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A two-year prospective study of the health-related quality of life of children with chronic illness – the parents' perspective

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Abstract

The aim of this study was to assess prospectively changes in the health-related quality of life (HRQL) of children and adolescents with diabetes, asthma or cystic fibrosis (CF). One hundred and twenty-two parents of children aged 10–16 years with asthma, diabetes, or CF were recruited from specialist paediatric clinics. Parents described their children's HRQL using the Child Health Questionnaire (PF98) at baseline, 6, 12, 18 and 24 months post-baseline. They reported that the general health of children with CF was significantly worse than that of children with asthma and diabetes at baseline. In other domains there were few differences between the HRQL of children in the three groups. In several domains, the HRQL of children with asthma or diabetes improved over the 2 years of the study. This improvement was less evident for children with CF.

Key words: Adolescents, Children, Chronic illness, Health-related quality of life, Parents, Prospective

Abbreviations: HRQL – health–related quality of life; CF – cystic fibrosis; CHQ – Child Health Questionnaire

Introduction

With the decline in the prevalence of acute childhood illnesses, treatment and management of chronic conditions is now a major proportion of the work of paediatric clinical practice [1]. Asthma and diabetes are the most common chronic disorders affecting children while cystic fibrosis (CF) is the most common life threatening autosomal recessive disorder [2]. The common feature of these conditions is that they persist over many years and have the potential to impose a substantial personal and financial burden on children and parents. In the absence of curative treatment, the cost of providing supportive care for children with these disorders consumes a substantial proportion of the budgets of paediatric health services.

Enabling children and adolescents with chronic illness to achieve and maintain the same standards of health as other children in the community has long been a goal of paediatric services. To achieve this it is necessary to monitor and support the physical, psychological and social functioning of children with chronic illness. The term health-related quality of life (HRQL) is used to describe this broad assessment of children's health based on reports from children or from parents acting as proxy informants [3].

Until recently, a lack of appropriate measures made it difficult to accurately assess changes in the

HRQL of children with chronic illness over time (for brevity, the term children will be used to describe both children and adolescents) as results from clinical and biomedical assessments provide only a limited assessment of childhood HRQL [4]. A failure by clinicians to regularly assess children's broader psychological and social functioning in the same way that they routinely evaluate children's clinical and biomedical parameters, disadvantages children for two reasons. First, it makes it less likely that problems in the former areas will be identified and appropriately managed. Second, problems in these areas may adversely influence the effectiveness of treatment regimes used to manage chronic childhood illness. This may occur, for example, because children who have emotional problems or whose illness and treatment adversely affects their peer and school functioning may be less likely to correctly implement treatment recommendations.

Recently several measures designed to assess the HRQL of children have become available. The availability of these measures makes it possible to now routinely assess the broader functioning of children without imposing an unreasonable questionnaire burden on parents and children. For example, both the Child Health Questionnaire (CHQ) and the Pediatric Quality of Life Inventory (PedsQL) [5, 6] can be completed in a relatively short period of time by children and parents. Each measure provides ratings of children's functioning in a broad range of areas. The CHQ also provides ratings of family functioning and the impact of children's health and behaviour on parents.

To date, studies have largely reported the HRQL of children with chronic illness assessed at a single point of time. As a result, little is known about the extent to which the HRQL of children with chronic conditions changes over time. There is also little information about the extent to which the HRQL of children varies for children with different conditions. Information in these areas is an important prerequisite for the development of interventions designed to improve the HRQL of children with chronic illness. For example, information about the extent to which the HRQL of children changes over time is needed to assist children, parents and clinicians to set realistic treatment goals for individual children with chronic conditions. It is has also been hypothesised that there may be commonality in the psychosocial sequelae of several chronic childhood conditions [1, 7, 8]. If empirical support is obtained for this hypothesis, reconsideration might be given in these areas to the traditional approach of organising delivery of services around specific diseases or organ systems.

This study had two broad goals. First, it compared the HRQL of children experiencing asthma, diabetes and CF. Second, it examined the extent to which the HRQL of children with these illnesses changes over time. In this latter area we investigated: (i) whether there was any consistent pattern to change in the domains comprising the HRQL of children with each illness, and (ii) whether the pattern of change was the same for children with different illnesses. Based on clinical experience, we hypothesised that the HRQL of children with CF would diminish over time, that the HRQL of children with diabetes would show little change, and the HRQL of children with asthma would improve.

Assessment of children's HRQL places emphasis on obtaining information from both children and their parents. This is important because there is evidence that reports from parents and children may differ [9]. The present study collected information from both parents and children describing the HRQL of children with asthma, diabetes, and CF over a 2-year period. We have previously reported the children's self-reported data [10]. This article describes findings from the parent-reported data.

Methods

Participants

A total of 122 children aged 10–16 years with asthma ($n = 40$), diabetes ($n = 44$), or CF ($n = 38$), and their parents, were recruited from specialist clinics or hospital records at the Women's and Children's Hospital in South Australia or from the specialist CF clinic at the Princess Margaret Hospital in Western Australia ($n = 22$). These hospitals are responsible for caring for the vast majority of children with diabetes and CF in South Australia and Western Australia. For children with asthma, entry criteria were that the

children had to have been admitted to the Women's and Children's Hospital and diagnosed with asthma on at least two occasions during the 2 years prior to the study. These criteria were adopted to ensure that the children with asthma had been correctly diagnosed with the condition and they were not suffering from only minor illness. The study focussed on children with diabetes, asthma or CF because these conditions are common chronic illnesses experienced by children. The age criterion of 10–16 years was utilised because a separate aim of this project was to test the level of agreement between parents' and children's reports of childhood HRQL.

All children had been diagnosed with their condition for at least 1 year as the study was focussing on the longer-term HRQL of children rather than on the immediate post-diagnosis period when children may experience higher levels of distress [11]. Potential participants were excluded if they had insufficient English to complete the study questionnaires, had intellectual delay, or if their clinician advised the research team that the child's family was experiencing major problems which precluded participation in the study (e.g. custody disputes, domestic violence).

The study also utilised the findings from a representative community sample of Australian children and adolescents who had participated in the Australian Child and Adolescent Mental Health Survey [12]. Information about the HRQL of all participants was obtained during the survey. For the purpose of this study, we utilised data for children aged 10–16 years (n = 2020). The mean age of these children was 13.1 ± 2.0 years and 48% of the sample was male.

Procedure

A total of 208 potential participants were identified from clinic records and asked to participate in the study. Of these, 154 completed the baseline assessment (74%). Thirty-two participants did not complete one or more of the subsequent assessments. There was no significant difference in the proportion of participants from each disease group who were lost to follow-up ($\chi^2 = 3.2$, $p = 0.2$). There were also no significant differences between the CHQ scores, nor their level of disease severity, for children who completed all assessments and those who completed the baseline assessment but who were subsequently lost to follow-up. The only demographic characteristic that differed between the two groups was that mothers of children lost to follow-up were more frequently unemployed (54.8%) than those who completed all the assessments (34.7%). Generally, losses occurred because families could not be contacted or parents and children advised that they no longer had the time required to participate in the study. This left 122 participants who completed all the assessments. The scores from these parents were utilised in the HRQL analyses reported in this study.

Assessments were completed at baseline, 6, 12, 18 and 24 months post-baseline. The data were collected between April 1999 and January 2002. Formal written consent was obtained at the time the research assistant met with children and parents in their homes. Parents and children independently completed their questionnaires with help being provided by the research assistant if this was requested. This procedure was approved by the Human Research Ethics Committee at the Women's and Children's Hospital. In Western Australia, the relevant research ethics committee requested that clinicians approach eligible families to seek their participation in the study. For those who agreed to participate, data collection then followed the same procedure as that employed in South Australia.

Measures

HRQL was measured using the 98-item parent-report version of the CHQ [5]. A 50-item version of the questionnaire is also available for use by parents. We utilised the 98-item version because it contains very comparable items to those used in the child-version of the CHQ and, as noted, a separate aim of this study was to identify the level of agreement between parent and child reports. The study utilised the 13 scales on the CHQ that describe children's physical, mental and family health, the perceived interference of health problems with physical activities, family activities, and peer and school activities, and the impact upon parent emotions and time. The ratings on all these scales are based on children's functioning over the previous 4 weeks. The validity and reliability

measurement characteristics of the scales are described in the CHQ manual [5]. For the purpose of reporting results, the names of some CHQ subscales were altered to better reflect the items that comprise them. The names that were changed (with the published name in parentheses) were: pain and discomfort (bodily pain), emotional problems (mental health), physical activities (physical functioning), and behavioural problems (behaviour). Questionnaires were scored according to the instructions in the CHQ Manual with scores having a range of 0–100 and higher scores indicating better HRQL.

Statistical analyses

Initially, *t*-tests were used to determine whether there were statistically significant differences between the CHQ scores describing children in the present study at the initial assessment and scores describing the HRQL of a large community sample of Australian children [12].

Two approaches were used to investigate changes in parents' CHQ scores over time. First, all the scores for parents of children with each disease were plotted on graphs and a visual inspection of changes over time was made. Subsequently, a series of three groups (Diabetes, Asthma and CF) × five times (Baseline, 6-, 12-, 18-, 24-months) repeated measures analyses of variance (MANOVA) was used to examine the significance of differences between mean scores. A group × time interaction term (with a Huynh–Feldt correction procedure) was included with each analysis. As the distribution of scores did not always meet the assumptions of multivariate normality, it is necessary to be cautious when interpreting results from these analyses. In the presentation of results, the term significant is used to refer to $p \leqslant 0.05$.

Results

Demographic characteristics of the sample

The demographic characteristics of the participants are shown in Table 1. With the exception of a small difference in the children's average age (Asthma $M = 12.1$, SD $= 1.9$; Diabetes $M = 13.2$, SD $= 1.9$; CF $M = 13.1$ SD $= 2.0$, $p = 0.02$), there were no significant differences in demographic characteristics of children with different illnesses.

Disease severity at the baseline assessment

The average blood glucose level of children with diabetes over the previous 8 weeks was assessed using HbA_{1C} levels. The mean HbA_{1C} ($\pm$SD) of the children was 9.0 $\pm$ 1.1 which is higher than that typically seen in children with diabetes in Australia. The mean ($\pm$SD) time since their diagnosis was 5.6 $\pm$ 3.4 years, and they required a mean ($\pm$SD) of 2.2 $\pm$ 0.5 insulin injections per day. The lung function of the children with CF was assessed by means of their forced expiratory volume (FEV_1; identified from the pulmonary function test conducted nearest to the date of their baseline assessment). FEV_1 tests showed that 22 of these children had mild reduction of lung function (FEV_1 >80% predicted), 10 children had moderate reduction (FEV_1 56–79% predicted), and two had severe reduction (FEV_1 <55% predicted) (FEV_1 was not available for four children). The Rosier Asthma Scale completed by parents of children with asthma was used to assess the severity of these children's illness [13]. On the basis of their scores on the questionnaire, children are classified as having low severity, mild, moderate or severe asthma. In the present study 12.5% of children had asthma of low severity, 22.5% had mild asthma, 42.5% had moderately severe asthma, and 22.5% had severe asthma.

Comparison of CHQ scores describing children in the community and children with asthma, diabetes or CF

Parents who participated in the National Mental Health Survey completed the CHQ-PF50. In order to make a direct comparison between scores from parents in the two studies, items that comprise the PF50 were extracted from the data collected in the present study and the appropriate scoring utilised to generate PF50 scale scores.

The results of independent samples *t*-tests showed that the scores of parents in the community were significantly higher than scores of parents of a child with illness on every subscale except family cohesion and perceived interference with peer and school activities due to emotional/

Table 1. Demographic characteristics of participants (n = 122)

	Diabetes (n = 44) N (%)	Asthma (n = 40) N (%)	CF (n = 38) N (%)	$p=$
Children's age				
Mean ± SD	13.2 ± 1.9	12.1 ± 1.9	13.1 ± 2.0	0.02
Children's sex				
Male	22 (50.0)	28 (70.0)	23 (60.5)	0.2
Female	22 (50.0)	12 (30.0)	15 (39.5)	
Family structure				
2 parents	35 (79.5)	26 (65.0)	30 (78.9)	0.4
1 parent	8 (18.2)	10 (25.0)	7 (18.4)	
Other	1 (2.3)	4 (10.0)	1 (2.6)	
Fathers' educational status				
Primary school	1 (2.6)	2 (5.9)	2 (5.7)	0.1
Some high school	5 (12.8)	12 (35.3)	11 (31.4)	
Year 12	2 (5.1)	3 (8.8)	6 (17.1)	
Technical/TAFE	15 (38.5)	7 (20.6)	6 (17.1)	
Tertiary	16 (41.0)	10 (29.4)	10 (28.6)	
Mothers' educational status				
Primary school	1 (2.3)	2 (5.0)	0 (0.0)	0.1
Some high school	11 (25.6)	14 (35.0)	16 (42.1)	
Year 12	7 (16.3)	7 (17.5)	7 (18.4)	
Technical/TAFE	1 (2.3)	6 (15.0)	4 (10.5)	
Tertiary	23 (53.5)	11 (27.5)	11 (28.9)	

Note: p values refer to results of χ^2 tests and t-tests.

behavioural problems (Table 2). The latter scale combines items from the two scales in the PF98 labelled perceived interference with peer and school activities due to emotional problems, and perceived interference with peer and school activities due to behavioural problems.

Effect sizes describing differences in mean scores on the scales labelled general health perceptions, perceived interference with family activities, and impact on parents' emotions were all $\geqslant 0.8$ which Cohen [14] describes as 'large'. Effect sizes describing differences on the pain and discomfort, behavioural problems, perceived interference with physical activities, perceived interference with peer and school activities due to physical health problems scales were all $\geqslant 0.5$ which is described as a medium effect size.

Comparison of baseline CHQ scores describing children with asthma, diabetes or CF

A series of one-way analyses of covariance, controlling for age, were used to test for the significance of differences between the parents' CHQ scores describing children with different diseases at the baseline assessment. Only two of the 13 comparisons identified significant differences between CHQ scores across the groups. These were on the general health perceptions ($F(2,118) = 5.2$, $p = 0.007$) and physical activities ($F(2,119) = 4.3$, $p = 0.03$) scales. *Post hoc* comparisons showed that the mean general health perceptions score describing children with CF was significantly lower than the score describing children with diabetes and the mean score on the physical activities scale describing children with asthma was significantly lower than that describing children with diabetes. For this analysis, with approximately 40 children in each group the study is powered to detect differences of around 0.7 SD with 80% power.

Comparison of CHQ scores at the baseline, 6, 12, 18 and 24 months assessments

Physical health

On the general health perceptions scale (Table 3) there was a significant main effect for disease group ($F(2,117) = 11.2$, $p < 0.001$) with scores

Table 2. Comparison of mean ± SE CHQ-PF50 scores from parents of children in the community with parents of children with chronic illness

CHQ subscale (PF50)	Chronic illness group	Community group	$p \leqslant$
Physical health			
General health perceptions	47.9 ± 1.5	77.5 ± 0.3	0.001
Pain and discomfort	71.3 ± 2.0	86.8 ± 0.4	0.001
Mental health			
Self-esteem	72.0 ± 1.7	80.1 ± 0.4	0.001
Emotional problems	78.8 ± 1.3	84.9 ± 0.3	0.001
Behavioural problems	74.1 ± 1.5	83.2 ± 0.3	0.001
Family health			
Family cohesion	71.6 ± 2.1	75.6 ± 0.5	0.07
Perceived interference			
Family activities	70.9 ± 1.8	87.9 ± 0.4	0.001
Physical activities	88.2 ± 1.4	95.3 ± 0.3	0.001
Peer and school activities (due to)			
Physical health problems	80.7 ± 2.5	95.7 ± 0.4	0.001
Emotional/behavioural problems	94.7 ± 1.4	94.4 ± 0.4	0.8
Impact on			
Parents' time	79.5 ± 1.9	92.9 ± 0.4	0.001
Parents' emotions	60.7 ± 2.2	83.4 ± 0.5	0.001

describing children with CF being consistently lower than those for children with asthma and diabetes. There was no significant main effect for time, however there was a significant interaction of time x disease group ($F(7.6, 444) = 4.0$, $p \leqslant 0.001$). This occurred because the scores for children with CF declined significantly over time while those for children with asthma increased significantly. Scores for children with diabetes did not change significantly. There was no significant main effect for disease group for scores on the pain and discomfort scale, however there was a significant main effect for time ($F(4,460) = 4.0$, $p = 0.003$) and a significant time × disease group interaction ($F(8,460) = 3.0$, $p = 0.003$). This reflected a pattern in which scores describing children with CF did not change significantly over time while those describing children with diabetes increased significantly. With the exception of the period from baseline to 6 months, scores describing children with asthma also consistently increased over time but this change was not statistically significant.

Mental health

There was a significant main effect for time on the Emotional Problems scale ($F(3.7, 435.1) = 2.9$, $p = 0.03$) reflecting an increase over time in scores reported by parents of children with asthma or diabetes (Table 3). There was also a significant main effect for time on the behavioural problems scale ($F(3.6, 430.5) = 6.3$, $p \leqslant 0.001$). This reflected a pattern for scores describing each disease group to increase over time although only the changes in scores of the children with diabetes were statistically significant. Scores on the self-esteem scale did not change significantly over time and there was no significant main effect for disease group, nor a significant time × disease group interaction.

Family cohesion

Scores rating the families of children with CF fluctuated somewhat, however for children with asthma or diabetes scores varied little over time. There were no significant main effects and there was also no significant time × disease group interaction (Table 3).

Perceived interference with family and physical activities

There was a significant main effect for time on the family activities scale ($F(3.9, 458.6) = 9.7$, $p \leqslant 0.001$). This reflected a pattern whereby scores for both children with diabetes or asthma

Table 3. Mean ± SE CHQ-PF98 scores describing the physical, mental and family health of children with diabetes (n = 44), asthma (n = 40) or CF (n = 38)

CHQ-PF98 scale	Baseline	6 months	12 months	18 months	24 months
Physical health					
General health perceptions					
Asthma	49.0 ± 2.6	51.9 ± 2.6	52.9 ± 2.7	54.8 ± 2.8	57.3 ± 2.5
Diabetes	54.3 ± 2.4	53.9 ± 2.6	55.4 ± 2.6	55.2 ± 2.5	57.2 ± 2.8
CF	43.0 ± 2.3	40.7 ± 2.5	40.4 ± 2.8	39.7 ± 2.7	37.2 ± 2.5
Pain and discomfort					
Asthma	76.9 ± 3.3	71.7 ± 3.8	75.2 ± 3.8	78.9 ± 3.3	83.2 ± 3.1
Diabetes	69.1 ± 2.8	76.9 ± 2.6	75.7 ± 2.9	80.0 ± 2.5	85.3 ± 2.3
CF	73.8 ± 3.6	73.6 ± 3.6	80.4 ± 2.7	72.3 ± 3.6	73.4 ± 3.6
Mental health					
Self-esteem					
Asthma	73.3 ± 2.9	72.9 ± 3.1	74.1 ± 2.8	71.6 ± 3.4	72.0 ± 3.6
Diabetes	71.1 ± 2.8	75.5 ± 2.5	75.8 ± 2.5	75.7 ± 2.8	76.5 ± 2.8
CF	71.5 ± 2.7	74.2 ± 2.7	74.6 ± 2.3	71.6 ± 3.4	70.4 ± 2.8
Emotional problems					
Asthma	75.3 ± 2.3	75.9 ± 1.9	76.6 ± 1.9	76.8 ± 2.2	79.8 ± 1.7
Diabetes	75.2 ± 1.9	78.3 ± 1.6	78.1 ± 1.3	77.9 ± 1.8	79.0 ± 2.0
CF	79.4 ± 1.8	80.3 ± 1.5	81.3 ± 1.3	79.5 ± 1.5	80.2 ± 1.4
Behavioural problems					
Asthma	76.0 ± 2.3	77.5 ± 2.2	77.6 ± 2.3	79.5 ± 2.7	79.4 ± 2.5
Diabetes	77.9 ± 2.0	79.7 ± 1.8	82.6 ± 1.6	82.6 ± 1.6	83.9 ± 1.7
CF	80.8 ± 1.5	81.9 ± 1.8	82.8 ± 1.6	82.6 ± 1.7	81.7 ± 1.8
Family health					
Family cohesion					
Asthma	68.0 ± 3.8	67.5 ± 4.1	71.0 ± 4.0	68.5 ± 4.3	65.4 ± 4.3
Diabetes	73.5 ± 3.6	75.8 ± 3.2	75.9 ± 3.5	74.4 ± 4.0	75.9 ± 3.9
CF	71.7 ± 3.8	75.8 ± 3.2	69.7 ± 4.5	76.8 ± 3.4	69.1 ± 4.3

increased significantly over time, reflecting reduced interference of their disease on family activities (Table 4). On the physical activities scale, a significant main effect of disease was identified ($F(2,119) = 4.9$, $p = 0.009$). Although neither the time × disease group interaction ($F(7.1, 424.5) = 1.9$, $p = 0.06$) nor the changes within the disease groups over time were statistically significant, a trend can be seen for scores describing children with asthma or diabetes to increase over time while those with CF declined.

Perceived interference with peer and school activities

On the scale rating interference with peer and school activities due to physical health problems there was a significant main effect for time ($F(4, 462.5) = 3.0$, $p = 0.02$). This reflected a pattern for scores describing children in each disease group to increase over time although only the changes for children with diabetes were statistically significant (Table 4). There were no significant main effects nor were there any significant interactions in the scores rating the extent to which children's emotional or behavioural problems interfered with their peer and school activities.

Impact on parents' emotions and time

On the scale rating the emotional impact of children's problems on parents, there was a significant main effect for time ($F(3.7, 435.5) = 7.0$, $p \leqslant 0.001$), as well as a significant time × disease group interaction ($F(7.4,435.5) = 2.5$, $p = 0.01$). This reflected a pattern whereby parents of children with diabetes or asthma reported a significant increase in scores over time while there was no significant change in the scores reported by parents of children with CF (Table 5). On the scale rating the impact of children's problems on the time parents have available for their own needs, there was no significant main effect for time ($F(3.9, 457.3) = 2.2$, $p = 0.07$), however there was a significant

Table 4. Mean ± SE CHQ-PF98 scores describing the perceived interference of health problems with the lives of families and children with diabetes (n = 44), asthma (n = 40) or CF (n = 38)

CHQ-PF98 scale	Baseline	6 months	12 months	18 months	24 months
Family activities					
Asthma	78.9 ± 2.9	80.7 ± 3.0	81.8 ± 3.2	84.8 ± 3.4	87.9 ± 2.3
Diabetes	72.6 ± 2.5	77.1 ± 2.4	79.9 ± 2.2	81.5 ± 2.6	82.1 ± 2.6
CF	76.7 ± 2.5	76.7 ± 2.7	74.9 ± 2.7	78.3 ± 2.4	81.7 ± 2.4
Physical activities					
Asthma	85.1 ± 2.4	87.1 ± 2.7	86.9 ± 3.0	90.6 ± 2.3	93.3 ± 1.7
Diabetes	93.5 ± 1.7	93.4 ± 1.6	91.8 ± 2.5	92.9 ± 2.1	96.4 ± 1.1
CF	89.5 ± 2.5	87.1 ± 2.7	86.1 ± 2.7	85.1 ± 2.9	84.8 ± 2.7
Peer and school activities (due to)					
Physical health problems					
Asthma	81.1 ± 4.2	77.8 ± 4.7	80.1 ± 4.8	88.9 ± 3.4	92.0 ± 2.7
Diabetes	80.6 ± 4.0	89.4 ± 2.7	86.4 ± 3.9	90.7 ± 2.8	93.5 ± 2.2
CF	79.2 ± 4.9	79.8 ± 4.9	83.3 ± 4.2	77.8 ± 5.1	81.9 ± 4.7
Emotional problems					
Asthma	88.1 ± 3.5	89.4 ± 3.6	89.2 ± 3.1	89.2 ± 3.9	91.2 ± 3.2
Diabetes	91.2 ± 2.8	93.7 ± 1.8	89.6 ± 3.1	90.7 ± 3.3	90.9 ± 2.9
CF	89.8 ± 3.7	94.2 ± 2.1	94.4 ± 2.5	91.2 ± 3.8	89.2 ± 3.9
Behavioural problems					
Asthma	88.3 ± 3.9	82.5 ± 4.2	84.0 ± 4.4	92.2 ± 3.8	92.0 ± 2.9
Diabetes	89.9 ± 3.1	93.2 ± 2.6	91.7 ± 2.5	92.9 ± 3.0	94.1 ± 2.3
CF	91.5 ± 2.5	96.5 ± 1.7	92.4 ± 2.4	90.9 ± 3.4	92.7 ± 2.5

Table 5. Mean ± SE CHQ-PF98 scores describing the impact of childhood health problems on parents of children with diabetes (n = 44), asthma (n = 40) or CF (n = 38)

CHQ-PF98 scale	Baseline	6 months	12 months	18 months	24 months
Time impact					
Asthma	84.3 ± 2.9	83.3 ± 3.4	85.0 ± 3.3	86.2 ± 3.4	91.8 ± 1.9
Diabetes	81.9 ± 2.8	87.7 ± 2.7	90.5 ± 1.9	88.7 ± 2.5	88.8 ± 2.9
CF	85.4 ± 1.9	87.7 ± 2.1	83.6 ± 2.8	86.7 ± 2.6	84.2 ± 2.9
Emotional impact					
Asthma	67.8 ± 3.5	69.9 ± 3.5	70.4 ± 4.2	73.4 ± 4.3	78.5 ± 3.1
Diabetes	64.4 ± 4.0	70.3 ± 3.2	76.3 ± 2.8	76.6 ± 2.6	74.5 ± 3.2
CF	67.6 ± 2.9	73.2 ± 2.5	73.2 ± 3.3	72.5 ± 3.2	68.2 ± 3.4

time × disease group interaction ($F(7.8, 457.3) = 2.3$, $p = 0.02$). This reflected a pattern in which parents of children with diabetes or asthma reported significantly increased scores over time while parents of children with CF reported no significant change over time.

Discussion

At the baseline assessment for the study, in a range of areas parents of children with asthma, diabetes or CF perceived the HRQL of their children to be significantly worse than that reported by the parents of a large community sample of children. For example, they more frequently reported that health problems interfered with their children's participation in physical activities, and with their peer and school activities. They also reported that children's health problems more frequently interfered with family activities and that they were a source of significant emotional worry and concern for the parents themselves. Differences between scores reported by parents of children in the two

groups on the scales labelled general health perceptions, perceived interference with family activities, and impact on parents' emotions were all in the range described by Cohen [14] as a large effect size. This suggests that in these areas parents perceive that the HRQL of children with chronic illness is substantially worse than that of other children and families.

At the time of the children's baseline assessment there were few differences between the parent-reported scores describing the HRQL of children with asthma, diabetes or CF. However, the general health of children with CF was perceived by their parents to be worse than that of children with asthma and diabetes. It is likely that clinicians would concur with this assessment of CF as being a more severe illness than asthma or diabetes. However in most other areas, children with CF were described as functioning at a level comparable to children with diabetes or asthma. It would be easy for clinicians who focus primarily on children's physical health and the results of biomedical assessments, to generalise findings in these areas to other areas of children's lives. The results from this study suggest that when they are younger, children with CF may function in many areas of their lives at a level comparable to that of children with asthma or diabetes.

In several areas, CHQ scores reported by children [10] were significantly higher than those reported by their parents. For example, at the baseline assessment children reported significantly higher scores than were reported by parents on the behavioural problems, self-esteem, general health perceptions, and the level of perceived interference due to behavioural problems and to physical health problems scales. In each of these areas, the pattern of differences persisted across all five assessments. On other CHQ scales, the size of difference between parent and child scores was generally in the same direction (i.e., children reporting higher scores) but the magnitude of differences between scores reported by the two informants was smaller. The differences suggested that as a group, children perceived their HRQL to be better than was reported by their parents. This finding is consistent with another recent study which reported that adolescents with CF rated themselves as having a higher HRQL than was reported by their parents [15].

Over the 2 years of the study, the pattern of changes to CHQ scores describing the impact of CF on children and their parents differed somewhat from those reported for diabetes or asthma. For example, a significant decline was reported in scores rating the physical health of children with CF. In contrast, a significant improvement was reported in these scores for children with asthma while no significant change was reported for children with diabetes. Parents of children with asthma or diabetes also reported a significant reduction in emotional worry about their child's health and the impact of children's problems on the time available for their own needs. In contrast, parents of children with CF did not report significant changes in either of these areas. The findings highlight the ongoing impact of CF on both children and parents. They also draw attention to the importance of providing support for both children with CF and their parents.

Interpreting the clinical significance of changes to scores on quality of life measures is difficult as there is still only limited experience in their use [16]. Broadly, two approaches can be utilised to address this issue. One approach is based on the statistical distribution of results while the alternative makes use of anchor-based or known-groups methods [16, 17]. In the present study, we utilised effect sizes to describe the magnitude of differences in scores. We also provided CHQ scores from a general community population as a reference point to aid interpretation of scores describing children with diabetes, asthma and CF. This makes it possible to see, for example, that in the area of general health perceptions, although the scores for children with asthma and diabetes increased over the course of the study, they continued to be well below those of other children in the community. Furthermore, scores describing children with CF declined to a point where they were only half those of other children in the community. A better understanding of the clinical significance of CHQ scores will be helped by further studies which describe children with varying disorders and their response to treatment interventions.

The pattern of changes to CHQ scores over time is consistent with clinical experience of these illnesses although the size of the differences in several

areas was smaller than we had anticipated. For example, there were significant time × disease interactions only for the scales assessing general health, pain and discomfort, and parental impact. Two interpretations are possible from these findings. First, it is possible that the differences between the HRQL of children with these illnesses remain relatively small over time. Alternatively, and perhaps more plausibly in the case of CF, it is possible that if the children were followed over a longer period of time, differences in their functioning across other areas may have become more evident.

Strengths of the study include its use of a carefully developed generic measure to evaluate children's HRQL and the retention of a large proportion of participants over the 2 years of the study. Limitations are firstly that the majority of the children were being treated in the same paediatric hospital. As a result, caution is necessary when generalizing the findings to children being managed in other settings. Secondly, the power of the study to detect differences between the disease groups was limited due to the number of subjects in each of the disease groups. In view of the latter it is interesting to note that there was a reasonably consistent trend for improving quality of life in the children with conditions that typically progress either slowly or not at all (diabetes and asthma) while the children with CF appeared to have static or even decreasing HRQL.

In conclusion, HRQL measures are increasingly being used to assess the effectiveness of new interventions delivered as part of routine clinical care. However, there is little information about how the HRQL of children with chronic illness changes over time. This study describes the HRQL of children with diabetes, asthma or CF who have received routine clinical care in a specialist paediatric hospital. The findings highlight the broad range of areas in which children's lives are adversely affected by chronic illness. While the HRQL of children with diabetes or asthma showed some improvements over the 2 years of the study, children with CF experienced little change or a decline in their HRQL. These findings challenge clinicians to identify new approaches that can improve the broader psychological and social functioning of children with chronic illness and their families.

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References

1. Power TJ, Dupaul GJ, Shapiro ES. Promoting Children's Health. Integrating School, Family and Community. New York: The Guilford Press, 2003.
2. Robinson MJ, Roberton, DM. Practical Paediatrics. 5th ed. Edinburgh: Churchill Livingstone, 2003.
3. Schipper H, Clinch JJ, Olweny, CLM. Quality of life studies: Definitions and conceptual issues. In: Spilker B (ed), Quality of Life and Pharmacoeconomics in Clinical Trials. 2nd ed. New York: Lippincott-Raven 1996, pp. 11–23.
4. Juniper EF, Guyatt GH, Feeney D, Griffith LE, Ferrie, PJ. Minimum skills required by children to complete health-related quality of life instruments for asthma: comparison of measurement properties. Eur Respir J 1997; 10: 2285–2294.
5. Landgraf JM, Abetz L, Ware, JE. Child Health Questionnaire (CHQ): A User's Manual. Boston, MA: The Health Institute, New England Medical Centre, 1996.
6. Varni JW, Seid M, Kurtin, PS. The PedsQL 4.0: Reliability and validity of Pediatric Quality of Life Inventory Version 4.0 Generic Core Scales in healthy and patient populations. Med Care 2001; 39: 800–812.
7. Wallander JL, Varni, JW. Effects of pediatric chronic physical disorders on child and family adjustment. J Child Psychol Psychiatry 1998; 39: 29–46.
8. Stein EK, Jessop, DJ. What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. Soc Sci Med 1989; 29: 769–778.
9. Eiser C, Morse, R. Can parents rate their child's health-related quality of life? Results of a systematic review. Qual Life Res 2001; 10: 347–357.
10. Sawyer MG, Reynolds KE, Couper JJ, et al. Health-related quality of life of children with chronic illness – A two year prospective study. Qual Life Res (in press).
11. Sawyer MG, Antoniou G, Toogood I, Rice, M. Childhood cancer: A two-year prospective study of the psychological adjustment of children and parents. J Am Acad Child Adolesc Psychiatry 1997; 36(12): 1736.
12. Sawyer M, Arney F, Baghurst P, et al. The Mental Health of Young People in Australia: Child and Adolescent Component of the National Survey of Mental Health and Well-Being. Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care. Australia. www.mentalhealth.gov.au
13. Rosier MJ, Bishop J, Nolan R, Robertson CF, Carlin JB, Phelan PD. Measurement of functional severity of asthma in children. Am J Respir Crit Care Med 1994; 149: 1434–1441.

14. Cohen, J. Statistical Power Analysis for the Behavioral Sciences. 2nd ed. 1988, London: Lawrence Erlbaum, 1988.
15. Britto MT, Kotagal UR, Chenier T, Tsevat J, Atherton HD, Wilmott RW. Differences between adolescents' and parents' reports of health-related quality of life in cystic fibrosis. Pediatr Pulm 2004; 37: 165–171.
16. Lydick E, Epstein, RS. Interpretation of quality of life changes. Qual Life Res 1993; 2: 221–226.
17. Varni JW, Seid M, Kurtin, PS. The PedsQL^{TM} 4.0: Reliability and validity of the Pediatrc Quality of Life Inventory^{TM}Version 4.0 Generic Core Scales in healthy and patient populations. Med Care 2001; 39: 800–812.

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