-PR; higher scores indicate greater burden) [13], the Life Events Checklist, (LEC; higher scores indicate more stressful life events)[14], the

Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales [15], and the PedsQL Type 1 Diabetes Module [16] (higher scores indicate greater quality of life).

Trained research staff abstracted demographic and treatment data from the electronic chart. HbA_{1c} values were used to assess the child's glycaemic control [Roche Integra 800, reference range 20–42 mmol/mol (4–6%)]. If an HbA_{1c} value was not obtained on the study day (8% of children), the value obtained closest to the time of survey completion was used.

Statistical analysis

Statistical analyses were conducted using SAS v.9.2 software. To validate the final 14-item survey, we first performed item-to-total correlations. We determined internal consistency using a standardized Cronbach's α value and convergent validity by comparison with the PAID-PR, LEC, PedsQL Generic Core Scales and PedsQL Type 1 Diabetes Module. We completed a factor analysis across the four domains using principle component analysis and an oblimin oblique-type rotation. In the factor analysis, 16 surveys were eliminated because of incomplete/non-applicable responses.

Descriptive statistics included mean $\pm$ SD values, median (range) values or percentages. Spearman or Pearson correlations were used to provide inter-item correlations and to test our hypothesis of how the DFI-S would correlate with other measures. A Wilcoxon rank-sum test was used to evaluate the DFI-S according to the child's sex.

Results

Study population

In all, 84% of the participants ($n=148$) were mothers (93% white; Table 1). Their children (50% girls) had a mean $\pm$ SD (range) age of 12.9 $\pm$ 3.3 (6.2–18.0) years and had Type 1 diabetes for 6.2 $\pm$ 3.6 years. The mean $\pm$ SD HbA_{1c} of the children included in the study was 68 $\pm$ 14 mmol/mol (8.4 $\pm$ 1.3%).

Psychometric properties of the Diabetes Family Impact Scale

The median (range) score on the DFI-S was 15.4 (0–73.8), with a 25th to 75th quartile range of 8.9 to 26.2. The survey response distribution had a right skew. More than 95% of surveys were completely answered. All survey questions except one included the range of responses, 0 to 3 (Fig. 1).

The standardized Cronbach's α was 0.84, indicating good internal consistency. Item-to-total correlations ranged from 0.27 to 0.65 (Fig. 1), which was within the recommended range of 0.20 to 0.80 for scale development [17]; each item was correlated ($r>0.29$) with 3 other items. The inter-item correlations for the three items in the domain 'finances' were highly correlated ($r>0.78$), suggesting multicollinearity. All other inter-item correlations ranged from -0.04 to 0.69.

The Kaiser–Meyer–Olkin test (overall measure of sampling adequacy; 0.79) was 'middling' approaching 'meritorious' as per Kaiser's criteria [18]. There were four factors corresponding to the four survey domains. Items were assigned to the factor to which they

were most strongly correlated (all correlations >0.51), except for item 7 which loaded on 'well-being' ($r=0.54$) and 'work' ($r=0.51$); we assigned this item to 'work'. The 'finances', 'well-being', 'work', and 'school' factors explained 35, 13, 12 and 7% of the total score's variance, respectively, and had standardized Cronbach's α values of 0.93, 0.79, 0.68 and 0.68, respectively.

We examined correlations between the DFI-S score and other scales and clinical characteristics in order to measure convergent validity and test our hypotheses. The DFI-S positively correlated with the PAID-PR and the LEC ($r=0.48$, $P<0.0001$; $r=0.28$, $P=0.0007$, respectively). The DFI-S negatively correlated with the PedsQL (generic and Type 1 diabetes) ($r=-0.52$, $P<0.0001$ and $r=-0.54$, $P<0.0001$, respectively). DFI-S scores were weakly negatively correlated with child age ($r=-0.16$, $P=0.046$) and did not differ by child's sex. DFI-S scores did not correlate with HbA_{1c} or diabetes duration.

Discussion

The DFI-S is a novel, self-administered measure of the impact of diabetes on families; it was found to have good internal consistency and convergent validity. Four factors identified in a factor analysis corresponded with the four pre-specified domains.

Two well-validated and psychometrically sound scales, the Impact on Family Scale [10] and the Family Impact Module of the PedsQL [10,11], measure family impact for children with chronic illness. There is recognition of different family impacts related to various disorders, leading to scales for specific populations, such as individuals with chronic pain [19], using assistive communication technology [20] and with emotional/behavioural problems [21].

The DFI-S focuses on the particular impacts that are common and unique for families of children with Type 1 diabetes. Impacts in the domains of work and finances frequently occur [1]; therefore, we emphasized those domains. Additionally, multidisciplinary feedback highlighted concern about impact on the school domain; thus, the DFI-S includes this domain.

The concepts of diabetes burden and diabetes impact are similar but distinct; diabetes burden scales focus more heavily on the emotional aspects of caring for a child with diabetes, while the present scale focuses on the effects on daily family living. Because there are already validated scales available to assess burdens of diabetes [3,13] we did not focus on questions about psychosocial functioning and targeted school, work, finances and family well-being.

The present study has a number of limitations. It was a single-centre study, therefore, further validation studies should be performed in other populations representing greater geographic, financial and ethnic diversity and in a larger sample of fathers. In addition, test-retest reliability and the responsiveness of this scale to interventions aimed at diminishing negative family impact should be assessed. The school item-to-total correlations were lower than for the other domains, probably reflecting the school domain's focus on impacts related to the child while the other domains are focused on impacts related to the household.

The DFI-S is a self-reported measure of diabetes-specific family impacts, with good internal consistency and convergent validity. Responses indicate that many families experience family impacts; diabetes led to family impact in all four measured domains. The impacts on families of future therapeutic and/or policy interventions could be considered by quantifying them using the DFI-S.

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What's new?

- Families of children with Type 1 diabetes are substantially affected by the disease. To measure this diabetes-specific family impact, a short, valid, self-reported instrument is needed.
- The Diabetes Family Impact Scale is a promising new measure of diabetes family impact, with good internal consistency and strong convergent validity.

Table 1Characteristics of families and children with Type 1 diabetes ($n=148$)

Family characteristics	%	Child characteristics	% or Mean $\pm$ SD
Family member responding: mothers	84	Age, years	12.9 $\pm$ 3.3
Race/ethnicity: white	93	Sex: % female	50
Married/Living together	83	Type 1 diabetes duration, years	6.2 $\pm$ 3.6
Number of children (<18 years) in home		Daily insulin dose, units/kg	0.9 $\pm$ 0.3
1	18	Blood glucose monitoring, times/day	5.6 $\pm$ 2.9
2	53	Insulin regimen: % pump	66%
3	28	HbA1c, mmol/mol (%)	68 $\pm$ 14 (8.4 $\pm$ 1.3)
Parent education (highest level)			
High school or lower	12		
Some college education/Associate's degree	25		
		Parent surveys (score range)	Median (IQR)
College/Graduate degree	63	PedsQL Generic Core Scales (0–100)	83.2 (70.7–92.4)
Household income		PedsQL Type 1 Diabetes Module (0–100)	71.4 (63.2–79.9)
<\$50,000/year	27	LEC (0–25)*	2.0 (0.0–4.0)
\$50,000 to \$99,999/year	26	PAID-PR (0–100)	45.8 (37.5–55.1)
\$100,000/year	46		

IQR, 25th to 75th interquartile range; PedsQL, Pediatric Quality of Life Inventory; LEC, Life Events Checklist; PAID-PR, Problem Areas in Diabetes Survey- Parent Revised version.

* LEC gave the option to write in additional events.