Published in final edited form as:
J Pediatr. 2012 June ; 160(6): 911–917. doi:10.1016/j.jpeds.2011.11.026.

Health-Related Quality of Life in Adolescents With or at Risk for Type 2 Diabetes Mellitus

Erinn T. Rhodes, MD, MPH[1,2], **Michael I. Goran, PhD**[3,4], **Tracy A. Lieu, MD, MPH**[5,6], **Robert H. Lustig, MD**[7], **Lisa A. Prosser, MS, PhD**[5,8], **Thomas J. Songer, PhD**[9], **Marc J. Weigensberg, MD**[4], **Ruth S. Weinstock, MD, PhD**[10], **Tessa Gonzalez, AB**[1], **Kaitlin Rawluk, BA**[1], **Roula M. Zoghbi, MPH**[1], **David S. Ludwig, MD, PhD**[1,2], and **Lori M. Laffel, MD, MPH**[2,11]

[1]Division of Endocrinology, Children's Hospital Boston, Boston, MA

[2]Department of Pediatrics, Harvard Medical School, Boston, MA

[3]Department of Preventive Medicine, Keck School of Medicine, University of Southern California, Los Angeles, CA

[4]Department of Pediatrics, Keck School of Medicine, University of Southern California, Los Angeles, CA

[5]Center for Child Health Care Studies, Department of Population Medicine, Harvard Pilgrim Health Care Institute and Harvard Medical School, Boston, MA

[6]Division of General Pediatrics, Children's Hospital Boston, Boston, MA

[7]Department of Pediatrics, University of California, San Francisco, San Francisco, CA

[8]Child Health Evaluation and Research Unit, Division of General Pediatrics, University of Michigan, Ann Arbor, MI

[9]Department of Epidemiology, University of Pittsburgh, Pittsburgh, PA

[10]Department of Medicine, SUNY Upstate Medical University, Syracuse, NY

[11]Pediatric, Adolescent and Young Adult Section, Joslin Diabetes Center, Boston

Abstract

Objective—We evaluated how adolescents with or at risk for type 2 diabetes (T2DM) and their parent/guardians (parents) perceive adolescents' health-related quality of life (HRQOL).

Corresponding Author and Reprint Requests: Erinn T. Rhodes, MD, MPH; Division of Endocrinology, Children's Hospital Boston, 333 Longwood Ave. 6th Floor, Boston, MA, 02115; Telephone: 617-355-3209; Fax: 617-730-0194; Erinn.Rhodes@childrens.harvard.edu.

Disclosure

Dr. Rhodes was formerly Chief Medical Officer for Pediatric Weight Management Centers, LLC's Great Moves! Program, a company that was privately owned and operated in collaboration with the physicians of Children's Hospital Boston. Dr. Rhodes provided contracted clinical and administrative services for the company but neither had nor has equity or other economic interest in the business. Dr. Rhodes also received salary support from an unrestricted, philanthropic grant from the New Balance Foundation. Dr. Laffel is consultant for Sanofi-Aventis, Johnson & Johnson, Lilly, Bristol Myers Squibb, Astra Zeneca, and Menarini, and receives grant support from Bayer. The remaining authors have no disclosures.

Study Design—We interviewed overweight/obese, 12–18-year-old youth with T2DM, prediabetes, or insulin resistance (IR) and one parent from 5 US sites. Assessments included Pediatric Quality of Life Inventory™ (PedsQL), Health Utilities Index (HUI3), family conflict and diabetes burden.

Results—Among 108 adolescents, diagnoses included 40.7% T2DM, 25.0% prediabetes, and 34.3% IR. PedsQL summary score (SS) was higher among adolescents vs. parents (p=0.02). Parents rated physical functioning lower than adolescents (p<0.0001), but there were no differences in psychosocial health. Adolescent PedsQL SS did not differ by diagnosis but was inversely associated with adolescent BMI z-score (p=0.0004) and family conflict (p<0.0001) and associated with race/ethnicity (p<0.0001). Number of adolescent comorbidities (p=0.007) and burden of diabetes care (p<0.05) were inversely associated with parent PedsQL SS (p<0.05). There were no differences in HUI3.

Conclusions—Parents perceive their adolescents' physical functioning as more impaired than adolescents themselves. Contextual factors including severity of obesity, race/ethnicity, family conflict and burden of diabetes care influence HRQOL. Family-based approaches to treatment and prevention of T2DM may benefit from increased attention to the biopsychosocial context.

Keywords

overweight; obesity; children; family conflict; body mass index

---

Recent US data suggest a possible plateau in the prevalence of overweight and obese youth in the last decade (1). However, there is variability by race/ethnicity, and approximately one-third of children remain in this high risk group (1), at risk for metabolic complications that include insulin resistance (IR), prediabetes, and type 2 diabetes (T2DM) (2). While the adverse health outcomes of childhood obesity and potential longer term complications of T2DM diagnosed in youth(4) have been described (3, 4), the impact of these conditions on a child's health-related quality of life (HRQOL) are also a critical concern (5, 6).

HRQOL is a multidimensional construct that measures the impact of health or disease on physical and psychosocial functioning (7). Several studies have demonstrated impairments in HRQOL among overweight and obese youth (6, 8–15); some suggesting that youth with obesity have deficits in HRQOL comparable to children with cancer (6). While fewer studies have specifically addressed this topic in youth with T2DM (16–18), youth with T2DM have reported lower HRQOL than healthy children and children with type 1 diabetes (T1DM) in several domains (16, 17). Diabetes treatments, glycemic control and comorbid conditions, including depression, may also influence various aspects of HRQOL (5, 17, 18). In adults, racial/ethnic differences in self-reported health and quality of life concerns have been reported (19, 20). Among youth with T1DM, family conflict has been shown to diminish HRQOL (21, 22). Similarly, family support and connectedness has been associated with increased HRQOL and less psychosocial distress in obese youth (13, 23). Further work is needed to describe the biopsychosocial context for HRQOL among youth at the intersection of obesity and diabetes. Therefore, in this study, we evaluated how adolescents with or at risk for T2DM and their parent/guardians (parents) perceive adolescents' HRQOL and its relationship with the sociodemographic, family and medical context.

Methods

Subjects

Subjects were recruited between April 2006 and December 2007 from weight management, T2DM, and other specialty programs at Children's Hospital Boston, Joslin Diabetes Center (Boston, MA), University of California San Francisco, University of Southern California and State University of New York/Upstate Medical University treating adolescents with or at risk for T2DM.

Subjects were adolescents between 12 and 18 years of age with BMI for age ≥85th percentile within the prior 2 years and with a diagnosis of T2DM, prediabetes, or IR. One parent was required to participate in the study along with the adolescent, and the parent and child had to be fluent in English or Spanish. T2DM, prediabetes and IR were clinical diagnoses based on documentation in the medical record. For prediabetes, the terms "prediabetes," "impaired fasting glucose," or "impaired glucose tolerance" were accepted. Alternatively, laboratory data consistent with the prevailing American Diabetes Association criteria were also accepted (24). For IR, the terms "insulin resistance," "metabolic syndrome," and "hyperinsulinemia" were accepted. Laboratory data were accepted as alternatives and included fasting insulin >16 uU/mL, insulin peak (post-OGTT load) >150 uU/mL, or insulin level at 120 minutes of OGTT >75 uU/mL. We did not require that laboratory criteria be met for all subjects as screening practices at sites varied, biochemical definitions for IR are not well established (25), and our goal was to identify patients perceived to be at heightened clinical risk for T2DM. To be eligible, the parent had to report awareness of the child's diagnosis or risk for T2DM.

Adolescents were excluded for depression or other psychiatric disorders (other than attention deficit disorder); impaired cognitive skills or developmental delay if functioning below a 6th grade academic level by parent report; significant organ system illness; hospitalization within the prior 6 months for a non-diabetes-related chronic illness; pregnancy or planned pregnancy (for females); or parenthood.

Potentially eligible patients were identified through clinicians, administrative records, research databases, or self-referral. Screening was in-person or by telephone. A total of 204 patients completed screening. Of these, 156 (76.5%) were eligible and 132 (64.7%) enrolled. After enrollment, 24 subjects were withdrawn prior to interview because interviews could not be scheduled (N=13); they were no longer interested (N=8); or they were found to be ineligible (N=3). The study was approved by the Institutional Review Boards of all 5 participating institutions.

Data Collection

Subjects from Children's Hospital Boston and Joslin Diabetes Center were interviewed in person, and subjects from the other sites were interviewed by telephone by research staff from Children's Hospital Boston. Interviewers were fluent in English and Spanish. The adolescents' most recent height and weight were abstracted from the clinical record to calculate BMI. Demographic data, family history, parents' self-reported height and weight, and adolescents' treatment regimen and medical history were collected during the parent interview. All interviews were audiorecorded, and a subset of both the in-person and telephone interviews was reviewed by the first author for quality control.

Measures

Pediatric Quality of Life Inventory- Generic Core Scales (PedsQL 4.0)—The Pediatric Quality of Life Inventory™ (PedsQL) (7) assessed adolescent HRQOL by self-report and parent-proxy. There are 23 items with a 5-point Likert scale for the extent to which each item was a problem during the past 1 month (0=never a problem, 5=almost always a problem). Results include a PedsQL summary score (SS) as well as psychosocial health score (comprised of emotional, social, and school functioning scales) and physical health score (7). The scores are transformed to a 0 to 100 scale, where higher scores reflect better HRQOL.

Health Utilities Index – Mark 3 (HUI3)—The Health Utilities Index, a preference-based, generic measure of HRQOL, describes an individual's perception about the value of a health condition (26). Utilities can be used in economic evaluations to guide recommended practice that considers health-related quality of life (27). The interviewer-administered version of the Health Utilities Index assessed the adolescent's health status over the prior 4 weeks by self-report and parent-proxy (26). The HUI3 classification system calculates a multi-attribute utility score for HRQOL on a scale from −0.36 (worst HUI3 health state) to 1 (perfect health) with 0 representing dead. The utility includes the attribute domains of vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain (26). Single-attribute utility scores for the 8 domains are measured on a scale from 0 (lowest function) to 1 (full function) (26).

Family Conflict—Adolescents completed a family conflict scale adapted from a generic family conflict scale (28) in order to incorporate both general family conflict as well as family conflict related to weight management. Subjects were asked to respond to 6 statements about family conflict on a four level scale (1=definitely false; 4=definitely true). A score based on the mean of the responses was generated and normalized to a scale of 0 to 100 with lower numbers reflecting less family conflict.

Health Concerns—Adolescents and parents were asked how much they worry about their own health (0=not at all; 3=a great deal), and parents were asked how much they worry about their child's health, using the same scale.

Burden of Diabetes Management—For subjects with T2DM, perceived burden of diabetes care was assessed by self- and parent-proxy report. Respondents were asked about their agreement or disagreement with a list of 5 statements applicable to T2DM and its management selected from the Problem Areas in Diabetes Survey–Parent Version (29, 30). Items were answered on a 5-point scale (1=agree, 5=disagree). A score based on the mean of the responses was generated and normalized to a scale of 0 to 100 with higher scores indicating higher perceived burden.

Statistical Analysis

Descriptive data are presented as medians with interquartile range, mean with standard deviation or proportion, as appropriate. The primary outcomes were the PedsQL SS and HUI3 multi-attribute utility for current health by self- and parent-proxy report. Secondary outcomes included the PedsQL subscales, HUI3 single-attribute utility scores, family conflict (adolescents only), and perceived burden of diabetes management (T2DM only). Adolescent/parent dyad comparisons were analyzed with the Wilcoxon signed-rank test and Spearman correlation coefficient for the HUI3 and with paired t-tests and Pearson correlation coefficient for the PedsQL based on the normality of the distributions. For other analyses of normally distributed data, ANOVA, t-test, and Pearson correlation were used; comparable non-parametric tests were used for data that were not normally distributed. Fisher's exact test was used to evaluate the association between categorical variables. Multivariable linear regression, incorporating all variables significant in bivariate analyses, was used to assess the independent effect of adolescent and parent characteristics on HRQOL assessed by PedsQL. With 16 adolescent and 15 parent outcomes, the expected number of type I errors with critical p value of <0.05 is less than 1 for each group. SAS version 9.1 (Cary, NC) was used for analyses.

Results

Study Sample

Among 108 dyads interviewed, 31% of parents and 5% of adolescents completed the surveys in Spanish. There were 78 (72.2%) families from the northeast (Boston, MA and Syracuse, NY) and 30 (27.8%) from the west (Los Angeles, CA and San Francisco, CA). Characteristics of the subjects are summarized in Table 1. Overall, adolescents had a mean age of 15.5 ± 2.0 years; more than three-quarters had a BMI≥95th percentile; and approximately one-third (36.5%) had at least two medical comorbidities such as high blood pressure or elevated cholesterol. Characteristics of the adolescents that varied by region included BMI, diagnosis, and race/ethnicity. Specifically, the greatest proportion (53%) of subjects recruited from the northeast had a BMI>99th percentile and the greatest proportion (57%) from the west had a BMI between the 95th and 99th percentile (p=0.02). The majority of adolescents recruited from the west also had T2DM (63% vs. 32%, p=0.01) and a higher prevalence of Hispanic race/ethnicity (90% vs. 18%, p<0.0001). Overall, T2DM, prediabetes and IR were almost equally represented, and there was no significant difference in race/ethnicity across diagnoses (p=0.21). However, those with T2DM were the oldest (16.1 ± 2.0 vs. 15.4 ± 1.9 vs. 14.9 ± 1.8, p=0.02) and had the lowest BMI z-score (2.0 ± 0.6 vs. 2.3 ± 0.4 vs. 2.3 ± 0.4, p=0.03).

For the adolescents with T2DM, average duration of disease at the time of enrollment was 3.3 ± 2.0 years. Of these, 4.6% were treated with diet alone, 34.1% with oral medication, 18.2% with insulin, and 40.9 % with oral medication and insulin (2.3% unknown). Oral medication was also used for treatment by 14.8% with prediabetes and 10.8% with IR.

The parents were 83% mothers, and on a 5-point Likert scale ranging from 1 (poor) to 5 (excellent), 33% (N=35) of parents rated their own current health as poor or fair, while 11%

(N=12) rated their health as excellent. Parental education varied significantly by region; only 13% from the west had at least some college or technical school vs. 73% in the northeast (p<0.001). Like the adolescents, the parents from the west also reported a higher prevalence of Hispanic race/ethnicity (87% vs. 16%, p<0.0001). However, there was no difference in the parents' relationship, age, BMI, personal history of T2DM/prediabetes or self-rating of current health by region (data not shown).

Parent and Adolescent Rating of Health-Related Quality of Life

Results of the PedsQL and HUI3 are summarized in Table 2. On the PedsQL, adolescents rated their physical health significantly higher than the parent-proxy report. There were no significant differences in mean psychosocial health scales assessed by adolescents and parents and, therefore, only a slightly higher PedsQL SS was observed for adolescents compared to parents (p=0.02). Adolescent and parent-proxy scores demonstrated modest, significant correlations for the PedsQL SS, physical health score, and the school and social functioning scales. The school functioning scale (within the psychosocial domain) revealed the greatest deficit in HRQOL based on both self- and parent-proxy report.

In bivariate analyses, adolescents' HRQOL based on the PedsQL SS was inversely associated with adolescent BMI z-score (p=0.0004) and parent BMI (p=0.03) and was also associated with the adolescents' race/ethnicity (p<0.0001). Adolescent PedsQL SS did not differ significantly by diagnosis [T2DM 82.0 ± 10.6; prediabetes 82.8 ± 9.9; IR 83.7 ± 11.7, p=0.79]. Adjusted for the adolescents' race/ethnicity, the inverse association between adolescent BMI z-score and PedsQL SS remained significant (p=0.005) although there was no longer an association with parent BMI. Adjusted for adolescent BMI z-score, black adolescents had the lowest mean PedsQL SS [75.3, (95% CI 71.2, 79.3)] compared to Hispanic, white, and adolescents of other race/ethnicity, respectively [83.7 (95% CI 80.7, 86.7); 85.0 (95% CI 81.8, 88.3); 87.6 (95% CI 81.7, 93.6); p=0.0008]. Adolescent PedsQL SS was not associated with the adolescents' age, gender, number of adolescent comorbidities, geographic region of recruitment, family history of diabetes, parents' age, parents' self-reported health, parents' history of T2DM, parents' education, or treatment regimen (among those with T2DM) (data not shown).

Among the adolescent and parent characteristics described above, the parent-proxy PedsQL SS was inversely associated with the adolescent BMI z-score (p=0.003), parent BMI (p=0.02) and the number of adolescent comorbidities (p=0.007) and positively associated with parents' age (p=0.03). Adjusted for these characteristics, only parents' age (p=0.01) and number of adolescent comorbidities [none 83.1 (95% CI 79.0, 87.3); one 78.7 (95% CI 74.1, 83.3); two or more 74.9 (95% CI 70.7, 79.1); p=0.03] remained significantly associated with the parent-proxy PedsQL SS.

The HUI3 multi-attribute utility is shown in Table 2. Adolescent HUI3 multi-attribute utility score did not differ by diagnosis [T2DM median 0.91 (IQR 0.79, 1.0); prediabetes 0.92 (0.81, 1.0); IR 0.92 (0.81, 0.97), p=0.96]. Single-attribute utility scores were significantly skewed toward a rating of 1 (highest level of function) in all domains. Only the pain scores were significantly different between adolescents and parent-proxy (p<0.0001) with a mean difference of 0.03 (95% CI 0.02, 0.04), indicating better perceived functioning (i.e., less pain) among the adolescents. There were no significant differences between the adolescent and the parent-proxy HUI3 multi-attribute utility scores, and highly significant (p<0.0001) positive correlations between adolescent and parent-proxy assessments in the single-attributes of vision (r=0.56) and dexterity (r=0.49) were observed. Neither adolescent nor parent-proxy HUI3 utilities were significantly associated with any adolescent or parent characteristics (data not shown).

As shown in Table 3, there were weak correlations between adolescent and parent-proxy assessments of HRQOL with the PedsQL and HUI3. Adolescent and parent-proxy assessments of HRQOL with the two methods were also moderately correlated with each other.

Health Concerns, Family Conflict, and Burden of Diabetes Management

A similar proportion of adolescents and parents reported that they worried “a great deal” about their own health (43% and 40%, respectively) although only approximately half overlapped. Of the parents, 75% reported that they worried “a great deal” about their child’s health. Worry about health was not associated with HRQOL (data not shown).

Adolescent family conflict score ranged from 0 to 78 with mean of 32.5 ± 20.3. Family conflict was inversely correlated with the adolescents’ PedsQL SS as well as with both the adolescent and parent-proxy HUI3 multi-attribute utility (Table 3). Greater family conflict was also positively correlated with adolescents’ BMI z-score (p=0.003). In multivariable analysis, family conflict remained significantly associated with adolescent PedsQL SS (p<0.0001) even after adjustment for BMI z–score and race/ethnicity. This adjustment attenuated the significance of the relationship between adolescent PedsQL SS and adolescent BMI z-score (p=0.07), although association with race/ethnicity remained significant (p=0.004).

For subjects with T2DM, mean score for perceived burden of diabetes care was 32.9 ± 16.3 for adolescents and 32.3 ± 18.9 for parents. For adolescents, burden of diabetes care was positively correlated with family conflict; for parents, burden of diabetes care was inversely correlated with parent-proxy PedsQL SS (Table 3). Parents’ perceived burden of diabetes care was also associated with race/ethnicity (p=0.0003); parents of Hispanic youth had the highest burden [43.8 (95% CI 36.8, 50.7)] and parents of white youth, the lowest [15.0 (95% CI 3.9, 26.1)].

Discussion

Overall, we found that adolescents with or at risk for T2DM reported deficits in HRQOL assessed by the PedsQL that were associated with severity of obesity, race/ethnicity and characteristics of their daily home life including family conflict. Adolescents’ diagnosis was not a significant modifier of HRQOL in this population. For parents, adolescents’ comorbid health conditions and perceived burden of diabetes care influenced their assessment of the adolescents’ HRQOL. Both adolescents and parents identified the greatest deficits in HRQOL in the subdomain of school functioning, but parents reported significantly lower assessment of adolescents’ overall HRQOL based on the PedsQL due to lower rating of adolescents' physical functioning. No differences in adolescent and parent-proxy assessment of HRQOL by the HUI3 were observed.

HRQOL is an independent health outcome that measures physical and psychosocial health; both of which may be impaired in youth with diabetes (16–18) as well as obesity (6, 8–15). However, studies comparing HRQOL between youth with T1DM and T2DM have generally shown lower HRQOL among youth with T2DM (16, 17), and several studies suggest youth with T1DM have HRQOL similar to their healthy peers (17, 21). Studies among youth with obesity have shown a spectrum of results with severely obese youth in tertiary care with HRQOL similar to children with cancer (6) but less significant deficits in community-based samples (8, 12). In our study, there was greater impairment in psychosocial than physical health as described among youth with T2DM in the SEARCH for Diabetes in Youth study (17) and for overweight and obese youth in both treatment-seeking and community-based samples (6, 8, 9, 12, 13). However, the severity of the deficits we observed was modest in comparison to most of these studies and was more similar to that observed for youth with T1DM and healthy youth (16, 17, 21). Compared to the study by Belfort et al. using the HUI3 in overweight and obese youth, the HUI3 multi-attribute utility we observed was also higher by both self-report and parent-proxy (31). Differences in the characteristics of these populations may contribute to the observed differences in HRQOL.

Consistent with our findings, several studies have documented an inverse association with child's BMI and overall HRQOL (6, 9, 11, 14, 15) although this relationship has not been uniformly observed (13). We also found that even after adjustment for BMI z-score, black adolescents reported the greatest impairment in PedsQL SS. A limited number of studies have evaluated the relationship between race/ethnicity and HRQOL among obese youth or those with T2DM (6, 9, 10, 14, 17) and most have not identified an independent relationship (6, 9, 17). Swallen et al. reported a heterogeneous relationship between race/ethnicity and measures of HRQOL in adolescents in the National Longitudinal Study of Adolescent Health, most notably with higher prevalence of low self-esteem in Hispanic and black adolescents and of depression in Hispanic adolescents, both compared to white adolescents (10). In contrast to our findings, Fallon et al. found that overweight white adolescents had greater deficit in HRQOL in a number of domains compared to black adolescents (14). However, the relationship between race/ethnicity and HRQOL may be different in a population of youth enriched for T2DM or risk for T2DM such as our study population. The SEARCH for Diabetes in Youth study reported that youth with diabetes and race/ethnicity other than non-Hispanic white had a higher prevalence of depression (32), which has been has been correlated with lower HRQOL (9, 13). While we excluded patients with an established history of depression in our study, it is likely that some subjects may still experience depressive symptoms. Racial and ethnic disparities in glycemic control have also been observed in youth with T2DM, with worse control seen among non-white youth (33). Differences in self-management behaviors may contribute to these observed disparities (33) and could be consistent with our findings of higher perceived burden of diabetes care among parents of non-Hispanic white youth with T2DM.

We found a significant inverse association between the adolescents' rating of perceived family conflict and (1) their overall rating of HRQOL using both the PedsQL and the HUI3 and (2) the parents' rating of HRQOL using the HUI3. In multivariable analysis, family conflict remained significantly associated with the adolescents' PedsQL SS even after adjustment for BMI z–score and race/ethnicity. In T1DM, diabetes-specific conflict has been linked to poorer adherence to diabetes self-management and glycemic control (34) and to lower adolescent and parent-proxy report of HRQOL (21). Among overweight youth, Janicke et al. have reported that parental distress can negatively impact HRQOL assessed by self- and parent-proxy report (13), and Mellin et al. studied an overweight adolescent population and found that higher levels of family connectedness and parental expectations and moderate parental monitoring were associated with the lowest levels of psychosocial distress (23). In our bivariate analyses, we found that higher parental BMI was associated with lower adolescent and parent-proxy assessment of HRQOL with the PedsQL. Although we do not have measures of parental distress, parents with worse self-reported health had a significantly higher BMI (data not shown). Additional evaluation focusing on parental measures is likely needed help to tease apart these findings. Further, the links between family conflict and measures of HRQOL are likely multifactorial. While some family conflict is natural, addressing family conflict may be a means to improve HRQOL and possibly the effectiveness of treatment programs for youth with obesity and T2DM.

Finally, we found weak correlations between the adolescent and parent-proxy assessments of HRQOL by the PedsQL and HUI3. One might expect to see some differences in child and parent-proxy assessments of HRQOL given the differing contexts in which parents make these observations (35). Parent-proxy measures may not serve as direct substitutes for self-report but rather they may provide additional perspectives (36). A number of studies have compared child and parent-proxy reports of HRQOL with the PedsQL in overweight and obese youth (9, 11–13) and those with T2DM (16) with most reporting good correlations (11–13, 16). In contrast, comparison with the HUI3 in overweight and obese youth has only recently been performed in a study by Belfort et al. (31). Belfort et al. reported a higher parent-proxy HUI3 utility than self-reported utility among overweight/obese youth (31) in a pattern similar to that which we observed in this study. Also similar to our findings, Belfort et al. reported single attribute utility scores that were skewed toward a rating of 1 (31) suggesting that the HUI3 domains may not fully capture the relevant range of experience for this pediatric population (37, 38). Importantly, however, the adolescent and parent-proxy HUI3 multi-attribute utilities do provide a measure of health utility in youth with or at risk of T2DM. While variability may exist in utilities generated using different methods (39), these data can continue to inform the research and development of economic analyses in youth (40).

Our study has limitations that merit comment. First, this was a convenience sample and the characteristics of the subjects, including the sociodemographic characteristics and the exclusion of adolescents with depression or other psychiatric disorders, must be considered before generalizing our findings to a clinical population. However, our recruitment across 5 sites allowed us to recruit a study population with both geographic and sociodemographic diversity. Further, while our sample included both youth with T2DM as well as those at risk, as we did not identify variation in our findings by the adolescents' diagnosis, our summary results should be applicable to both groups. Second, our measures of family conflict and perceived diabetes burden were adapted from previously validated measures (28–30). While they can be compared conceptually to measures of similar constructs in the literature, direct correlation with other studies is not possible. Finally, the cross-sectional design of our study does not allow us to assign causality to the relationships observed between adolescent and parent characteristics and HRQOL. A longitudinal analysis, similar to that performed in youth with T1DM (21), may further inform these findings.

Overall, we found that adolescents' physical functioning is perceived to be more impaired by parents than adolescents themselves. However, HRQOL is influenced by contextual factors including severity of obesity, comorbid health conditions, race/ethnicity, family conflict, and perceived burden of diabetes care. To improve outcomes, family-based approaches to treatment and prevention of T2DM may benefit from increased focus on the biopsychosocial context, including assessment of family conflict.

Acknowledgments

The study was supported by the Centers for Disease Control and Prevention grant K01DP000089 (Rhodes, Ludwig, Prosser). Additional support to investigators included the Katherine Adler Astrove Youth Education Fund (Laffel); Maria Griffin Drury Fund (Laffel); National Institute of Diabetes and Digestive and Kidney Diseases grant K24DK082730 (Ludwig), and the New Balance Foundation (Rhodes, Ludwig). We would like to thank the project coordinators at each site; Clinical Research Program at Children's Hospital Boston for project management, database development and statistical support and members of our Data and Safety Monitoring Board for their careful review and feedback

Abbreviations

T2DM	type 2 diabetes
HRQOL	health-related quality of life
IR	insulin resistance
HUI3	Health Utilities Index
SS	summary score
T1DM	type 1 diabetes

References

1. Ogden CL, Carroll MD, Curtin LR, Lamb MM, Flegal KM. Prevalence of high body mass index in US children and adolescents, 2007–2008. JAMA. 2010; 303:242–9. [PubMed: 20071470]
2. Williams DE, Cadwell BL, Cheng YJ, Cowie CC, Gregg EW, Geiss LS, et al. Prevalence of impaired fasting glucose and its relationship with cardiovascular disease risk factors in US adolescents, 1999–2000. Pediatrics. 2005; 116:1122–6. [PubMed: 16263998]
3. Barlow SE. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. Pediatrics. 2007; 120:S164–92. [PubMed: 18055651]
4. Pinhas-Hamiel O, Zeitler P. Acute and chronic complications of type 2 diabetes mellitus in children and adolescents. Lancet. 2007; 369:1823–31. [PubMed: 17531891]
5. Anderson BJ, Cullen K, McKay S. Quality of life, family behavior, and health outcomes in children with type 2 diabetes. Pediatr Ann. 2005; 34:722–9. [PubMed: 16222949]
6. Schwimmer JB, Burwinkle TM, Varni JW. Health-related quality of life of severely obese children and adolescents. JAMA. 2003; 289:1813–9. [PubMed: 12684360]

7. Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambul Pediatr. 2003; 3:329–41. [PubMed: 14616041]
8. Friedlander SL, Larkin EK, Rosen CL, Palermo TM, Redline S. Decreased quality of life associated with obesity in school-aged children. Arch Pediatr Adolesc Med. 2003; 157:1206–11. [PubMed: 14662577]
9. Zeller MH, Modi AC. Predictors of health-related quality of life in obese youth. Obesity (Silver Spring). 2006; 14:122–30. [PubMed: 16493130]
10. Swallen KC, Reither EN, Haas SA, Meier AM. Overweight, obesity, and health-related quality of life among adolescents: the National Longitudinal Study of Adolescent Health. Pediatrics. 2005; 115:340–7. [PubMed: 15687442]
11. Pinhas-Hamiel O, Singer S, Pilpel N, Fradkin A, Modan D, Reichman B. Health-related quality of life among children and adolescents: associations with obesity. Int J Obes (Lond). 2006; 30:267–72. [PubMed: 16231035]
12. Williams J, Wake M, Hesketh K, Maher E, Waters E. Health-related quality of life of overweight and obese children. JAMA. 2005; 293:70–6. [PubMed: 15632338]
13. Janicke DM, Marciel KK, Ingerski LM, Novoa W, Lowry KW, Sallinen BJ, et al. Impact of psychosocial factors on quality of life in overweight youth. Obesity (Silver Spring). 2007; 15:1799–807. [PubMed: 17636099]
14. Fallon EM, Tanofsky-Kraff M, Norman AC, McDuffie JR, Taylor ED, Cohen ML, et al. Health-related quality of life in overweight and nonoverweight black and white adolescents. J Pediatr. 2005; 147:443–50. [PubMed: 16227028]
15. de Beer M, Hofsteenge GH, Koot HM, Hirasing RA, Delemarre-van de Waal HA, Gemke RJ. Health-related-quality-of-life in obese adolescents is decreased and inversely related to BMI. Acta Paediatr. 2007; 96:710–4. [PubMed: 17381471]
16. Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL in type 1 and type 2 diabetes: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales and type 1 Diabetes Module. Diabetes Care. 2003; 26:631–7. [PubMed: 12610013]
17. Naughton MJ, Ruggiero AM, Lawrence JM, Imperatore G, Klingensmith GJ, Waitzfelder B, et al. Health-related quality of life of children and adolescents with type 1 or type 2 diabetes mellitus: SEARCH for Diabetes in Youth Study. Arch Pediatr Adolesc Med. 2008; 162:649–57. [PubMed: 18606936]
18. Wilfley D, Berkowitz R, Goebel-Fabbri A, Hirst K, Ievers-Landis C, Lipman TH, et al. Binge eating, mood, and quality of life in youth with type 2 diabetes: baseline data from the today study. Diabetes Care. 2011; 34:858–60. [PubMed: 21357794]
19. Huang ES, Brown SE, Thakur N, Carlisle L, Foley E, Ewigman B, et al. Racial/ethnic differences in concerns about current and future medications among patients with type 2 diabetes. Diabetes Care. 2009; 32:311–6. [PubMed: 19017766]
20. Thomas SB, Sansing VV, Davis A, Magee M, Massaro E, Srinivas VS, et al. Racial differences in the association between self-rated health status and objective clinical measures among participants in the BARI 2D trial. Am J Public Health. 2010; 100:S269–76. [PubMed: 20147671]
21. Laffel LM, Connell A, Vangsness L, Goebel-Fabbri A, Mansfield A, Anderson BJ. General quality of life in youth with type 1 diabetes: relationship to patient management and diabetes-specific family conflict. Diabetes Care. 2003; 26:3067–73. [PubMed: 14578241]
22. Grey M, Boland EA, Yu C, Sullivan-Bolyai S, Tamborlane WV. Personal and family factors associated with quality of life in adolescents with diabetes. Diabetes Care. 1998; 21:909–14. [PubMed: 9614606]
23. Mellin AE, Neumark-Sztainer D, Story M, Ireland M, Resnick MD. Unhealthy behaviors and psychosocial difficulties among overweight adolescents: the potential impact of familial factors. J Adolesc Health. 2002; 31:145–53. [PubMed: 12127384]
24. American Diabetes Association. Standards of Medical Care in Diabetes-2006. Diabetes Care. 2006; 29:S4–S42. [PubMed: 16373931]
25. Reaven GM. Insulin resistance/compensatory hyperinsulinemia, essential hypertension, and cardiovascular disease. J Clin Endocrinol Metab. 2003; 88:2399–403. [PubMed: 12788834]

26. Feeny D, Furlong W, Torrance GW, Goldsmith CH, Zhu Z, DePauw S, et al. Multiattribute and single-attribute utility functions for the health utilities index mark 3 system. Med Care. 2002; 40:113–28. [PubMed: 11802084]

27. Russell LB, Gold MR, Siegel JE, Daniels N, Weinstein MC. The role of cost-effectiveness analysis in health and medicine. Panel on Cost-Effectiveness in Health and Medicine. JAMA. 1996; 276:1172–7. [PubMed: 8827972]

28. [Accessed 11/15/2010] Student Survey of Risk and Protective Factors/Family Conflict. http://www.activeguidellc.com/cmi/instruments/family/family_fc_ssorapffc_desc.rtf

29. Butler DA, Zuehlke JB, Tovar A, Volkening LK, Anderson BJ, Laffel LM. The impact of modifiable family factors on glycemic control among youth with type 1 diabetes. Pediatr Diabetes. 2008; 9:373–81. [PubMed: 18774997]

30. Markowitz JT, Volkening LK, Butler DA, Antisdel-Lomaglio J, Anderson BJ, Laffel LM. 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). Diabet Med. 2011 Accepted Article. 10.1111/j.1464-5491.2011.03434.x

31. Belfort MB, Zupancic JA, Riera KM, Turner JH, Prosser LA. Health state preferences associated with weight status in children and adolescents. BMC Pediatr. 2011; 11:12. [PubMed: 21299875]

32. Lawrence JM, Standiford DA, Loots B, Klingensmith GJ, Williams DE, Ruggiero A, et al. Prevalence and correlates of depressed mood among youth with diabetes: the SEARCH for Diabetes in Youth study. Pediatrics. 2006; 117:1348–58. [PubMed: 16585333]

33. Rothman RL, Mulvaney S, Elasy TA, VanderWoude A, Gebretsadik T, Shintani A, et al. Self-management behaviors, racial disparities, and glycemic control among adolescents with type 2 diabetes. Pediatrics. 2008; 121:e912–9. [PubMed: 18381520]

34. Anderson BJ, Vangsness L, Connell A, Butler D, Goebel-Fabbri A, Laffel LMB. Family conflict, adherence, and glycaemic control in youth with short duration Type 1 diabetes. Diabet Med. 2002; 19:635–42. [PubMed: 12147143]

35. Eiser C. Children's quality of life measures. Arch Dis Child. 1997; 77:350–4. [PubMed: 9389244]

36. Drotar D. Validating measures of pediatric health status, functional status, and health-related quality of life: key methodological challenges and strategies. Ambul Pediatr. 2004; 4:358–64. [PubMed: 15264947]

37. Petrou S. Methodological issues raised by preference-based approaches to measuring the health status of children. Health Econ. 2003; 12:697–702. [PubMed: 12898666]

38. Prosser LA, Hammitt JK, Keren R. Measuring health preferences for use in cost-utility and cost-benefit analyses of interventions in children: theoretical and methodological considerations. Pharmacoeconomics. 2007; 25:713–26. [PubMed: 17803331]

39. Rhodes ET, Prosser LA, Lieu TA, Songer TJ, Ludwig DS, Laffel LM. Preferences for type 2 diabetes health states among adolescents with or at risk of type 2 diabetes mellitus. Pediatr Diabetes. 2011 Published online 4/13/11. 10.1111/j.1399-5448.2011.00772.x

40. Prosser LA. Current challenges and future research in measuring preferences for pediatric health outcomes. J Pediatr. 2009; 155:7–9. [PubMed: 19559288]

Table 1

Characteristics of Subjects

	Adolescent	Parent
	N= 108	**N=107***
Age, yr	15.5 ± 2.0	44.7 ± 8.1
Age at diagnosis, yr	12.8 ± 3.3	
BMI, kg/m^2		32.5 ± 7.8
BMI z-score	2.2 ± 0.5	
BMI Percentile		
<95^{th}	19 (17.6)	
95^{th} to 99^{th}	41 (38.0)	
>99^{th}	48 (44.4)	
Race/Ethnicity		
Hispanic (any race)	41 (38.0)	38 (35.5)
Non-Hispanic White	34 (31.5)	43 (40.2)
Non-Hispanic Black	22 (20.4)	18 (16.8)
Other/unknown	11 (10.2)	8 (7.5)
Diagnosis		
Type 2 Diabetes	44 (40.7)	26 (24.3)
Prediabetes	27 (25.0)	10 (9.4)
Insulin Resistance	37 (34.3)	N/A
Number of Comorbidities†		
None	39 (36.5)	
One	29 (27.1)	
Two or more	39 (36.5)	
Family History of Diabetes		
No/Unknown	13 (12.0)	
Yes	95 (88.0)	
Education		
Less than high school		22 (20.6)
High school graduate or GED		25 (23.4)
Some college or technical school		25 (23.4)
College graduate or beyond		35 (32.7)

Data are mean ± standard deviation or N (%)

*One incomplete parent interview.

†One subject missing data on this variable.

N/A = not available.

Table 2

Health-Related Quality of Life by Self-Report and Parent-Proxy Report

	Adolescent	Parent/Guardian	Correlation Coefficient
PedsQL[a]	**N=107**[b]	**N=107**[b]	
Summary Score	82.8 ± 10.8	79.4 ± 12.9§	0.22§
Physical Health Summary Score	89.7 ± 9.3	81.9 ± 16.0*	0.27‡
Psychosocial Health Summary Score	79.1 ± 13.3	78.1 ± 13.4	0.15
School Functioning Scale	73.6 ± 16.9	74.9 ± 19.1	0.24§
Social Functioning Scale	85.4 ± 15.6	85.5 ± 15.5	0.19§
Emotional Functioning Scale	78.8 ± 16.2	75.1 ± 15.9	−0.01
Health Utilities Index- Mark 3[c]			
HUI3 Multi-attribute Utility[d]	0.91 (0.80, 1.0)	0.93 (0.78, 1.0)	0.24§

Results presented as mean ± standard deviation or median (interquartile range).

[a] PedsQL compared by paired t-test

[b] 1 Missing child interview, 1 missing parent interview

[c] HUI3 compared by Wilcoxon signed rank

[d] N=99 child and N=102 parent scores, N=96 dyads

* $p<0.0001$

† $p<0.001$

‡ $p<0.01$

§ $p<0.05$

Table 3

Correlation of Adolescent and Parent Measures.

	PedsQL Parent	HUI3 Adolescent	HUI3 Parent	Adolescent Conflict	Adolescent Diabetes Burden	Parent Diabetes Burden
PedsQL Adolescent	0.22§ (106)	0.57* (99)	0.39* (101)	−0.52* (107)	−0.28 (43)	0.03 (41)
PedsQL Parent		0.00 (98)	0.47* (102)	−0.08 (106)	0.04 (42)	−0.39§ (42)
HUI3 Adolescent			0.24§ (96)	−0.38* (99)	−0.31 (41)	−0.11 (39)
HUI3 Parent				−0.36† (101)	−0.03 (42)	−0.28 (42)
Adolescent Conflict					0.40‡ (43)	−0.13 (41)
Adolescent Diabetes Burden						0.19 (41)

Number is Spearman correlation coefficient with number of subjects compared in parentheses.

* $p<0.0001$

† $p<0.001$

§ $p<0.05$