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# A Parent-Child Dyad Approach to the Assessment of Health Status and Health-Related Quality of Life in Children with Asthma

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## Abstract

**Background—**Assessment of health state and health-related quality of life (HR-QOL) are limited by a child's age and cognitive ability. Parent-proxy reports are known to differ from children's reports. Simultaneous assessment using a parent-child dyad is an alternative approach.

**Objective—**Our objective was to assess the validity, reliability and responsiveness of a parent-child dyad approach to utility and HR-QOL assessment of paediatric asthma health states.

**Methods—**The setting was specialist care in a hospital-based asthma clinic. Participants were 91 girls and boys with asthma aged 8 to 17 years and 91 parents. The intervention employed was parent-child dyad administration of the Health Utilities Index (HUI) 2 and 3, the Pediatric Quality of Life Inventory™ (PedsQL™) Core and Asthma modules, and the Pediatric Asthma Quality of Life Questionnaire (PAQLQ).

Questionnaires were administered by interview to children and parents separately and then together as a dyad to assess the child's health state. The dyad interview was repeated at the next clinic visit. Dyad-child agreement was measured by intra-class correlation (ICC) coefficient; Spearman correlations were used to assess convergent validity. Test-retest reliability was assessed in 28 children who remained clinically stable between visits with a two-way ICC coefficient. Responsiveness to change from baseline was assessed with Spearman coefficients in 30 children who demonstrated clinical change between visits.

**Results—**There was no significant agreement between parent and child for the HUI2 or HUI3 whereas agreement between dyad and child was 0.55 (95% confidence interval [CI] 0.36, 0.69) for the HUI2 and 0.74 (95% CI 0.61, 0.82) for the HUI3 overall. With respect to dyad performance characteristics, both HUI2 and HUI3 overall scores demonstrated moderate convergent validity with the generic PedsQL™ Core domains (range $r = 0.30–0.52$; $p < 0.01$). Dyad HUI2 attributes demonstrated moderate convergent validity with the generic PedsQL™ Core domains of similar constructs (range $r = 0.35–0.43$; $p < 0.001$) and weaker convergent validity with disease-specific domains (range $r = 0.13–0.32$). Dyad HUI3 attributes demonstrated weaker convergent validity

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compared with the HUI2. For the assessment of test-retest reliability, significant agreement between baseline and follow-up was observed for dyad HUI2 total (r = 0.53), dyad PedsQL™ Core summary (r = 0.70) and select dyad disease-specific domains. Significant responsiveness (r > 0.4; p < 0.05) was observed for dyad HUI2 total score change over time as correlated with dyad HUI3, dyad PedsQL™ Core summary and select disease-specific domains.

**Conclusions—**The parent-child dyad approach demonstrated moderate to strong performance characteristics in generic and disease-specific questionnaires suggesting it may be a valuable alternative to relying on parent proxies for assessing children's utility and HR-QOL. Future research in additional paediatric populations, younger children and a population-based sample would be useful.

## Introduction

Preference-based measures of health-related quality of life (HR-QOL) have a special role in economic evaluations of health interventions. Preferences for diverse health states can be summarized in a single score and be incorporated in a universal measure such as a QALY, thereby enabling comparisons of the cost effectiveness of interventions across patient populations. Because of the importance of preference-based measures of HR-QOL for both clinical and health resource decision making, much attention has been focused on the measurement properties, validity and reliability of various indices. These issues are especially relevant when considering the use of preference-based measures of HR-QOL in children, as HR-QOL measurement in children poses unique challenges.[1,2] First, children's ability to respond to questionnaires depends on age, cognitive ability and the effects of disease. Second, the context such as the physical and family environment and dependency on parents and other caregivers may affect responses.[3–5] Third, children's valuation of HR-QOL may depend on the measurement tool, suggesting that construct validity of available tools remains an issue.[6,7]

A key aspect of measuring HR-QOL in children is the reliance on parents as proxy respondents, particularly for the very young as well as children of all ages who have difficulty meeting the cognitive and communication demands of HR-QOL assessment. Yet several studies have shown poor to moderate correlations between parent and child responses,[8–13] questioning the validity of the parent proxy as a true representation of a child's HR-QOL. To a certain extent, parents' own preferences and values may be incorporated into their proxy measures.[14] Previous studies suggest that parents may be reliable reporters for observable behaviours, such as the expression of symptoms and physical function, but less so for cognition- and emotion-related attributes.[9,15]

To address some of these concerns, a novel approach to preference-based child HR-QOL measurement that brings the parent and the child together as a dyad is proposed. The goal of the dyad interview approach is to utilize the interviewer as a moderator to facilitate discussion between the parent and child as they progress through the HR-QOL questionnaire items. While it may be especially useful for very young children, a dyad approach may also facilitate communication and expression of preferences in children of all ages. Many items will engender no discussion and the joint selection may be clear. For other items,

particularly those related to mood and cognition, the moderator will encourage discussion and revelation of feelings, attitudes, beliefs and perceptions with a view to clarification of preferences of both parent and child. Educational psychologists recognize that initial preference selection may be unstable and that discussion is required for affirmation.[16] The dyad dynamic offers an opportunity for such reflection and discussion. By encouraging discussion and clarification of views, the dyad approach has the potential to achieve greater stability compared with individual proxy or child assessments. The interaction between parent and child in the dyad context more closely resembles real-world preference expression compared with structured quantitative interviews in an experimental or controlled environment. One important challenge of the dyad approach is to ensure that parents do not impose their views or preferences upon the child. In a previous qualitative study, the interaction between parent and child that occurred during the administration of HR-QOL instruments was observed and recorded for 16 parent-child pairs.[17] In that study, the data were analysed using grounded theory methods and findings were grouped in 11 themes: recall difficulty, respondent bias, interviewer bias, frustration, coercion/parental influence, inter-relational conflict, psychic discomfort for health states, emotional sensitivity, parent as advocate, parent as enabler, and comprehension.[17] The specification of these categories facilitated the creation of a structured interview guide with scripted cues and prompts to accompany the administration of standardized HR-QOL questionnaires to parent-child dyads. Using the interview guide as a companion to interviewer-administered HR-QOL questionnaires has the potential to facilitate discussion between parent and child, mitigate coercion and bias, enhance the overall accuracy of the responses, and ensure consistency of the interview process.

Health utility and HR-QOL assessment have been previously investigated in children with asthma[17,18] and this patient population may serve as useful sample for assessment of the dyad approach. Asthma is the most common chronic paediatric illness and can have a profound impact on QOL given the prominence and frequency of the symptoms, the limitations imposed on physical activity, and the need for self-management.[19] A diagnosis of asthma and public use of inhalers can also be stigmatizing to children.[20] As asthma is a chronic disease that may fluctuate over time, longitudinal repeat assessments are necessary to capture changes in HR-QOL that reflect changes in health status. Measuring the responsiveness of an instrument allows an assessment of how well that questionnaire or approach reflects true fluctuations in health status. The study objectives were to (i) measure respondent agreement and (ii) assess the performance characteristics (validity, reliability and responsiveness) of the dyad approach to utility and HR-QOL assessment in children with asthma.

## Methods

### Study Design

In this prospective cohort study, children with asthma and their primary caregiver were recruited at the outpatient asthma clinic in the Division of Respiratory Medicine at The Hospital for Sick Children, Toronto, Canada; otherwise, healthy boys and girls with a clinical diagnosis of asthma aged 8 to 17 years and with good comprehension of English by

caregiver and child were eligible. Children with significant co-morbidities that would impact on their QOL were excluded, including congenital conditions, cancer, musculoskeletal abnormalities and major psychological impairments. As children with asthma can experience anxiety and other emotional disorders that can affect their behaviour and ability to concentrate, children with co-morbidities that could be related to their asthma condition, including attention, behavioural, learning and mood disorders were eligible. All parents provided written informed consent and children provided assent. The study was approved by The Hospital for Sick Children Research Ethics Board.

Sample size tables for reliability studies are available. It is desirable to have sufficient power to detect the presence of moderate to high levels of agreement between a dyad approach to instrument completion and a standard approach. A study that is designed to test the hypothesis that $\rho_0$, the minimum acceptable intra-class correlation (ICC) coefficient, equals 0.4 requires a sample size of 87 pairs to detect an ICC coefficient of 0.6 or greater at $\alpha = 0.05$ and $\beta = 0.20$.[21]

## Data Collection

Two interviewers trained in the use of the study instruments were responsible for all data collection. Baseline data collection included a brief demographics questionnaire for completion by the parent. The Health Utilities Index (HUI), Pediatric Quality of Life Inventory™ (PedsQL™) and Pediatric Asthma Quality of Life Questionnaire (PAQLQ) were administered in random sequence to prevent ordering effects between dyads but the same sequence was used within each dyad. The completion times for each questionnaire were recorded. Questionnaires were first administered by interviewers to parents and their children separately and immediately following this were administered to the child and parent together as a dyad. In the separate interviews, parents were administered the proxy versions and children the standard versions. In all interviews respondents were provided with laminated cards representing the response options for the various questionnaires. Questions were asked aloud and respondents could respond aloud or point to the relevant response option on the response card. During the dyad administration, a single trained interviewer guided the participants through the standard versions of the questionnaires using the interview guide, encouraging them to share their thoughts while keeping the discussion on track. Interviewers validated what was said using exact word repetition and acknowledgement. The interviewer encouraged participants to respond to the questions by discussing them with each other rather than with the interviewer. Parent-child disagreement was used to encourage participants to elucidate and clarify their specific point of view. Only the child's responses regarding their current health state were recorded and the interviewer did not require consensus. After completion of HR-QOL questionnaires, all children were assessed by a clinic respirologist.

To minimize the burden on research subjects, the follow-up interview was scheduled for the next clinic appointment, which typically occurred 3 to 6 months later. At the follow-up visit, the questionnaires were administered in the same order as at baseline. Only the dyad assessment was conducted at the follow-up visit since the reliability and responsiveness of the independent assessments have been studied previously.[18,22–24] The same interviewer

who conducted the baseline interview conducted the follow-up interview. After completion of HR-QOL assessment, a clinical assessment was performed.

## Outcome Measurement

Due to the cognitive challenges associated with administering direct preference measures such as a standard gamble to children, the use of an indirect measure such as the HUI is often preferred. In a prior quality appraisal of paediatric HR-QOL instruments, the HUI was among three instruments with the highest performance characteristics of 19 generic instruments studied.[25] Of 24 disease-specific instruments studied, the PAQLQ was the only asthma questionnaire with high performance.[25] The present study assessed generic HR-QOL with the preference-based HUI versions 2 and 3 and the non-preference-based Core PedsQL™. Asthma-specific HR-QOL was assessed with the PAQLQ and the Asthma module of the PedsQL™. All of these instruments have child and parent-proxy versions.

The HUI is a generic health status classification system that uses a statistical algorithm to apply pre-derived preference weights to health states described by the system.[22,26] The same questionnaire can be used to generate scores for versions 2 and 3. Both versions were analysed to improve comparability with published research. The HUI2 and HUI3 have been used in paediatric populations.[8,12,13,18,27,28] For this study, the fertility attribute was omitted from the HUI2. The interviewer-administered version was used with a 1-week recall period. The PedsQL™ Core instrument, a 23-item generic HR-QOL instrument designed for use with community, school, and clinical paediatric populations,[24,29] measures the core dimensions of health along four scales: physical, emotional, social functioning and role (school) functioning. The instrument has demonstrated reliability and validity with high discriminatory power and responsiveness.[24,29] The 28-item PedsQL™ Asthma module, designed to measure paediatric asthma-specific HR-QOL, has high internal consistency and is able to distinguish between healthy children and children with asthma.[30] The Asthma module generates scores for four domains, including asthma symptoms, treatment problems, worry and communication. As with the generic Core instrument, developmentally appropriate versions are available for different age groups. The validity of the PedsQL™ Asthma module has been demonstrated through correlation with the PAQLQ.[23] The instrument has also demonstrated good responsiveness by detecting clinical change over time.[23] The PAQLQ, a disease-specific HR-QOL instrument for use in children 7 years or older with asthma,[31,32] is an interviewer-administered questionnaire with 23 items that map onto three domains: symptoms, activities and emotions. A 1-week recall is used. The PAQLQ has demonstrated validity and reliability.[18,19]

For each child, clinical measurements of asthma were undertaken following completion of all HR-QOL assessments so these measures would not bias the HR-QOL responses. In accordance with current clinical practice guidelines,[33,34] disease severity was evaluated by measuring pulmonary function, symptoms and medication use. The physician's global assessment was recorded on a scale from 1 (very well controlled) to 5 (very poorly controlled). Spirometric evaluation of the forced expiratory volume in 1 second ($FEV_1$) and the $FEV_1$ percentage predicted for each child according to age/sex norms was recorded at each visit. Exhaled nitrogen oxide results were also recorded. The child's asthma control

was assessed with the Asthma Control Questionnaire (ACQ), which examines daytime and night-time symptoms, need for rescue medication and activity limitations.[35] Medication use in the last week was recorded, including frequency of short-acting β-agonist use, dose and frequency of inhaled corticosteroids and long-acting β-agonists and the use of oral steroids. Based on these clinical measures, physicians classified each child's current asthma as intermittent, mild persistent, moderate persistent or severe persistent.[34]

## Statistical Analysis

All data were entered into a Microsoft® Access™ database and exported into SAS release 9.0 (SAS Institute Inc., Cary, NC, USA) for statistical analyses. HR-QOL instruments were scored using each instrument's scoring formula. Individual attributes for HUI were scored using the single-attribute utility function. The sample size available for the calculation of each attribute and domain score varied slightly due to missing data, which occurred when subjects did not provide a response. For the first study objective, it was hypothesized that the agreement between dyad HUI scores and independent child HUI scores would be greater than the agreement between parent-proxy HUI scores and independent child HUI scores. This acknowledges the perceived limitations of parent-proxy assessment. Agreement was ascertained with a two-way mixed effects ICC coefficient model with 95% confidence intervals (CIs). The ICC coefficients between the dyad and child and between the parent proxy and child were computed for overall utility and for select attributes of the HUI2, HUI3, PedsQL™ and PAQLQ.

The second objective was to assess the performance characteristics of the dyad approach through measures of validity, reliability and responsiveness. Since there is no gold standard for paediatric HR-QOL, convergent validity was used to assess how well the approach correlated with other measures. To assess validity of the dyad approach, *a priori* hypotheses regarding expected correlations between domains and attributes measuring similar constructs were stated. It was hypothesized that moderate to strong correlations ≥0.5 would be observed for similar attributes of generic instruments related to physical function, such as HUI2 mobility and PedsQL™ Core physical, and emotion, such as HUI2 emotion and PedsQL™ Core emotional. Weaker correlations in the 0.35 to 0.5 range were expected between HUI total utilities and select domain scores for the generic and disease-specific instruments. These projections were based on previously observed correlations between the HUI and generic HR-QOL measures in the 0.35 to 0.6 range.[8,36] For all analyses, Spearman correlation coefficients and 95% CIs were calculated from the baseline data with Bonferroni adjustments for multiple testing. Discriminant validity of the dyad HUI2/HUI3 was assessed by determining if the mean current overall health state utility was significantly different for children classified as having mild, moderate or severe persistent asthma. Means were compared using an analysis of variance (ANOVA), with a two-sided level of significance of 0.05.

Test-retest reliability for the dyad approach was assessed by comparing baseline with follow-up scores for children who were clinically stable. Children were classified as stable if they remained within the same category of severity and their asthma control score did not change by more than 0.5. Reliability was reported using a two-way mixed-effects ICC

coefficient model with 95% CIs between time points for the current health state for the dyad HUI, PedsQL™ and PAQLQ.

Responsiveness of the dyad approach was assessed by comparing the mean change from baseline in the dyad HUI, PedsQL™ and PAQLQ in clinically stable patients with the mean change from baseline in patients who improved or worsened using ANOVA. A responsiveness index for the dyad approach for each instrument was calculated to reflect effect size by dividing the mean change in unstable patients by the variance in clinically stable patients.[37] Changes from baseline in the dyad HUI, PedsQL™ and PAQLQ for unstable patients were also reported in a correlation matrix of Spearman correlation coefficients.

## Results

### Study Sample

Of 145 children and parents approached to participate, 93 (64%) enrolled in the study. After the baseline interviews, 11 subjects were lost to follow-up, 14 declined further participation or did not have a follow-up appointment scheduled, and 68 returned for a follow-up assessment. Two cases were excluded as these children did not have a clinical diagnosis of asthma, resulting in baseline and follow-up data from 91 and 66 child-parent pairs, respectively. The mean interval between baseline and follow-up assessments was 23.7 weeks (standard deviation [SD] 12.2 weeks). The sample demographics are presented in table I. More boys than girls were enrolled, which reflects the epidemiology of paediatric asthma.[38] In addition to allergies, common co-morbid conditions included learning, attention and behavioural problems. Approximately half the parent respondents were born outside of Canada. With regard to the child's asthma (table II), the children were fairly evenly distributed across the severity continuum. Almost all children reported use of a controller medication (inhaled corticosteroid with or without other medications) in the last week. Complete data for health services utilization and health outcomes between the baseline and follow-up assessments were available for 64 children. Fifty-six percent of children experienced one or more asthma attacks and approximately 10% required a visit to an ED or a doctor's office for urgent care.

### Child-Parent Agreement

There was no consistent pattern of parent scores exceeding or being less than child scores for any of the instruments except the PedsQL™ Asthma module, where the parent scores were slightly but not significantly greater than child scores for every domain (results not shown). As seen in table III, there was little agreement between independent child and parent responses for key attributes and overall utility for the HUI2 and HUI3. The generic PedsQL™ Core questionnaire displayed moderate agreement between parent and child (ICC coefficient = 0.48; $p < 0.0001$). Select domains in the PedsQL™ Asthma module and the PAQLQ displayed moderate agreement between parent and child ranging from 0.37 for the treatment domain of the PedsQL™ Asthma module to 0.63 for the PedsQL™ Asthma module symptoms domain.

### Child-Dyad Agreement

Table III also presents the agreement between the independent child and dyad responses. As expected, agreement in responses between the child alone and the dyad and was higher than seen in the child versus the parent but was not perfect. The HUI2 demonstrated stronger agreement between child and dyad for physical attributes whereas the HUI3 demonstrated stronger agreement for emotion. Agreement between child and dyad was higher for HUI3 for overall utility (ICC coefficient = 0.74; $p < 0.0001$) compared with HUI2 (ICC coefficient = 0.55; $p < 0.0001$). In contrast to the HUI, agreement between the child and dyad scores for the PedsQL™ Core and the disease-specific instruments was substantial (ICC coefficient ≥ 0.78; $p < 0.0001$).

### Performance Characteristics of the Dyad Instruments

The mean (SD) completion times for the battery of HUI, PAQLQ and PedsQL™ were 17.4 (4.9), 20.7 (6.1), 19.9 (6.0) and 16.9 (5.7) minutes for the baseline child, baseline parent, baseline dyad and follow-up dyad, respectively. Thus the dyad administration took no more time to complete than the solo questionnaires and the dyad duration decreased over time. Table IV presents the results of the assessment of convergent validity of the dyad administration for HUI2 and HUI3 attributes related to emotion and physical function and for overall scores. Moderate correlation was observed for physical and emotional attributes between the HUI2 and the generic PedsQL™ Core module. Weaker correlations were observed for like attributes for the HUI3. Weak or non-significant correlations were found between the HUI and the disease-specific PedsQL™ Asthma module and the PAQLQ. Although the observed correlations were stronger between similar attributes than between HUI2/HUI3 total utilities and domain scores for generic and disease-specific instruments, overall the correlations were generally not as strong as predicted. With respect to discriminant validity, there were no significant differences in HUI2/HUI3 scores between children grouped by severity level (results not shown).

An assessment of test-retest reliability of the dyad approach was conducted in 28 children who remained clinically stable with respect to asthma severity and the results are presented in table V. Agreement between baseline and follow-up scores was moderate (ICC coefficient = 0.53) for the HUI2 overall utility and weak (ICC coefficient = 0.35) for the HUI3 overall utility. Because stability between visits was defined in terms of asthma severity, it was expected that the test-retest reliability of dyad administration disease-specific instruments would be higher than the generic HR-QOL instruments. Strong agreement was observed for all the domains of the PAQLQ and the PedsQL™ Asthma module, except the treatment domain, which displayed moderate agreement.

To assess responsiveness, the mean change from baseline for dyad administration of each of the instruments was compared for children who were stable, improved and who worsened. While the differences between groups were in the expected directions, they were not statistically different. For the 36 children who were clinically unstable between visits, complete data were available for 30 children. The responsiveness indices for each domain and attribute for dyad administration of the generic and disease-specific instruments were all <1.0, meaning that that the instruments could not detect true clinical change above and

beyond between-patient variance. The correlations between change from baseline for dyad HUI2 and HUI3 overall utilities with changes in the other measures in clinically unstable patients are presented in table VI. In general, the dyad HUI2 appeared more responsive than the dyad HUI3 to change over time, demonstrating moderate correlation with the dyad PedsQL™ Core overall score and the dyad PedsQL™ Asthma treatment domain.

## Discussion

This study observed that there was no significant agreement between child and parent responses for the HUI and only moderate agreement for the generic PedsQL™ Core (ICC coefficient = 0.48) and most of the disease-specific domain measures (ICC coefficient range = 0.37–0.54). The greatest agreement between parent and child was observed for the PedsQL™ symptoms domain (ICC coefficient = 0.63). This is consistent with previous findings that parents are more accurate proxy reporters for aspects of a child's disease that are easier to observe.[9,15] When these questionnaires were administered to the child and parent as a dyad, agreement with the child's independent scores improved significantly but was not perfectly congruent for any of the instruments, suggesting that the child changed his or her responses in the presence of the parent. An assessment of the dyad HUI administration revealed moderate convergent validity with the generic PedsQL™ Core. The test-retest reliability of the dyad HUI was moderate compared with substantial reliability for the PedsQL™ Core and the disease-specific questionnaires. The dyad HUI demonstrated limited responsiveness to observed changes in asthma disease severity or asthma control. One possible explanation is that changes in the child's disease severity in the range observed in this study did not have a substantial impact on the child's HR-QOL. This was also seen in the lack of discriminant validity when HUI scores were compared between children grouped by severity. Changes in the dyad HUI over time were weakly to moderately correlated with changes in the other measures.

The lack of a gold standard for the measurement of paediatric HR-QOL makes it difficult to assess whether the dyad approach results in more accurate responses compared with a parent proxy or indeed with the child alone. However, several operational advantages of a dyad approach can be identified. Since young children are not cognitively well developed, adult cognitive skills may assist in the elicitation of preferences. In the present study, trained interviewers prompted parents to assist their child grasp the meaning of questions by asking them 'Can you help [*child name*] understand that question?' Cognitive skills of children also change over time. As the development of age-specific versions of HR-QOL instruments may be impractical, parent interaction can mitigate the confounding effect of changing cognitive skills. Specific cognitive challenges that may be ameliorated by having a parent present include helping a child's recall ability. In the present study when a child had difficulty with the recall aspect of a question, the parent was able to provide events in the child's life to bookmark the recall time frame for each questionnaire. Thus if a child has difficulty grasping 'in the past week', a parent can enable the child to answer accurately by suggesting bookmark events. The parent may offer similar assistance for other questions as the parent may best understand what information the child needs to respond accurately. A parent's presence may also have the benefit of inhibiting response bias or the use of a response set.[6] A response set, where children use an identical response pattern for many questions,

especially ‘I don’t know’, is a common pitfall of questionnaire use in children and can lead to a large volume of missing or unreliable data. In the presence of the parent, the volume of missing data for the HUI decreased from 21% to 2%.

Another cognitive challenge relates to symptom interpretation. Children may not know that what they are experiencing are symptoms of disease.[39] Young children have an undeveloped understanding of what constitutes ‘normal’ for various domains.[4] They may lack scaling ability and numeracy skills.[40] In addition, disabled teen children have reported near normal HR-QOL.[27] This may be due to adaptation to disability and a reinforced view that they are as able as their peers. The presence of a parent may lend some objectivity to observable symptoms and behaviours in children of all ages. Since adults have been observed to under-report effects related to a child’s emotion or mood,[15] the dyad approach serves as an opportunity for the parent to amplify his/her understanding of the child’s emotional state according to the child’s frame of reference. Interviewing a child and parent together also more closely resembles how information is obtained about a child’s health status in the clinical office setting.

Despite these advantages, there are potential disadvantages to the dyad approach. Interviewers require special training, including facilitator skills, to ensure accurate capture of information and consistent interpretation of responses. Another potential limitation is that the child’s preferences may be influenced by a parent’s views. The child may change their responses to please the parent or to meet the parent’s expectations. Children may also be inhibited in expressing their emotion/mood, pain or social functioning. Independent reports of a child’s HR-QOL from a parent and child may still be of value, particularly from young children.[41] The preferences of young children who display adaptation to their health condition must be considered authentic and not be dominated by the views of others. It is important to understand which paediatric health conditions children adapt to with respect to their HR-QOL. In the administration of the instruments to the dyad, careful steps were taken to mitigate bias or coercion by the parent and only the child’s preferences and responses were recorded. As discussed above, the interviewer’s role as a facilitator will encourage expression by the child.

The present study adds to the literature that has compared child and parent assessments of HR-QOL. Several researchers found good agreement between child and parent for items that were concrete, observable and unambiguous, with poor agreement on items where a judgement was required, such as those related mood, pain or unobservable symptoms.[9,42–46] Poor agreement for judgement items may be related to the lack of stability of the instrument or the need for clarification of one’s views.[47] Eiser and Morse[9] caution that heterogeneity in the constructs of social and emotional domains across instruments makes interpretation of these results difficult. Several researchers have suggested that parents may provide valuable information on the behavioural and external context of a child’s HR-QOL while the child can contribute information on his/her emotional state.[4,41] They suggest that both perceptions taken together can enrich understanding of a child’s HR-QOL.[4,41,48]

A small number of studies compared HUI scores between children and parent proxies for a variety of chronic paediatric conditions including cancer, musculoskeletal disorders, weight

disorders and disability stemming from extreme prematurity. Agreement in overall HUI scores between parents and children ranged from not significant[11] or weak[13] to moderate.[8,12,28] With regard to specific attributes, agreement was weaker for domains related to emotion and cognition.[10,12,13,48,49] While children's HUI scores were higher than their parents in some studies,[8,11] other researchers found lower overall HUI scores[13] or lower scores for emotion and cognition in children.[12,13,48]

The symptom burden of asthma suggests that this disease is a good candidate for assessing preference-based HR-QOL. In a study by Juniper et al.[31] that administered the HUI and the PAQLQ to children with asthma aged 7 to 17 years, the correlation between the child's HUI2 and a parent-proxy PAQLQ was 0.36, very similar to the result observed for the dyad in the present study. The test-retest reliability of the child HUI2 in the Juniper et al. study[31] was greater than in the present study; however, in that study children returned twice for reassessment at intervals of 4 weeks. The shorter follow-up period and additional repeated measures would have contributed to the greater observed reliability. Like the present study, Juniper et al.[31] found that the HUI was not responsive to change over time in children with asthma. Asthma, although a chronic condition, can fluctuate widely over time. The HUI, as a generic measure, may not be sufficiently responsive for fluctuating conditions, or for paediatric conditions that are transient or temporary.[50]

## Study Limitations

A number of limitations are recognized in the present research. The lack of a gold standard for paediatric HR-QOL is a perpetual issue. The goal of this study was not to revisit the psychometric properties of the individual instruments, but rather to focus on the dyad approach and conventional methods for assessing validity, reliability and responsiveness were utilized. By overcoming some of the process challenges associated with proxy and individual child HR-QOL ascertainment, the dyad approach may result in more valid responses but the lack of a gold standard hampers a definitive answer. This study focuses on an asthma patient population, thus extrapolations to other paediatric patient populations are limited. As the patients enrolled were all referred to the asthma clinic for care, they represent a more severe sample of paediatric asthma than would be seen in the community. However, the range and Normal distribution of asthma severity in the study sample allowed for the detection of changes in HR-QOL across the severity spectrum. The study sample may also reflect a higher socioeconomic status compared with the larger population of families with children with asthma. Despite demographic differences from the overall population of children with asthma, the study, by utilizing the generic HUI and PedsQL™ Core instruments, enables comparisons with other research in asthma and in other patient populations.

One limitation relates to the response burden imposed by multiple assessments. The study was piloted to ensure that the questionnaire set was not burdensome and the follow-up assessment was limited to dyad administration only. It was found that the dyad administration took no longer than the independent administrations of these questionnaires and duration time for completion decreased at the follow-up assessment. Another challenge was the concern that parent responses would unduly influence the child's responses in the

dyad context. Training the interviewers to detect and mitigate parental coercion and the use of the standardized interview guide as a companion instrument were key strategies to minimize response bias. Another limitation was the long and variable interval between the baseline and follow-up assessments (mean 24 weeks). To maximize the sample size for a repeat assessment and reduce the risk of loss to follow-up, the child's regularly scheduled next appointment was used for the follow-up assessment rather than a protocol-driven visit. Thus the length of follow-up varied by child and during this period children continued to develop physically, emotionally and cognitively. Normal growth and maturation, as well as an increased awareness and understanding of asthma, could have induced a response shift in the child, in effect 'resetting' the child's frame of reference.[51] While the child's asthma may have remained stable according to clinical measures, other impacts on the child's QOL may have occurred during follow-up. All of these effects may have contributed to the moderate test-retest reliability. The lack of responsiveness observed for the HUI in children with asthma was also found previously.[18] The sample size for assessment of test-retest reliability and responsiveness was low and these aspects require further investigation. Finally, this study evaluated children aged 8–17 years, whereas asthma usually affects younger children. It was considered appropriate to first test the study hypotheses regarding the dyad approach in an older, more cognitively developed group.

### Future Research

This study raises important avenues for future research. A next step is to evaluate the dyad approach in children too young to be administered the HUI directly, e.g. those aged 6 to 8 years. The successful performance of the dyad HUI with younger children would be an advantage over current approaches that rely solely on a parent proxy. Dyad results should also be compared between age groups, e.g. 6–8 years, 9–11 years and 12 years and older. Other patient populations worthy of study include children with other physical, emotional, behavioural and learning conditions who experience a range of decrements in HR-QOL. It would also be important to apply this approach to a general sample of otherwise healthy children in the population to establish norms for this approach. Given the importance attributed to the standard gamble and time tradeoff approaches to the assessment of utility and the great challenges in administering them to children, it would also be useful to ascertain the value of a dyad approach to these preference-based measures of utility.

## Conclusions

In the present study, dyad administration of the HUI, PedsQL™ Core and two asthma-specific HR-QOL measures demonstrated moderate performance. Provided administration occurs with a trained interviewer and an interview guide, the dyad administration of the HUI holds promise as an improved approach to health status assessment in children compared with a parent proxy. It may allow more valid responses to be collected from children at the younger age range of the instrument's performance, i.e. 8 to 10 years. The use of the dyad HUI and PedsQL™ Core will allow the results to be directly compared with other studies and patient populations that have used these instruments. By enhancing current conceptual frameworks of paediatric HR-QOL and developing novel approaches, this study contributes

to the growing research examining utility assessment in child health. These research efforts will lead to improvements in QALY estimation and economic evaluation in child health.

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**Key points for decision makers**

- Preference-based measures of health-related quality of life (HR-QOL) that measure utility are recommended because they can be incorporated in a universal measure such as a QALY, thereby enabling comparisons of the cost effectiveness of interventions across patient populations
- HR-QOL measurement in children poses unique challenges as children's ability to respond to questionnaires depends on age, cognitive ability and the effects of disease. Parents have been found to be poor proxy reporters for many HR-QOL attributes
- This study found that in children with asthma interviewing a parent and child together as a dyad may improve the validity and reliability of the response from children or parent proxies alone
- The dyad approach to HR-QOL measurement may be a useful alternative approach, particularly for children at the lower end of a HR-QOL instrument's age limit

**Table I**

Baseline sample demographics

| Characteristic | n (%)[a] |
|---|---|
| Parent/caregiver respondent | |
| Mother | 81 (89.0) |
| Father | 10 (11.0) |
| Child's sex | |
| Male | 50 (55.0) |
| Female | 41 (45.0) |
| Child's age, y [mean (SD)] | 10.9 (2.4) |
| Child's co-morbid conditions | |
| Chronic allergies or sinus troubles | 40 (44.4) |
| Vision problems | 17 (18.9) |
| Learning problems | 10 (11.1) |
| Attention problems | 10 (10.1) |
| Behavioural problems | 7 (7.8) |
| Anxiety problems | 3 (3.3) |
| Depression | 2 (2.2) |
| Other problem affecting activity, behaviour or emotions | 16 (17.8) |
| Speech problems | 8 (8.9) |
| Sleep disturbance | 6 (6.7) |
| Chronic orthopaedic bone or joint problems | 5 (5.6) |
| Parent born in Canada | 49 (54.4) |
| Marital status | |
| Married or living common law | 72 (80.0) |
| Single, divorced, separated, widowed | 18 (20.0) |
| Parent respondent education | |
| Elementary school | 1 (1.1) |
| Some secondary/high school | 6 (6.7) |
| Completed secondary/high school | 19 (21.1) |
| Some post-secondary college or university | 11 (12.2) |
| Received university or college degree/diploma | 53 (58.9) |
| Parent respondent employment status | |
| Employed full-time | 48 (53.3) |
| Employed part-time | 27 (29.6) |
| Homemaker | 18 (20.0) |
| Receiving social assistance, disability or pension | 5 (5.5) |
| Unemployed | 1 (1.1) |
| Student | 1 (1.1) |
| Number in household | |
| Three or fewer | 20 (22.2) |
| Four | 29 (32.2) |

| Characteristic | n (%)[a] |
|---|---|
| Five | 27 (30.0) |
| Six or more | 14 (15.5) |
| Drug plan benefits | 76 (84.4) |
| Total annual household income | |
| Less than $Can40 000 | 15 (16.7) |
| $Can40 000–79 999 | 23 (25.5) |
| $Can80 000 or more | 41 (45.6) |
| Don’t know, or refused to answer | 11 (12.3) |

[a]Unless otherwise indicated.

**SD =** standard deviation.

## Table II

Disease characteristics

| Characteristic | n (%)[a] |
|---|---|
| Asthma severity classification at baseline (n = 91) | |
| Intermittent | 6 (6.6) |
| Mild persistent | 30 (33.0) |
| Moderate persistent | 41 (45.1) |
| Severe persistent | 14 (15.4) |
| Asthma medications in last wk (n = 89) | |
| ICS alone or with LA | 5 (5.6) |
| BD with ICS or BD with LA | 46 (51.7) |
| BD plus ICS plus LA | 34 (38.2) |
| Oral steroid alone or with any other asthma medication | 4 (4.5) |
| Physician baseline global asthma control assessment (n = 91) [mean (SD)] | 2.3 (1.1) |
| Number of asthma attacks since baseline[b] (n = 64) | |
| None | 28 (43.8) |
| One | 19 (29.7) |
| Two or more | 17 (26.7) |
| Number of visits to ED for urgent asthma treatment since baseline (n = 64) | |
| None | 57 (89.1) |
| One or more | 7 (11.0) |
| Number of unscheduled visits to doctor's office or walk-in clinic for urgent asthma treatment since baseline (n = 64) | |
| None | 58 (90.6) |
| One or more | 6 (9.5) |
| Number of school days missed because of asthma since baseline (n = 64) | |
| None | 36 (56.3) |
| One | 8 (12.5) |
| Two | 7 (10.9) |
| Three or more | 13 (20.3) |

[a] Unless otherwise indicated.

[b] An asthma attack is defined as the sudden worsening of symptoms that results in difficulty breathing and may require taking additional medication. It may or may not require a visit to an ED or a doctor.

**BD =** bronchodilator; **ICS =** inhaled corticosteroid; **LA =** leukotriene antagonist; **SD =** standard deviation.

## Table III

Agreement between measures [intra-class correlation coefficient (95% confidence interval)][a]

| Outcome measure | n | Solo child–solo parent | Solo child–dyad |
|---|---|---|---|
| **HUI2 attributes** | | | |
| Overall | 72 | 0.021 (−0.222, 0.262) | 0.545# (0.360, 0.689) |
| Mobility | 88 | 0.108 (−0.101, 0.308) | 0.713# (0.593, 0.802) |
| Emotion | 83 | 0.065 (−0.155, 0.278) | 0.468# (0.281, 0.621) |
| **HUI3 attributes** | | | |
| Overall | 75 | 0.169 (−0.070, 0.389) | 0.735# (0.611, 0.824) |
| Ambulation | 89 | −0.024 (−0.230, 0.185) | 0.155 (−0.052, 0.350) |
| Emotion | 86 | 0.119 (−0.095, 0.322) | 0.787# (0.690, 0.856) |
| **PedsQL™ Core** | | | |
| Summary | 90 | 0.482# (0.305, 0.626) | 0.829# (0.751, 0.885) |
| **PedsQL™ Asthma domains** | | | |
| Symptoms | 91 | 0.628# (0.486, 0.737) | 0.806# (0.696, 0.875) |
| Treatment | 91 | 0.367# (0.178, 0.531) | 0.780# (0.683, 0.851) |
| **PAQLQ domains** | | | |
| Activities | 91 | 0.544# (0.381, 0.674) | 0.815# (0.725, 0.876) |
| Emotions | 91 | 0.500# (0.328, 0.640) | 0.842# (0.733, 0.903) |

[a]Two-way mixed effects ICC coefficient model. Significance was ascertained by an F-test for difference between the observed ICC coefficient and ICC coefficient = 0.

**HUI =** Health Utilities Index; **ICC =** intra-class correlation; **PAQLQ =** Pediatric Asthma Quality of Life Questionnaire; **PedsQL™** = Pediatric Quality of Life Inventory™;

# $p < 0.0001$.

**Table IV**

Correlation between dyad Health Utilities Index and other measures[a]

| Questionnaire | Dyad HUI2 | | | Dyad HUI3 | | |
|---|---|---|---|---|---|---|
| | **Mobility** | **Emotion** | **Overall** | **Ambulation** | **Emotion** | **Overall** |
| **Dyad PedsQL™ Core** | | | | | | |
| Physical | 0.43# | NR | 0.52# | 0.25* | NR | 0.46# |
| Emotional | NR | 0.40# | 0.30** | NR | 0.17 | 0.30** |
| Social | NR | 0.35*** | 0.48# | NR | 0.20 | 0.45# |
| **Dyad PedsQL™ Asthma** | | | | | | |
| Worry | NR | 0.13 | 0.23* | NR | 0.13 | 0.14 |
| Communication | NR | 0.20 | 0.27** | NR | 0.25* | 0.24* |
| **Dyad PAQLQ** | | | | | | |
| Activities | 0.32** | NR | 0.31** | 0.02 | NR | 0.22* |
| Emotions | NR | 0.23* | 0.34*** | NR | 0.14 | 0.22* |

[a]Point estimate represented by Spearman correlation coefficient (n = 91).

**HUI** = Health Utilities Index; **NR** = not reported; **PAQLQ** = Pediatric Asthma Quality of Life Questionnaire; **PedsQL™** = Pediatric Quality of Life Inventory™;

* $p < 0.05$,

** $p < 0.01$,

*** $p < 0.001$,

# $p < 0.0001$.

## Table V

Test-retest reliability of dyad measures for clinically stable patients[a]

| Questionnaire | ICC coefficient (95% CI) |
|---|---|
| Dyad HUI2 Overall | 0.530 ** (0.192, 0.755) |
| Dyad HUI3 Overall | 0.346 * (−0.029, 0.637) |
| Dyad PedsQL™ Core summary | 0.695 # (0.352, 0.860) |
| Dyad PedsQL™ Asthma domains | |
| Symptoms | 0.841 # (0.680, 0.924) |
| Treatment | 0.513 ** (0.173, 0.742) |
| Dyad PAQLQ domains | |
| Activities | 0.751 # (0.532, 0.876) |
| Emotions | 0.764 # (0.551, 0.883) |

[a]Two-way mixed effects ICC coefficient model. The analysis was performed on subjects who remained clinically stable between baseline and follow-up (n = 28). Clinically stable was defined as no change in asthma severity classification by a physician and a change in the Asthma Control Questionnaire less than or equal to 0.5. Significance was ascertained by an F-test for difference between the observed ICC coefficient and ICC coefficient = 0.

**CI =** confidence interval; **HUI =** Health Utilities Index; **ICC =** intra-class correlation; **PAQLQ =** Pediatric Asthma Quality of Life Questionnaire; **PedsQL**™ = Pediatric Quality of Life Inventory™;

* $p < 0.05$,

** $p < 0.01$,

# $p < 0.0001$.

## Table VI

Correlation between changes in dyad measures for clinically unstable patients[a]

| Change in questionnaire response | Change in dyad HUI2 overall utility | Change in dyad HUI3 overall utility |
|---|---|---|
| Dyad HUI3 overall utility | 0.85# | NA |
| Dyad PedsQL™ Core overall score | 0.57*** | 0.44* |
| Dyad PedsQL™ Asthma symptoms | 0.45* | 0.37* |
| Dyad PedsQL™ Asthma treatment | 0.60*** | 0.40* |
| PAQLQ activities | 0.32 | 0.17 |
| Dyad PAQLQ emotion | 0.42* | 0.41* |

[a]Point estimate represented by Spearman correlation coefficient. The analysis was performed on subjects who exhibited a clinically significant change between baseline and follow-up (n = 30). Clinically significant change was defined as a change in asthma severity classification by a physician and/or a change in the Asthma Control Questionnaire greater than 0.5.

**HUI =** Health Utilities Index; **NA =** not applicable; **PAQLQ =** Pediatric Asthma Quality of Life Questionnaire; **PedsQL**™ = Pediatric Quality of Life Inventory™;

* $p < 0.05$,

*** $p < 0.001$,

# $p < 0.0001$.