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Relationship of Type 1 Diabetes Self-Management Barriers to Child and Parent Quality of Life

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Abstract

Aims: Families of children and adolescents with type 1 diabetes experience self-management challenges, which negatively impact diabetes control. This study assesses whether self-management challenges are also associated with quality of life (QOL) for children and adolescents with type 1 diabetes and their parents.

Methods: Children ages 8–12 years (n=135), adolescents 13–16 years (n=132) and their parents completed QOL assessments (diabetes-specific QOL from the PedsQL Diabetes Module or the Family Impact Module, both scaled 0–100) and a validated survey of up to six self-management barriers (PRISM; scaled 1 (low) - 5 (high)). Regression coefficients were calculated to assess association of self-management barriers with the children and adolescents' diabetes-specific QOL or parent QOL, including interaction effects to assess stability of the associations.

Results: Mean duration of diabetes was 4.7 years for children and 6.1 years for adolescents. The majority of children and adolescents did not meet target values for glycaemic control. All barriers but one (Healthcare Team Interactions) were associated with lower diabetes-specific QOL for children and adolescents, as well as lower QOL for parents (all $p < 0.05$). Barrier scores that were 1 unit higher were associated with diabetes-specific QOL that was 3.7–5.1 points lower for children and 5.8 to 8.8 points lower for adolescents, as well as 6.0 to 12.6 points lower QOL for parents. Diabetes-specific QOL was most strongly associated with “Denial of Disease and Its Consequences” for children and with “Regimen Pain and Bother” for adolescents. Parent QOL was most strongly associated with “Understanding and Organizing Care.” Associations were stable across numerous demographic and disease factors.

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CONFLICTS OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this article.

Conclusions: Single unit differences in self-management barrier scores are associated with clinically meaningful QOL differences for children and parents. Interventions specifically tailored to address individual self-management barriers may improve both diabetes control and QOL.

Keywords

Children and adolescents; hypoglycaemia; psychological aspects; self-management

INTRODUCTION

Type 1 diabetes (T1DM) can reduce health related quality of life (QOL) for children, adolescents, and their parents. Diabetes-specific QOL varies among affected children and adolescents and can be impacted by factors related to the disease and its management, such as family conflict and interactions, emotional burden from T1DM, or advances in treatment regimens [1–5]. T1DM also affects parental QOL, with parental distress impacting self-management, and in turn, the child's diabetes-specific QOL [6, 7]. While previous studies of the relationship between diabetes-specific QOL and barriers in T1DM have generally focused on one factor such as family interactions, or on a subgroup of factors such as psychosocial barriers [4, 5], to our knowledge, studies of the relationship between QOL and multiple self-management barriers are lacking. Thus, we sought to understand how a comprehensive set of problems with self-management affects QOL for both children and adolescents with T1DM and their parents.

Children and adolescents with T1DM often have self-management difficulties, and the majority of affected children and adolescents do not meet HbA1cs targets [8]. Self-management includes complex insulin and diet regimens, requiring involvement from both the children and their parent(s) [9]. Several challenges exist to adequate self-management, such as limited knowledge, lack of skills or motivation, ineffective interactions with healthcare providers, family conflict, and lack of peer support [2, 10–12]. A validated tool known as PRISM (Problem Recognition in Illness Self-Management) comprehensively assesses T1DM self-management barriers, which are significantly associated with HbA1c levels [13]. We hypothesize that these self-management barriers are also associated with diabetes-specific QOL for children and adolescents with T1DM and also QOL for their parents. Hence, this study quantifies the relationship of diabetes-specific QOL among children and adolescents as well as parent QOL with self-management barriers as assessed by PRISM.

METHODS

Participants and Recruitment:

Participants were 267 children and adolescents ages 8–16 years with T1DM and their parents. They were from two large multidisciplinary diabetes clinics, which serve both urban and rural populations, and were recruited as part of a randomised clinical trial evaluating the impact of self-management resources, described in detail in a separate publication [14]. In that trial participants received self-management resources in a group setting, tailored to the family's needs identified through the PRISM tool. The study sites were selected to ensure

adequate size and diversity of the study population, improving the generalizability of findings. Eligibility criteria for participants were: diagnosis of T1DM for at least 1 year, seeing a participating study provider, ability to speak and read English, ability to engage in group-based trial activities, and ability to provide informed consent/assent. Seventy-four percent of eligible participants provided consent, with full details of our recruitment process available in other publications about the trial [14]. With the exception of one parent, data for QOL and barrier scores were complete.

Study Design:

A cross-sectional research design based on pre-randomization baseline data was used in this study. Children (ages 8–12 years) and adolescents (ages 13–16 years) meeting eligibility criteria self-reported diabetes-specific QOL using the Diabetes Module of the PedsQL, referred to hereafter for readability as QOL. Parents of both children and adolescents self-reported their QOL with six disease-relevant subscales of the PedsQL Family Impact Module [15, 16]. Adolescents and parents of both children and adolescents completed the PRISM tool to assess self-management barriers [13, 17]. Parents provided demographic information, T1DM-related characteristics, and an assessment of their child's health status (Table 1). All surveys were administered electronically unless the parent or adolescent requested a paper copy.

Measures:

Problem Recognition in Illness Self-Management (PRISM): PRISM is a validated 28-item scale identifying up to six T1DM self-management barriers based on reports by parents of children and adolescents, as well as by adolescents themselves [13]. The six barriers are: Understanding and Organizing Care, Regimen Pain and Bother, Denial of the Disease and Its Consequences (Denial), Healthcare Team Interactions, Family Interactions, and Peer Interactions. PRISM, including all the survey items, can be found at <https://www.hipxchange.org/PRISM>. PRISM identifies all six self-management barriers when reported by parents of adolescents, five self-management barriers when reported by adolescents, and four self-management barriers when reported by parents of children. PRISM was developed through factor analytic techniques, with the measurement models demonstrating recommended criteria for good model fit such as root mean square error of approximation and Tucker-Lewis indices [13, 18]. Average variances extracted (AVE) suggested discriminant validity for nearly all PRISM domains for each of our three participant types. For parents of children, all PRISM domains displayed discriminant validity. For parents of adolescents, discriminant validity was demonstrated for all domains except Peer Interactions (AVE = 0.42), with Denial and with Family Interactions. Similarly, for adolescents, discriminant validity for all domains was demonstrated except for Understanding and Organizing Care (AVE = 0.54) with Regimen Pain and Bother and for Family Interactions (AVE = 0.57) with Healthcare Team Interactions. Item response options are on a 5-point Likert scale, with 1 = strongly disagree and 5 = strongly agree. Items within each domain are averaged for a total score between 1 and 5 for each self-management barrier, with a higher score indicating greater levels of a barrier.

Quality of Life: The PedsQL Diabetes Module, used to assess diabetes-specific QOL for children and adolescents, is a 28-item measure consisting of five scales: T1DM symptoms ($\alpha = 0.81$), treatment barriers ($\alpha = 0.66$), treatment adherence ($\alpha = 0.66$), worry ($\alpha = 0.63$), and communication ($\alpha = 0.77$). The PedsQL Family Impact Module is a 36-item survey to assess the impact of children's chronic health conditions on parents' QOL and family functioning [16]. To minimise survey burden, we selected six of the Family Impact Module's eight scales to administer (emotional functioning ($\alpha = 0.88$), social functioning ($\alpha = 0.85$), communication ($\alpha = 0.79$), worry ($\alpha = 0.87$), daily activities ($\alpha = 0.87$), and family relationships ($\alpha = 0.93$)), based on relevance in the study population [19]. Both of these instruments use 5-point Likert scale with 0 = never a problem and 4 = almost always a problem. Items are reverse-scored and then transformed to a 0 to 100 scale, with higher scores indicating better QOL. In recognition of the potential conceptual overlap between PRISM's assessment of self-management barriers and two scales from the PedsQL Diabetes Module (treatment barriers and treatment adherence), we followed the same procedure to create a QOL score that excluded these two domains.

Demographics: Parents reported their child's gender, birthdate, and race/ethnicity. The child's age was calculated from their birthdate and dichotomised into children (ages 8–12 years) or adolescent (ages 13–16 years). In analyses, race/ethnicity was represented dichotomously as Non-Hispanic White versus all others. Parents also reported their year of birth from which parent age was calculated, their educational attainment, and their relationship to the child.

Diabetes-Related Factors: In addition, parents reported their relationship to the participating child, as well as T1DM-related characteristics including the year of their child's diagnosis, HbA1c at recruitment, and use of an insulin pump. The child's HbA1c value was abstracted from the clinic record, and dichotomised as either meeting target values (less than 58 (7.5%)) or not meeting target values (greater than or equal to 58 (7.5%)) for analysis.

Health Status: Parents also reported the child's health status using a standard single item, with response options on the poor, fair, good, very good, excellent scale [20]. For analysis, health status was dichotomised as into good to excellent versus fair or poor health.

Analysis Plan:

Descriptive statistics were calculated to examine demographic and T1DM-related characteristics of our participants. For each respondent's report of self-management barriers, a separate linear regression was used to understand its association with child, adolescent, or parent QOL. For children ages 8–12 years, we examined how parent reports of self-management barriers were related to both child and parent QOL. For adolescents, regression examined how their self-reported barriers to managing their T1DM were related to their QOL and their parent's QOL. In addition, self-management barriers as reported by parents of adolescents were examined in relation to both adolescent and parent QOL. We examined the association of self-management barriers with the full PedsQL Diabetes Module as well as with the QOL score that excludes the two domains with conceptual overlap. Our results

were similar, so we report results that reflect the full PedsQL module, but also note two instances where the association between PedsQL and the self-management barrier scores were no longer significant when excluding the two domains. In addition, we examined both adolescent and parent reports of self-management barriers with parent QOL. Hypothesis tests were considered significant at the $p < 0.05$ level. Additionally, to assess whether the association between self-management barriers and QOL was stable across sociodemographics and disease factors, regression models with interaction effects for the child or adolescent's health status, gender, and race; the parent's education and age; and insulin pump use were fitted. These interactions were considered significant at the $p < 0.01$ level in order to avoid complicating the models with clinically insignificant interactions and to reduce the likelihood of spurious statistical significance among the large number of possible interactions.

RESULTS

Participant Characteristics:

Among child and adolescent participants, most were Caucasian, in good to excellent health, and both sexes were fairly equally represented. Average T1DM duration was 4.7 years for children, and 6.1 years for adolescents. Overall, approximately half of participants used insulin pumps, and relatively few had adequate T1DM control as defined by the ADA-recommended target of less than 7.5% [21]. Mean QOL was 68.5 (SD=12.7) for children and 67.2 (SD=12.8) for adolescents. Most participants were accompanied by their mothers, the majority of whom were Caucasian and had a wide range of education levels. Mean QOL was approximately 64 (SD=16) for parents of both children and adolescents (Table 1).

PRISM Scores:

In general, mean PRISM barrier scores were similar across participant types and ranged from 1.6 to 2.9, on a 5-point scale, with higher scores indicating greater barriers. For adolescents, Family Interactions was the self-management barrier with the greatest mean score. For parents of both children and adolescents, Denial was the self-management barrier with the highest mean score. Across all participant types, the smallest mean barrier scores were reported for Healthcare Team Interactions (Table 3).

Association of Adolescent Reported Self-Management Barriers with Quality of Life:

Adolescent Quality of Life: Each of the PRISM-identified self-management barriers was significantly negatively associated with adolescent QOL. Specifically, 1-unit higher self-management barriers scores were associated with 5.8 to 8.8 points lower QOL. For adolescents, the self-management barrier with the greatest association with their QOL was Regimen Pain and Bother (Table 4).

Parent Quality of Life: All but one of the adolescent-report self-management barriers were significantly negatively associated with parent QOL. Among those associations, 1-unit higher self-management barriers scores were associated with 3.7 to 6.0 points lower parent QOL. Parent QOL was most strongly associated with adolescents' self-management barriers

related to Peer Interactions. The only adolescent-reported barrier that was not significantly associated with parent QOL was Healthcare Team Interactions (Table 4).

Association of Parent Reported Self-Management Barriers with Quality of Life:

Child and Adolescent Quality of Life: Parent report of all self-management barriers was significantly negatively associated with both child and adolescent QOL. 1-unit higher parent-reported self-management barriers scores were associated with child QOL that was 3.0 to 5.1 points worse and adolescent QOL that was 2.9 to 5.2 points worse. However, when the treatment barriers and treatment adherence scales were excluded from the QOL assessment, the association of child QOL with two barriers (Healthcare Team Interactions and Regimen Pain and Bother) were no longer significant. Among children, QOL was most strongly associated with barriers around Understanding and Organizing Care and also Denial of the Disease and Its Consequences. For adolescents, QOL was most strongly associated with parent reports of self-management barriers around Understanding and Organizing Care and also Family Interactions (Table 5).

Parent Quality of Life: All parent-reported self-management barriers were significantly negatively associated with QOL for parents of both children and adolescents. Among those associations, 1-unit higher self-management barriers scores were associated with parent QOL 6.0 to 12.6 points lower. For parents of children, QOL was most strongly associated with barriers around Denial, while QOL for parents of adolescents was most strongly associated with self-management barriers related to Understanding and Organizing Care (Table 5).

Stability of the Associations between Self-management Barriers and QOL:

All associations between PRISM-identified self-management barriers and QOL for the children, adolescents, and parents were compared across multiple demographic and disease-related factors. No significant interactions were found, providing evidence that the associations do not vary significantly by these factors (results not shown).

DISCUSSION

QOL for children and adolescents with T1DM as well as their parents was negatively associated with nearly all of the self-management barriers identified by PRISM, regardless of whether the parent or the adolescent reported the self-management barriers. Clinically significant differences in QOL were seen with a 1-unit difference in response on the 5-unit scale for nearly all the self-management barriers. Further, the self-management barrier associated with the greatest change in QOL differed for children, adolescents, and parents. These results have implications for the delivery of T1DM self-management resources for these families. Specifically, QOL for children and adolescents with T1DM as well as for their parents might be most effectively improved when self-management resources are tailored to specific, identifiable self-management barriers.

To place the relationship between self-management barriers and QOL in context, the magnitude of the associations can be compared to established minimally important

differences for the study's QOL measures. A minimally important difference for the diabetes-specific PedsQL is considered to be 5.27 units based on self-reported data from adolescents [22]. For the Family Impact Module, to our knowledge, there are no published reports of minimally important differences. However, using a recommended distribution-based statistical method that relies on the standard deviation of the measure [23], we calculated a minimally important difference of 3.53 for the Family Impact Module from our data. For adolescents and also for parents of children and adolescents, the magnitude of the association of QOL with a single unit change in almost all self-management barrier scores exceed these minimally important differences. This suggests important QOL differences accompany even a 1-unit change in self-management barrier scores.

The self-management barrier associated with the greatest change in QOL differed for children, adolescents, and parents, as might be expected. Previous research on stages of illness suggests that self-management challenges among children with chronic illness vary over time [24], and normal developmental processes can create new self-management challenges. Given that T1DM is typically diagnosed at around 8 years of age [25], it is not surprising that Denial is the barrier most strongly related to QOL for children ages 8–12 years and for their parents. For adolescents, QOL is most strongly related to Regimen Pain and Bother, while their parents' QOL is most strongly related to barriers around Understanding and Organizing Care. In addition, Family Interactions is associated with a large change in QOL for adolescents and their parents, likely related to the normal development of autonomy that occurs during adolescence [2].

Findings from this work suggest that assessment of self-management barriers with PRISM could aid in selecting the most effective interventions for each individual child, adolescent, and family. While previous studies of the relationship between diabetes-specific QOL and barriers in T1DM have generally focused on one factor such as family interactions, or on a subgroup of factors such as psychosocial barriers [4, 5], to our knowledge the use of a single tool to assess multiple self-management barriers is novel and offers efficiency. Further, evidence-based interventions already exist to address PRISM-identified self-management barriers, providing a potential pathway to improve QOL for children and adolescents with T1DM and/or their parents. For example, the T1DM self-management barriers related to family interactions could be addressed with Behavioral Family Systems Therapy [26]. In addition, self-management barriers arising from family or peer interactions can be addressed with group-based therapies [27]. Further, self-management barriers related to Understanding and Organizing Care could be addressed by educational programmes such as the curriculum developed by the American Diabetes Association [28, 29]. Similarly, motivational interviewing approaches could address self-management barriers related to Denial, as well as Regimen Pain and Bother [30]. Using PRISM could help to select among these resources for each individual family.

While this study was able to establish multiple associations between self-management barriers and QOL, there are some notable limitations. First, this study cannot establish causality, and we have consequently framed our results as associations. Future work could further establish causality by observing QOL and self-management barriers over time or through randomised trials assessing how QOL may change in response to interventions that

address self-management barriers. Second, this study only considered the six self-management barriers assessed by PRISM, so other self-management barriers may exist that impact QOL. However, our prior work with children and adolescents with T1DM and their families uncovered no additional barriers to be considered [13]. Third, this study was performed at two clinical sites, and we excluded families who were unable to speak or read English. However, the characteristics of our participating families were similar to those of the US population of children and adolescents with T1DM. Additionally, QOL for participants in our study was similar to QOL reported for children and adolescents with T1DM and for parents of children with chronic illness [16, 31, 32]. We also did not recruit families when parents believed their child might be uncomfortable participating in the trial's future group-based activities. Although very few families were excluded based on this criterion, these exclusions may lead us to underestimate the relationship between QOL and self-management barriers. Lastly, to reduce survey burden, we administered only six of the eight subdomains of the Family Impact Module. Because we did not include two domains that were thought to be less influenced by T1DM self-management barriers, our results may overestimate the relationship between self-management barriers and parent QOL. However, our parents' scores on this tool were similar to those previously reported, so it is unlikely that this substantially impacted our findings [16, 32, 33].

In conclusion, T1DM self-management barriers as determined by PRISM are associated with QOL for children and adolescents with T1DM as well as their parents. The magnitude of differences in QOL associated with single-unit differences in PRISM barrier scores suggests meaningful impact on QOL for those experiencing self-management barriers. Thus, taken together with our work demonstrating that PRISM-identified barriers are also associated with HbA1c, using PRISM to select the self-management barriers to be addressed in clinical practice may result in greater likelihood of improving glycaemic control and QOL. Because PRISM identifies barriers for which interventions already exist, the tool could be used to identify specific actionable self-management barriers as targets to effectively address QOL and glycaemic control for children and adolescents with T1DM and their families. Tailoring referrals in the clinical setting to resources that address specific self-management barriers associated with QOL for children and adolescents with T1DM and their parents has the potential to improve the lived experience for children with T1DM and their families. Future studies could examine the impact of tailoring T1DM resources to the unique needs of individual children, adolescents, and families as well as modeling how self-management barriers affect both A1c and QOL over time.

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Novelty statement:

- Type 1 diabetes self-management barriers have the potential to impact diabetes-specific QOL for children and adolescents as well as QOL for their parents.
- This study highlights the relationship between six specific, actionable, and common self-management barriers and diabetes-specific QOL for children (8–12 years) and adolescents (13–17 years) with T1DM, as well as QOL for their parents.
- Findings point to the potential utility of identifying and addressing self-management barriers in clinical settings as a potential pathway to improve both diabetes self-management and QOL.

Table 1.

Family characteristics *

Child and adolescent characteristics	Child (n=135)	Adolescent (n=132)
Age, years (mean (sd))	10.8 (1.4)	15.0 (1.1)
Girl	46.7% (63)	47.0% (62)
Non-Hispanic, White	83.7% (113)	84.1% (111)
In good to excellent health	95.6% (129)	91.7% (121)
Years since diagnosis (mean (sd))	4.6 (2.7)	6.1 (3.7)
Insulin pump use	48.2% (65)	51.5% (68)
HbA1c < 58 (7.5%)	16.3% (22)	21.2% (28)
HbA1c mmol/mol (mean (sd))	70 (16.4)	75 (19.7)
HbA1c % (mean (sd))	8.6 (1.5)	9.0 (1.8)
Parent characteristics		
Age, years (mean (sd))	40.5 (6.5)	44.1 (5.6)
Mother	88.2% (119)	84.9% (112)
Non-Hispanic, White	85.9% (116)	89.4% (118)
Education		
High school graduate or less	19.3% (26)	15.9% (21)
Some college	38.5% (52)	33.3% (44)
Bachelor's degree or more	42.2% (57)	50.8% (67)
Quality of Life		
Child or adolescent [†] (mean (sd))	68.5 (12.7)	67.2 (12.8)
Parent [‡] (mean (sd))	63.9 (16.5)	64.3 (16.2)

* Values may not add to 100% due to rounding or non-response.

[†] Child and adolescent quality of life (QOL) assessed with the PedsQL Diabetes Module.

[‡] Parent QOL assessed with the PedsQL Family Impact Module.

Table 2.

PRISM domains and items *

Understanding and Organizing Care
It's hard for my child and I to stay organized enough to keep track of medications or other things related to his/her illness.
My child and I have trouble understanding what the doctors tell us to do for his/her regimen.
It's hard for my child and I to plan things out carefully, so sometimes we don't get around to following his/her regimen.
When there are changes to his/her regimen, my child and I sometimes get confused.
Sometimes my child and I can't remember everything we're supposed to do about his/her illness.
When my child feels anxious or nervous about something, it's hard for him/her to follow his/her regimen.
Regimen Pain and Bother
Following his/her regimen causes my child physical pain and discomfort.
My child's regimen has side effects that he/she really doesn't like.
My child feels that his/her regimen takes a lot of time and work.
My child's regimen causes changes to his/her body that he/she really doesn't like.
Denial
My child feels that nothing bad would happen to him/her if he/she didn't follow his/her regimen.
My child refuses to give up time with his/her friends to take care of his/her illness.
My child tries to forget that he/she has an illness.
I get angry when my child makes a slip in taking care of his/her diabetes (he/she doesn't take care of his/her diabetes).
My child thinks, "None of my friends have to deal with this, why do I?"
My child feels that our family doesn't understand what it's like to live with his/her illness.
Healthcare Team Interactions
My child and I don't always trust the doctors and nurses.
The doctors treat my child like a little kid who can't take care of him/herself.
The doctors are too busy or rushed to talk with my child and I about his/her illness and regimen.
The doctors don't seem to understand how much my child's regimen gets in the way of important things in his/her life.
My child feels that his/her doctors are friendly and easy to talk to. †
The doctors do a good job of explaining things to my child and me. †
Family Interactions
My child feels that our family doesn't understand what it's like to live with his/her illness.
Our family gives my child a lot of support to help him/her follow his/her regimen. †
My child has someone in our family to talk to about his/her diabetes. †
I listen to my child's ideas about taking care of his/her diabetes. †
I understand how my child feels about having diabetes. †
I get angry when my child makes a slip in taking care of his/her diabetes (he/she doesn't take care of his/her diabetes).
Peer Interactions
My child doesn't want his/her friends to know about his/her illness.
My child thinks, "None of my friends have to deal with this, why do I?"
My child doesn't mind if his/her friends bring up his/her illness or ask him/her questions about it. †

* Item wording is based on parent survey, and all items may not load for each respondent type. See PRISM toolkit for details.

† Items are reverse scored.

Table 3.

Mean and standard deviation of PRISM scores for the adolescent and parent

Self-management barrier	Adolescent (n=132)	Parent of adolescent (n=132)	Parent of child (n=135)
Understanding and Organizing Care	2.3 (0.9)	2.3 (0.7)	2.2 (0.9)
Regimen Painand Bother	2.1 (0.8)	2.6 (0.8)	2.6 (0.9)
Denial	-	2.9 (0.9)	2.9 (0.8)
Healthcare Team Interactions	1.8 (0.7)	1.6 (0.6)	1.6 (0.6)
Family Interactions	2.7 (0.9)	2.2 (0.6)	-
Peer Interactions	2.1 (0.8)	2.8 (1.0)	-

Table 4.

Regression coefficients and 95% confidence intervals (CI) for association of adolescents' self-management barrier scores with quality of life (QOL) of the adolescent and parent (n=132)

Self-management barrier	Adolescent QOL [*]		Parent QOL [†]	
	$\beta^{\ddagger}$	95% CI	$\beta^{\ddagger}$	95% CI
Understanding and Organizing Care	-7.6	(-9.7, -5.5)	-4.1	(-7.2, -1.0)
Regimen Pain and Bother	-8.8	(-11.2, -6.4)	-3.7	(-7.2, -0.2)
Healthcare Team Interactions	-6.2	(-9.0, -3.4)	-2.4	(-6.1, 1.4)
Family Interactions	-5.8	(-8.2, -3.4)	-3.9	(-7.1, -0.7)
Peer Interactions	-5.8	(-8.4, -3.2)	-6.0	(-8.7, -3.3)

Bolded values indicate p<0.05.

^{*} Adolescent quality of life (QOL) assessed with the PedsQL Diabetes Module.

[†] Parent QOL assessed with the PedsQL Family Impact Module.

[‡] Beta indicates the mean change in QOL associated with a 1-unit higher self-management barrier score.

Table 5.

Regression coefficients and 95% confidence intervals (CI) for association of parent-reported self-management barrier scores with child and adolescent quality of life (QOL)

Self-management barrier	Child QOL* (n=135)		Adolescent QOL* (n=132)		Parent of child QOL (n=135) [†]		Parent of adolescent QOL (n=132) [‡]	
	$\beta^{\dagger}$	95% CI	$\beta^{\dagger}$	95% CI	$\beta^{\dagger}$	95% CI	$\beta^{\dagger}$	95% CI
Understanding and Organizing Care	-5.1	(-7.5, -2.6)	-5.2	(-8.2, -2.2)	-11.1	(-13.9, -8.4)	-12.6	(-15.9, -9.3)
Regimen Pain and Bother	-3.0	(-5.4, -0.6)	-2.9	(-5.7, -0.2)	-9.0	(-11.8, -6.3)	-9.9	(-12.9, -6.8)
Denial of Disease and Consequences	-5.1	(-7.6, -2.7)	-4.1	(-6.5, -1.7)	-11.3	(-14.1, -8.5)	-7.8	(-10.7, -4.9)
Healthcare Team Interactions	-3.7	(-7.2, -0.2)	-4.4	(-8.3, -0.5)	-11.0	(-15.2, -6.8)	-9.4	(-14.1, -4.6)
Family Interactions	-	-	-5.2	(-9.1, -1.3)	-	-	-11.0	(-15.8, -6.3)
Peer Interactions	-	-	-3.6	(-5.7, -1.4)	-	-	-6.0	(-8.7, -3.3)

Bolded values indicate $p < 0.05$.

* Child and adolescent quality of life (QOL) assessed with the PedsQL Diabetes Module.

[†] Parent QOL assessed with the PedsQL Family Impact Module.

[‡] Beta indicates the mean change in QOL associated with a 1-unit higher self-management barrier score.