Health-Related Quality of Life and Metabolic Control in Children With Type 1 Diabetes

A prospective cohort study

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OBJECTIVE — To assess change in health-related quality of life (HRQOL) in children with diabetes over 2 years and determine its relationship to change in metabolic control.

RESEARCH DESIGN AND METHODS — In 1998, parents of children aged 5–18 years attending a tertiary diabetes clinic reported their child's HRQOL using the Child Health Questionnaire PF-50. Those aged 12–18 years also self-reported their HRQOL using the analogous Child Health Questionnaire CF-80. HbA_{1c} levels were recorded. In 2000, identical measures were collected for those who were aged ≤18 years and still attending the clinic.

RESULTS — Of 117 eligible subjects, 83 (71%) participated. Parents reported no significant difference in children's HRQOL at baseline and follow-up. However, adolescents reported significant improvements on the Family Activities ($P < 0.001$), Bodily Pain ($P = 0.04$), and General Health Perceptions ($P = 0.001$) scales and worsening on the Behavior ($P = 0.04$) scale. HbA_{1c} at baseline and follow-up were strongly correlated ($r = 0.57$). HbA_{1c} increased significantly (mean 7.8% in 1998 vs. 8.5% in 2000; $P < 0.001$), with lower baseline HbA_{1c} strongly predicting an increase in HbA_{1c} over the 2 years ($r^2 = 0.25$, $P < 0.001$). Lower parent-reported Physical Summary and adolescent-reported Physical Functioning scores at baseline also predicted increasing HbA_{1c}. Poorer parent-reported Psychosocial Summary scores were related to higher HbA_{1c} at both times but did not predict change in HbA_{1c}.

CONCLUSIONS — Changes in parent and adolescent reports of HRQOL differ. Better physical functioning may protect against deteriorating HbA_{1c}, at least in the medium term. While the HRQOL of children with diabetes does not appear to deteriorate over time, we should not be complacent, as it is consistently poorer than that of their healthy peers.

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Recent research has shown that the health-related quality of life (HRQOL) in children and adolescents with diabetes is markedly poorer than the HRQOL of children in the general population (1,2), more closely resembling that of children with serious chronic diseases such as cystic fibrosis and leukemia (3).

HRQOL is an important outcome indicator for people with chronic diseases, including diabetes (4,5). Over the last few years, important information about HRQOL in children with diabetes has been published. Some cross-sectional evidence suggests that particular domains of HRQOL relate to routinely collected clinical measures (6), and children with diabetes who score poorly on psychosocial domains of HRQOL measures tend to concurrently score poorly on behavioral measures (7). Longitudinal research has shown that poorly controlled diabetes is associated with subtle neuropsychological deficits, which may impact academic achievement and ultimately reduce career options and lifestyle choices (8–10). In addition, behavioral indexes at diagnosis predict maladaptive behaviors and lifestyle practices up to 8 years later (E.A. Northam, personal communication/unpublished data). Conversely, children showing adjustment to their condition early on have improved longer-term outcomes and make more adaptive lifestyle choices (8,11).

This piecemeal information has not, however, been synthesized to answer two important questions: *1*) Does HRQOL in children with diabetes change over time? *2*) Do generic HRQOL measures in children with diabetes predict later health and metabolic outcomes? This latter question is particularly important because it might add an important tool to assist our efforts to detect the child at risk of metabolic deterioration before deterioration begins.

The aims of this study were to prospectively assess the HRQOL of children with diabetes over a 2-year period and to determine whether baseline HRQOL predicted changes in HbA_{1c} levels over this time.

RESEARCH DESIGN AND METHODS

— The methodology of the baseline study has been described in detail elsewhere (1). Briefly, the baseline sample was representative of 5- to 18-year-old children attending the Diabetes

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Abbreviations: CHQ, Child Health Questionnaire; HRQOL, health-related quality of life.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

Table 1—*Description of CHQ scales*

Domain	Scale	Description of what scale is intended to measure
Physical	Physical Functioning	Presence and extent of physical limitations experienced due to health problems
	General Health Perceptions*	Subjective assessment of overall health; past, present, and future
	Role/Social Limitations–Physical	Limitations on school work and activities with friends due to physical health problems
	Bodily Pain	Intensity and frequency of general pain and discomfort
Psychosocial	Role/Social Limitations–Emotional/Behavioral (parent form only)	Limitations on school work and activities with friends due to emotional or behavioral difficulties
	Role/Social Limitations–Emotional (adolescent form only)	Limitations on school work and activities with friends due to emotional difficulties
	Role/Social Limitations–Behavioral (adolescent form only)	Limitations on school work and activities with friends due to behavioral difficulties
	General Behavior*	Frequency of behavior problems; ability to get along with others
	Mental Health	Frequency of both negative and positive states
	Self-esteem	Satisfaction with school and athletic abilities, looks and appearance, ability to get along with others, and life overall
Family	Family Activities	Frequency of disruption to usual family activities due to child's general health and well-being
	Family Cohesion†	Subjective assessment of how well the family gets along with one another
	Parent Impact–Emotional (parent form only)	Level of distress experienced by parent due to child's health and well-being
	Parent Impact–Time (parent form only)	Limitation on parental time for personal needs due to child's health and well-being
None	Change in Health†	Change in child's health over the preceding year

Adapted from the US CHQ manual (14). *Multi-item scales containing a single-item scale also; †single-item scales not contained within a multi-item scale.

Outpatient Clinic at the Royal Children's Hospital in Melbourne, Australia (population 3.4 million), between May and August 1998. Parents of all children completed questionnaires written in English in the clinic waiting room; in addition, children aged 12–18 years were invited to participate in the self-report arm of the study. One hundred forty-one children aged 5.4–18.9 years (12.3 ± 3.6 [mean ± SD]) participated in the baseline study. Of these, 70 had parent-proxy reports only, 58 had both parent-proxy reports and adolescent self-reports, and 13 had adolescent self-reports only (90% parent response and 92% adolescent response).

The follow-up study was conducted between November 1999 and April 2001. Of the original 141 subjects, 24 were ineligible for the follow-up study (13 were aged ≥19 years and a further 11 were no longer attending the Royal Children's Hospital Diabetes Clinic). Parents of the remaining 117 subjects were invited to participate in the follow-up study, as were the 53 eligible adolescents who had provided self-reports in the baseline study. Most questionnaires were completed in the waiting area before scheduled appointments, with the remainder posted to the children's homes and returned directly to the researchers.

Both the baseline and follow-up studies received ethics approval from the Royal Children's Hospital Ethics in Human Research Committee.

Measures

Child Health Questionnaire parent-proxy report. At both baseline and follow-up, parents completed the 50-item Australian authorized adaptation of the Child Health Questionnaire (CHQ) PF-50 (12). The CHQ PF-50, which was originally developed in the U.S. (13), is a standardized HRQOL measure with 4 single-item and 11 multi-item subscales assessing the domains of physical health and well-being, psychosocial health and well-being, and the impact of the child's health on parents and family (Table 1). All items are based on 4-week recall, except the single-item Change-in-Health scale, which inquires about change in the child's health over the past 12 months and has a possible range of 0 to 4. All multi-item scale scores are transformed to a range of 0 to 100, with lower scores indicating worse health and higher scores indicating better health. In addition, two summary scores (Physical and Psychosocial) are derived from the CHQ PF-50.

CHQ adolescent self-report. Adolescents aged 12–18 years at baseline completed the 80-item self-report version of the Australian authorized adaptation of the CHQ CF-80 at both baseline and follow-up (14). The CHQ CF-80 is analogous to the CHQ PF-50 and derives 10 multi-item and 4 single-item scales but no summary scores (Table 1). In the baseline study, both the CHQ PF-50 and the CHQ CF-80 demonstrated good psychometric properties (1).

HbA_{1c}. At each clinical visit, HbA_{1c} levels are assessed using the Bayer DCA 2000 immunoagglutination method (Calabria, Barcelona, Spain). HbA_{1c} levels are recorded as a percentage of total hemoglobin. The mean HbA_{1c} level for the baseline study sample was 8.1%, which was somewhat lower than the mean levels of 8.6% reported in other Australian

Table 2—*Comparison of CHQ PF-50 (parent report) scale and summary scores at baseline and follow-up*

Scale	Score		*P* value (paired sample *t* test)	Correlation
	Baseline	Follow-up		
Physical Functioning	94.2 ± 9.9	93.4 ± 15.9	0.62	0.48
Role/Social Limitations–Emotional/Behavioral	91.0 ± 16.3	90.4 ± 18.3	0.82	0.12
Role/Social Limitations–Physical	91.2 ± 19.6	91.4 ± 17.7	0.93	0.33
Bodily Pain	78.4 ± 22.0	78.2 ± 19.8	0.92	0.44
Behavior	70.8 ± 17.0	71.6 ± 17.6	0.64	0.60
Mental Health	78.0 ± 13.9	78.6 ± 13.7	0.72	0.43
Self-esteem	78.9 ± 17.9	76.6 ± 17.8	0.30	0.42
General Health Perceptions	58.3 ± 15.5	59.6 ± 16.5	0.42	0.64
Parent Impact–Emotional	63.6 ± 25.5	64.3 ± 24.8	0.83	0.42
Parent Impact–Time	78.7 ± 21.7	82.9 ± 22.2	0.10	0.50
Family Activities	72.1 ± 21.1	74.8 ± 21.2	0.23	0.63
Family Cohesion*	72.6 ± 24.2	74.5 ± 21.2	0.49	0.47
Change in Health*	3.4 ± 0.9	3.4 ± 0.7	1.00	0.45
Physical Summary score	49.1 ± 7.5	49.5 ± 9.6	0.71	0.60
Psychosocial Summary score	48.5 ± 10.1	48.8 ± 9.7	0.83	0.50

Data are means ± SD. *Single-item scales (two of the four single-item scales of the CHQ have not been included in analyses because they are incorporated in multi-item scales).

youth samples (15,16) and in an amalgam of 18 international pediatric diabetes centers (17). In the baseline study, we used the sample's 75th percentile (HbA_{1c} level 8.8%) to divide the 25% of children with the poorest control from the other children in the sample (1). The 75th percentile represents a practical cut point that allows for sufficient numbers of children in both groups to perform statistical comparisons. As clear international criteria still remain to be established, we again used an HbA_{1c} level >8.8% to define children with poor metabolic control in this follow-up study.

Analyses

CHQ PF-50 scale and summary scores and CHQ CF-80 scale scores were calculated according to the manual (13). Independent sample *t* tests were used to compare characteristics of children retained and those lost to follow-up, mean CHQ scores for children with HbA_{1c} levels >8.8% and ≤8.8% at follow-up, and mean change in HbA_{1c} for children with baseline HbA_{1c} levels >8.8% and ≤8.8%. Paired sample *t* tests were used to compare mean baseline and follow-up CHQ scores and HbA_{1c} levels. Pearson correlation coefficients were calculated for baseline and follow-up CHQ scores and HbA_{1c} levels. McNemar's χ^2 statistic was used to compare the proportions of children with HbA_{1c} levels >8.8% at baseline and follow-up. Univariate linear regression models assessed whether HbA_{1c} at follow-up or change in HbA_{1c} could be predicted from HbA_{1c} at baseline or from CHQ scores (adjusting for baseline HbA_{1c}).

RESULTS — Of the 117 eligible subjects, 83 consented to participate in the follow-up study (71% response rate; 55% male children). Seventy-six subjects (43 male and 33 female; mean age 12.8 years at follow-up) had parent reports at both time points, and 29 (15 male and 14 female; mean age 15.6 years) had adolescent self-reports at both time points. Eleven subjects moved from the 5–11 years to the 12–18 years age-group over the course of the study. On average, subjects who participated in the follow-up study had lower mean HbA_{1c} levels at baseline than eligible subjects lost to follow-up (7.8 vs. 8.6%; $P = 0.006$), were younger (11.1 vs. 13.0 years; $P = 0.01$), and had been diagnosed more recently (3.6 vs. 5.3 years since diagnosis; $P = 0.015$).

CHQ (parent report)

Parent-reported child HRQOL at follow-up was not significantly different from their baseline HRQOL (Table 2). The correlation between baseline and follow-up scores were ≥0.40 on all CHQ scales and summary scores, except the Role/Social Limitations–Emotional/Behavioral ($r = 0.12$, $P = 0.29$) and the Role/Social Limitations–Physical scales ($r = 0.33$, $P = 0.004$).

CHQ (adolescent report)

Unlike parents, whose reports of child HRQOL were quite stable from baseline to follow-up, some domains of adolescent-reported HRQOL changed over time (Table 3). Small improvements were reported on the Bodily Pain ($t = -2.14$, $P = 0.04$) and General Health Perceptions ($t = -3.79$, $P = 0.001$) scales, along with a moderate worsening of Behavior scale scores ($t = 2.21$, $P = 0.04$). Most strikingly, Family Activities scale scores improved markedly ($t = -4.88$, $P < 0.001$) over the 2 years. Baseline and follow-up scores correlated strongly ($r \geq 0.40$) for all scales except Physical Functioning ($r = 0.34$, $P = 0.08$), Role/Social Limitations–Behavioral ($r = -0.01$, $P = 0.97$), and Family Activities ($r = 0.27$, $P = 0.17$).

HbA_{1c}

Mean HbA_{1c} levels for the 83 children rose significantly over the 2 years from baseline to follow-up (7.8 vs. 8.5%; $t = 6.42$, $P < 0.001$), with a mean rise in HbA_{1c} of 0.75 ± 1.1 (mean ± SD; range −2.4 to 2.6) and a strong correlation between baseline and follow-up HbA_{1c} levels ($r = 0.57$). Nearly twice as many children had HbA_{1c} levels >8.8% at follow-up as at baseline (41 vs. 22%; $P < 0.001$) (Table 4). Whereas mean HbA_{1c}

Table 3—*Comparison of CHQ CF-80 (adolescent self-report) scale and summary scores at baseline and follow-up*

Scale	Score		*P* value (paired sample *t* test)*	Correlation
	Baseline	Follow-up		
Physical Functioning	96.2 ± 5.2	95.8 ± 6.3	0.80	0.34
Role/Social Limitations–Emotional	88.9 ± 14.2	91.7 ± 14.0	0.24	0.62
Role/Social Limitations–Behavioral	94.8 ± 15.0	92.1 ± 12.2	0.46	−0.01
Role/Social Limitations–Physical	91.7 ± 14.4	95.8 ± 8.6	0.08	0.54
Bodily Pain	80.7 ± 20.2	87.6 ± 12.1	<0.001	0.52
Behavior	81.2 ± 10.8	76.0 ± 13.8	0.04	0.49
Mental Health	78.7 ± 12.7	76.1 ± 13.5	0.32	0.43
Self-esteem	79.3 ± 11.6	78.8 ± 15.8	0.86	0.44
General Health Perceptions	65.9 ± 14.5	71.8 ± 14.4	0.001	0.83
Family Activities	71.3 ± 13.4	85.3 ± 11.8	<0.001	0.27
Family Cohesion*	59.8 ± 27.0	66.9 ± 22.3	0.16	0.49
Change in Health*	3.8 ± 0.9	3.6 ± 0.9	0.25	0.46

Data are means ± SD. *Single-item scales (two of the four single-item scales of the CHQ have not been included in analyses because they are incorporated in multi-item scales).

increased by 0.97% in children whose HbA_{1c} was initially ≤8.8%, it fell only slightly (−0.36%) in children with initially high baseline HbA_{1c} ($P < 0.001$). Lower HbA_{1c} levels at baseline therefore predicted increases in HbA_{1c} levels ($r^2 = 0.25$, $P < 0.001$), accounting for 25% of the variance in HbA_{1c} change between baseline and follow-up.

As in the baseline study, children with HbA_{1c} >8.8% ($n = 31$) had significantly poorer Psychosocial Summary scores than children with HbA_{1c} ≤8.8% ($n = 44$) (mean 46.1 vs. 50.9, $P = 0.03$). They therefore also scored more poorly on most of the psychosocially related subscale scores: Behavior (mean 66.4 vs. 75.7; $P = 0.02$), Mental Health (mean 74.7 vs. 81.7; $P = 0.02$), Family Activities (mean 68.9 vs. 78.6; $P = 0.04$), and Family Cohesion (mean 67.5 vs. 77.5; $P = 0.04$). None of the adolescent self-reported scales indicated differences in health according to HbA_{1c} levels >8.8 or ≤8.8%. However, neither the baseline Psychosocial Summary score nor any of its subscales predicted HbA_{1c} at follow-up or change in HbA_{1c} between baseline and follow-up.

Table 4—*Change in HbA_{1c} levels of subjects between baseline and follow-up*

HbA_{1c} level at baseline	HbA_{1c} level at follow-up		
	<8.8%	>8.8%	Total
<8.8%	41	26	67
>8.8%	5	8	13
Total	46	34	80

Again replicating the baseline study, Physical Summary scores did not differ significantly between children with HbA_{1c} >8.8% and those with HbA_{1c} ≤8.8% (mean 48.5 vs. 50.2, $P = 0.45$). However, the baseline Physical Summary score predicted both follow-up HbA_{1c} level ($\beta = -0.04$, 95% CI: −0.06 to −0.01) and change in HbA_{1c} (−0.04, −0.06 to −0.01) after accounting for baseline HbA_{1c}. In other words, on average every 10 additional points on the baseline Physical Summary score equated to a 0.4% decrease in HbA_{1c} at follow-up. Similarly, adolescent self-reports on the Physical Functioning scale at baseline predicted follow-up HbA_{1c} and change in HbA_{1c} (−0.07, −0.13 to −0.01 and −0.07, −0.13 to −0.01, respectively) after accounting for baseline HbA_{1c} level.

CONCLUSIONS — Parents of children and adolescents with diabetes consistently report the health of their children as considerably poorer than the health of children and adolescents in the wider community (1), and this is remarkably stable over a 2-year period. In contrast, adolescents with diabetes consistently report that their health is very similar to adolescents without diabetes (1), but unlike their parents they reported that, with time, their health was having less impact on the family's activities. Poorer parent-reported psychosocial health was consistently associated with poorer metabolic control at both time points.

Although poorer parent-reported psychosocial health and metabolic control seemed linked at any given time, poorer baseline psychosocial health as reported by parents did not predict a deterioration in metabolic control over the 2 years of the study. Somewhat surprisingly, it was baseline physical health (as reported by both parents and adolescents) that predicted changes in metabolic control over time. This might indicate that poorer physical health is a risk factor for deteriorating metabolic control. Alternatively, better physical health might actively protect against the usual deterioration in metabolic control seen over these years (18); perhaps better functioning in the domain of physical health enables children to participate more fully in the range of social and other activities open to them and thus protects against deteriorations in both metabolic control and psychosocial well-being. Interestingly, while the relationship between psychosocial health and concurrent metabolic control was only apparent in parent reports, the longitudinal relationship between physical well-being and later metabolic control held for both parent and adolescent reports—this was the only finding that was consistent for both proxy and self-reports.

Parents and young people often diverge in their reports of children's health (19), even when the child is relatively healthy (20). The disparity between parent and adolescent reports of the health of

children and adolescents with diabetes corresponds with similar trends seen for children with cancer (21). However, no previous studies have considered changes in HRQOL over time as viewed by parents and adolescents. Unlike the proxy views of parents, adolescents' views of their own HRQOL changed somewhat over time. Adolescents may be more aware of, and thus able to report, small changes in their HRQOL that are less apparent to their parents. This highlights the importance of incorporating child self-report measures, when the age and cognitive ability of the child allows, in the assessment of HRQOL.

Partially by virtue of the inclusion criteria for the follow-up study, those subjects lost to follow-up tended to be older (and therefore less recently diagnosed) and had significantly higher HbA_{1c} levels at baseline than those children retained in the cohort. This reflects the logistics of the study, which precluded follow-up subjects who were outside the age range of the CHQ (≥19 years) and those who were no longer attending the clinic. While this may limit the generalizability to older children, it should not compromise the internal validity of the findings.

In our earlier research, we showed that the HRQOL of children and adolescents with diabetes is poor compared with the health of children in the wider community and that poorer metabolic control goes hand in hand with poorer psychosocial functioning (1). Furthermore, the CHQ can be readily incorporated into everyday diabetes clinic practice (1) and relevant CHQ scales correlate strongly with childhood behavior problems as measured against a behavioral "gold standard" (7). In this study, we have demonstrated that the parent-reported HRQOL of children and adolescents with diabetes appears relatively stable over a 2-year period and that better baseline physical functioning may protect against the deteriorating metabolic control apparent in the group as a whole. While the use of a disease-specific HRQOL instrument may have detected greater changes in diabetes-specific health issues over time, there are important benefits of looking at changes over time as detected by a generic instrument such as the CHQ. Generic instruments allow investigation of changes in aspects of health important to all children, regardless of the presence or type of health condition, and potentially allow the comparison of such changes between healthy children and children with different health conditions.

As these children make the transition to young adulthood, it is likely that their HRQOL will deteriorate due to acquired psychosocial comorbidities and comorbidities arising from other diabetes complications (22,23). Clearly, the relationship between HRQOL and metabolic control over time is complex and requires further study. Regardless of its predictive value, we believe that HRQOL is worthy of measurement and action in the clinical setting in its own right (7). Our challenge is to find ways of improving the quality of life of these children and to ensure that optimal HRQOL is maintained throughout childhood and adolescence.

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