

A qualitative analysis of a dyad approach to health-related quality of life measurement in children with asthma

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Abstract

The measurement of health-related quality of life (HRQOL) in children often relies on parents as proxy respondents. Yet, several studies have shown poor to moderate correlations between parent and child responses, questioning the validity of the parent as proxy. This qualitative study examined a dyad approach, where parent and child were interviewed together. The objective was to observe and describe the interaction in a dyad interview, wherein both parent and child perspectives are used and where the parent may expand the child's cognitive abilities to create a more meaningful description of the child's HRQOL. Children aged 8–15 years with a clinical diagnosis of asthma and their primary caregivers were recruited from The Hospital for Sick Children, Toronto, Canada. The dyads were administered the Health Utilities Index Mark II/III, the Pediatric Asthma Quality of Life Questionnaire and the PedsQL™ Pediatric Quality of Life Inventory. Interviews were audio-taped and a second researcher recorded observations. Consistent with Grounded Theory methodology, observations were indexed according to categories and subcategories related to the response process. Data were analysed using open, axial and selective coding and constant comparison. Saturation was achieved at 16 dyad interviews. A cultural review and reflexive role taking were included to minimize interviewer bias and enhance rigour. Findings were grouped in the following 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. The specification of these categories facilitated the creation of an interview guide to accompany the administration of standardized HRQOL questionnaires to parent–child dyads. Such a guide would facilitate discussion between parent and child and enhance the consistency of the interview process.

Keywords

Health-related quality of life; Children; Parents; Proxy; Asthma; Dyad interviews; Canada

Introduction

Health-related quality of life (HRQOL) is increasingly recognized as an important health outcome in children with a variety of conditions, including asthma. It represents the patient's

perception of four essential domains: disease state and physical symptoms, functional status, psychological functioning and social functioning (Aaronson, 1988; Ware, 1984). HRQOL has been widely recognized as an essential component of evaluations of health status, physical functioning, response to treatment and disease progression.

Critical to the measurement of HRQOL is the assessment of well-being from a patient's point of view. However, measuring HRQOL in children means relying on parents to act as proxy respondents for the very young as well as for children of all ages who are unable to meet the cognitive and communication demands of HRQOL assessment. Several studies have shown poor to moderate correlations between parent and child responses to HRQOL assessments, thereby questioning the validity of the parent proxy (Brunner et al., 2003; Eiser & Morse, 2001; Pal, 1996; Petrou, 2003; Saigal et al., 1998). Studies have shown that parents are reliable reporters for observable behaviours, such as the expression of symptoms and physical function, but less so for cognitive and emotion attributes (Petrou, 2003). This may be in part because parents' own preferences and values are incorporated into their proxy reports (Pal, 1996).

This study investigated a dyad approach, wherein parent and child are interviewed together. The dyad approach draws upon the parent's and child's attitudes, feelings, beliefs, experiences and reactions that are more likely to emerge together than in an individual context. From an interpretive research perspective, a dyad enables the observer to gain more information about the social construction of a child's reality living with asthma. By encouraging the exploration of language, consciousness and shared meanings between child and parent, the observer can learn about the context and individual perceptions that influence HRQOL among children with asthma. Furthermore, by encouraging participants to explore a given topic (Barbour & Kitzinger, 1999; Morgan & Kreuger, 1993), the dyad interview may provide a forum for parents and children to discuss and learn about asthma from each others' perspective. The dyad differs from a consensus approach in that the child's perceptions are paramount, with the parent adding their perceptions and acting as enabler and cognitive enhancer. Greater parental understanding of the social construction of their child's quality of life may also enhance parent proxy responses to structured questionnaires. The dyad interview, by bringing parent and child perspectives together and by placing the parent in the role of expanding the child's reflection and verbal expression, may create a more accurate picture of HRQOL in children with asthma. The objectives of this study were (a) to obtain a richly textured understanding of issues that impact parent-child dyad responses to standardized HRQOL assessment in children with asthma, and (b) to use the findings to build an interview guide to facilitate parent/child discussion and reporting of quality of life when administered standardized paediatric HRQOL measures.

Methods

Data collection

The study was approved by The Hospital for Sick Children Research Ethics Board. Parents provided written informed consent and children provided written assent. Children aged 8–15 with a clinical diagnosis of asthma and good understanding of English and their primary caregivers were recruited from the Hospital for Sick Children Asthma Clinic, Toronto.

Chosen by convenience sampling, parent and child dyads consented and were administered generic and disease-specific HRQOL questionnaires. Enrollment continued until saturation occurred, which was achieved at 16 dyads. Among the 16, 13 dyads included mothers and three included fathers. Two trained researchers conducted interviews with children and their primary caregivers. To respect the psychometric properties of the instruments, all the questionnaires were administered in a structured format without changes to the questions or response options. Questions were directed at the child, and parent and child were encouraged to discuss each question freely. One researcher administered the questionnaires by face-to-face interview while the second researcher independently recorded observations of the interview process. The interviews lasted an average of 25 min. Use of multiple researchers helped to minimize interviewer bias and enhance rigour. All interviews were audio-taped and transcribed verbatim, including all audible expressions.

Four questionnaires, two generic and two disease-specific, were used to assess HRQOL in children with asthma. These included the Health Utilities Index Mark II/III (HUI II/III) and the Paediatric Asthma Quality of Life Questionnaire (PAQLQ). Originally, the 87-item Child Health Questionnaire was included as a reliable and valid generic measure (Landgraf & Abetz, 1996). However, the response burden proved to be too great. Consequently the Child Health Questionnaire was replaced with the 23-item Pediatric Quality of Life Inventory Generic Core Scale (PedsQL™) and the 28-item PedsQL™ Asthma Module. Due to the replacement, the PedsQL Core Module was administered to five dyads and the PedsQL Asthma Module to four dyads. The five children who were administered the Core Module were aged 8, 9, 11, 11 and 15 years, respectively. The four children who were administered the Asthma Module were aged 8, 11, 11 and 15 years, respectively. These age distributions were consistent with the sample as a whole.

The Health Utilities Index is a generic health status and utility instrument that has been widely used in adults and children (Feeny, Torrance, & Furlong, 1996). The PAQLQ, developed by Juniper and colleagues (Juniper et al., 1996; Juniper, Guyatt, Feeny, Griffith, & Ferrie, 1997; Juniper, O'Byrne, Guyatt, Ferrie, & King, 1999) is a disease-specific HRQOL instrument for children with asthma that has been widely used in clinical trials. The PedsQL™ Core and Asthma Modules developed by Dr. James W. Varni are generic and disease-specific health status instruments, respectively that measure HRQOL in children with documented reliability and validity (Chan, Mangione-Smith, Burwinkle, Rosen, & Varni, 2005; Varni, Burwinkle, Rapoff, Kamps, & Olson, 2004; Varni, Seid, Knight, Uzark, & Szer, 2002; Varni, Seid, & Kurtin, 2001). Each questionnaire was administered to parent and child together in random order. Verbal dialogue and non-verbal (e.g. behavioural) cues that were observed between parent and child, interviewer and child, and interviewer and parent comprise the data that were analysed for the purpose of this study.

Qualitative analysis

Using grounded theory methodology, a priori categories were initially developed to identify issues that were expected to be encountered. Transcribed interviews were analysed thematically. Open, axial, selective coding and constant comparison were employed for interpreting data (Strauss & Corbin, 1990). Themes began to emerge as open coding was

conducted on the first two dyad interviews. As data collection proceeded and additional dyads were interviewed, new concepts were added when additional factors influencing dyad interaction became apparent. Newly gathered data were compared with previously collected data to develop categories. Data collection and open coding continued until new information produced little or no change to data categories, i.e. until theoretical saturation was achieved (Sandelowski, 1995). This occurred when the 16th dyad interview was completed and analysed.

Data from each interview were broken down, examined, compared, conceptualized and categorized in terms of properties and dimensions. Data were then reassembled using a coding paradigm that accounted for context, interactions between categories and outcomes. Selective coding was employed to identify the core categories that seemed to accurately describe the phenomenon of parent/child dyad interaction. Several a posteriori categories and sub-categories emerged based on observer field notes and discussions between researchers about interpretation of the findings. Frequently indicated categories and sub-categories formed a conceptual framework which was used to identify and explain parental strategies utilized during the dyad interview. The relative impact of the categories and subcategories on administration of each questionnaire was described. The framework of categories and sub-categories along with identified strategies informed the development of an interview guide to accompany the future administration of structured health-related quality of life questionnaires to parent–child dyads.

A cultural review, reflexive role-taking and field notes were included to minimize interviewer bias and enhance rigour. For the cultural review, interviewers engaged in an examination of their assumptions, biases and expectations for what would happen during the interview process. These judgments and expectations were identified and kept in check through reflexive reflection on each interview. Trustworthiness was also established using data triangulation with physicians' evaluations of asthma severity and member checking. Member checking involved (a) a debriefing with parent and child immediately following their interview and (b) discussing preliminary findings to explore the level of agreement between interviewer interpretations.

In addition to member checks, the truth value of our findings was enhanced through prolonged engagement. Data collection took place over a period of 6 months, with reflexive analysis occurring after each interview. This process involved an analysis of the interview at hand and a comparative review of previous interviews. Frequent reviews and re-assessments of emergent categories and subcategories facilitated the identification of a more complete set of dyad themes than if only one cycle of analysis had occurred.

Consistent with Lincoln and Guba's (1985, 2000) tenets of constructivist inquiry, our audit trail consisted of raw data (i.e., transcribed interviews), data reduction and analysis products (i.e., identification of themes, summaries), data reconstruction and synthesis products (i.e., clustering of themes into categories, the interview guide), process notes (i.e., field notes, decision rules), information about intentions and dispositions (i.e., the research proposal, protocol amendments), instrument development information (i.e., drafts of the interview guide).

Results

Sample characteristics

Children aged 8–15 years with a clinical diagnosis of asthma and their primary caregivers were recruited. Consistent with the outpatient population seen at the urban Asthma Clinic, the resulting sample was diverse in terms of race and ethnicity (Table 1). Three of the 16 parent respondents were immigrants, having arrived at least 1 year prior to the birth of the participant child. Most parent respondents were female (13 of 16 dyads), married with a college education. Less than half were employed full-time and the majority (62%) reported household incomes greater than \$CDN 70,000 per annum. Five of the child respondents were 11–15 years of age, with one aged 15 years, one aged 14 years, one aged 13 years and two aged 11 years. The remaining 11 were under 11 years, with five aged 10 years, two aged 9 years and four aged 8 years.

Dyad themes

Eight specific themes relating to dyad interaction were identified a priori as potentially influencing how parents and children understood health-related quality of life. These were (1) recall difficulty, (2) respondent bias, (3) interviewer bias, (4) frustration, (5) coercion/parental influence, (6) inter-relational conflict, (7) psychic discomfort for health states, and (8) emotional sensitivity. In addition, three a posteriori themes emerged during analysis: (9) parent as advocate, (10) parent as enabler and (11) comprehension. Using constant comparison, subcategories were identified from the transcripts that provided a deeper understanding of the phenomena contained within each theme. Table 2 illustrates the mapping of themes to sub-categories that was developed and analysed during axial coding.

Parents utilized a number of strategies to enable their child to answer questionnaire items as accurately as possible. They were a valuable resource in overcoming problems associated with recall, bias, frustration, anxiety and comprehension that frequently impede children's responses. Each category that arose during the interviews (does not include interviewer bias) is discussed in detail below.

Recall difficulty

The problem of recall difficulty by children was observed. Unlike adults, for whom recall difficulty relates to remembering distant events, children sometimes appeared to lack the cognitive skills required to comprehend time frames for recalling events accurately. Subcategories related to recall difficulty were recall of asthma-related events, frequency of asthma-related difficulties, severity of asthma-related difficulties and frequency of medication use. Child participants would often look to their parents to corroborate or seek validation for their answers. Parents often enhanced their child's ability to remember by providing examples of past activities as "bookmarks" in time to facilitate recall of medication use and asthma-related difficulties. Parents also assisted the child to remember instances of asthma-related difficulties by providing examples of when allergen exposures and other trigger exposures occurred. One parent used the following reference point:

Remember on the weekend, Father's Day and the stuff we did on the weekend and the end of school last week. So, that's the time frame that we're looking at.

Another parent used a particular event to help their child answer. This example is taken from the Cognition attribute of the Health Utilities Index:

Interviewer: How would you describe your ability to think and solve day-to-day problems, during the past week? Would you say that you're able to think clearly and solve problems, that you had a little difficulty, that you had some difficulty, that you had a great deal of difficulty, or that you're unable to think and solve problems?

Parent: Try to use Kim as a recent, as an example. Were you able to solve a problem between you and Kim?

Child: Sometimes.

Parent: Okay. Use that one as an example then.

By giving their child examples of events, parents enabled their children to answer questions that they were otherwise unsure about. This strategy was incorporated into the interview guide. Specifically, the interview guide encourages parents to help their child understand a question or think back to events or time periods by asking "[parent name], do you think you could help your child understand that?" This prompt was helpful in instances where the child appeared uncertain about their answer, which was indicated by hesitation, a confused look, or saying "not sure" or "don't know".

Respondent bias

In terms of respondent bias, it was observed that child participants seemed sometimes to search for the "right" answer, as though they were taking a test. This was often reflected by the statement "I don't know" or "I don't know the answer to that". Sub-categories of respondent bias were social desirability; embarrassment; lying to appear truthful or honest; lying to hide illness severity from parent; and fear of punishment. Overall, respondent bias involved instances where children answered based on what they think is socially acceptable, rather than what is actually true for them. Strategies that parents employed to help their child overcome respondent bias included the parent telling the child that there are no right or wrong answers; providing interviewers with additional information that enhances the accuracy of child responses (e.g., details of events); and reassuring their child that there are no negative consequences for their answers. When one child felt unsure about their answers and answering the interview questions, their parent reassured them by saying:

Parent: Don't tell me, tell (Interviewer's name). You're talking to (Interviewer's name), I'm just sitting here. There's no right or wrong answer. Just tell (Interviewer's name) what you think.

The interview guide adopts this strategy and includes a cue where interviewers tell the child to "remember, there are no right or wrong answers. We care about how you feel and what you think, so try to answer as honestly as possible". Another cue is "don't be afraid to tell us what you really think. No one will get upset with you".

Frustration

Frustration was observed when a child felt that the questions they were being asked were irrelevant to them. It was especially prominent when respondent burden was high in the case of numerous questionnaires. Indicators of frustration included restlessness, fidgeting, staring off, disinterest and hurriedness in their answers. Here, an effective parental strategy seemed to be offering to stop and have a break, like a recess. The interview guide therefore includes an opportunity for interviewers to offer the child a break at any time.

Coercion/parental influence

The category of coercion intersects with inter-relational conflict, as identified below. Sub-categories include strong parental opinion, overriding a child's answer and answering for their child. Coercion, as defined through field notes and interview transcripts, involved influencing or choosing a different answer for the participant child versus helping the child assert their own answer. Coercion, so defined, also intersects with the category of parent as enabler and advocate, which is described below. Non-verbal cues in the child's behaviour to the presence of coercion/parental influence included gaze aversion, fidgeting and silence. Verbal cues included verbal hesitation (e.g. repeatedly using the expression "umm"), telling their parent to stop answering for them, and changing answers to be congruent with their parent's, despite their original answer. Behaviours that parents exhibited to influence or coerce their child included denying the truth or accuracy of their child's answer with their child subsequently changing their answer to be congruent with their parent's, rushing or bullying the child to answer quickly even though they were trying to think their answer through and simply answering for them. The parent may also effectively silence their child even though the child had something to add to their answer. For example:

Child: [inaudible whispering to parent]

Parent: No, that's not what she (interviewer) is talking about, you gave her the right answer, that has nothing to do with the right answer.

Such coercion is a threat to a dyad rating of HRQOL, as the child's authentic perspective is largely omitted. Coercion did not, however, occur in every interview. It was observed in 10 of 16 interviews and its occurrence was seemingly age dependant, with participants aged 8–10 being more susceptible than participants aged 11–15. Instances of coercion were observed in six interviews of children aged 8–10 years. In one case, parent and child occasionally conversed in a language other than English, making it difficult for the interviewer to judge the essence of the interaction.

To mitigate the effects of coercion, interviewers developed a strategy to enable child participants to overcome parental coercion and encourage them to answer based on what they really think. This strategy focused on repeating and redirecting the question to the child. This redirection would include asking the child whether their answer is what they really want to say. Specific scripts that were used were, "[Child Name], given what your Mom/Dad said, and what you think, what do you think that the answer should be?" "Do you want to look at the response options again and then let me know what you want to answer?" and, "[Child Name], you can take as much time as you need". These cues served to re-emphasize to both parent and child that interviewers were interested in hearing the child's perspective.

They reassured the child that there was no rush and that they could think about what they wanted to answer. The cues also served to advise the parent indirectly against coercion.

Inter-relational conflict

The category of inter-relational conflict developed from observations of the underlying dynamic between parent and child that seemed to influence the interview process. Sub-categories include conflict avoidance, conflict aversion and laying blame. The themes of conflict aversion and avoidance can be broadly defined as the extent to which a child felt comfortable in revealing information about themselves to their parent. Conflict aversion is the set of feelings that reflects discomfort with the issue of conflict. Conflict avoidance, on the other hand, is the set of behaviours that the child exhibits in order to avert conflict altogether. Conflict avoidance may explain instances where the child participant may have tailored answers to what they thought was agreeable to their parent. Conflict avoidance and conflict aversion were observed through non-verbal and verbal cues of discomfort such as fidgeting, shifting in their seat, lack of eye contact, and hesitation. The notion of inter-relational conflict intersects with coercion and parental influence. Inter-relational dynamics describes the extent to which a parent influences or overrides their child's answers, as opposed to enabling them to answer on their own. It also intersects with respondent bias as, in some cases, the child may have answered based on what they think their parent wanted to hear in order to avoid conflict.

Interviewer: During the past week, have you been feeling happy or unhappy?

Child: [10 s hesitation] I'll have to say both.

Interviewer: You'll have to say both? Um, which would you say you feel, you felt more in the past week? Happy or unhappy?

Child: [4 s hesitation and glance over at parent] [Looking downward] Happy.

Interviewer: So would you describe yourself as having felt happy and interested in life, or somewhat happy?

Child: [5 s hesitation] Umm. [6 s hesitation] Not quite, I don't understand that.

Interviewer: Okay, I'll ask you again. In the past week, would you describe yourself as having felt happy and interested in life or somewhat happy?

Child: [Glance at parent] I would be feeling interested in life and happy.

The interview guide helps the interviewer overcome conflict aversion and avoidance behaviour by reassuring the parent and child that there are no negative consequences for their answers. It also emphasizes that there are no right or wrong answers; that the child is free to answer however they truly feel. Specific cues include "there are no right or wrong answers, just answer based on what *you* think and how *you* feel", "we really care about what you think/feel, so try to answer as honestly as possible", "Don't be afraid to tell us what you really think. No one will get upset with you". These cues help reassure the child that they could answer what they wanted to, regardless of what anyone else thought. They were appropriate for use with the categories of respondent bias, inter-relational conflict and parental coercion.

Psychic discomfort for possible past, present and future health states

Psychic discomfort for possible past, present and future health states is specific to real, perceived or anticipated limits to functional ability and to decline. Field notes and dialogue surrounding negative and positive health-related self-descriptors were analysed. Sub-categories included concerns about past health and ability; concerns about present health and ability; and concerns about future health and ability. The development of this category and relevant sub-categories was founded in dialogue where participant children, in some instances, expressed discomfort with questions surrounding their past, present and future health states. More specifically, four participant children exhibited verbal and non-verbal cues of discomfort when asked to think about future, past or present abilities and health status. Such discomfort was particularly evident when these children were asked to think about not being able to participate fully in everyday life. For example:

Interviewer: How much have you been bothered by your asthma in physical activities during the past week? Would you say extremely bothered, very bothered, quite bothered, somewhat bothered, bothered a bit, hardly bothered at all or not bothered.

Child: [5 s hesitation, looking downward, flushed] A bit bothered.

Interviewer: How much have you been bothered by your asthma in activities with friends and family, during the past week?

Child: Umm [hesitation] quite maybe, quite bothered.

Strategies that parents employed included reassuring the child that it is okay to answer based on how they feel and if they feel too uncomfortable, they don't have to answer. The interview guide adopts this strategy by validating the child's experience and reassuring them by stating that "It's okay to feel uncomfortable. Some of these questions might be hard to answer. But we want to know if something is making you uncomfortable, it helps us better understand how you think and feel about your health". This cue was developed for use when there are signs of anxiety including fidgeting, shifting, restlessness, hesitation, the child becoming very quiet, or when there are additional signs that might suggest depression, such as listlessness, indecisiveness, aggression/acting out.

Emotional sensitivity

Emotional sensitivity intersects with psychic discomfort for past, present and future health states insofar as psychic discomfort is inextricably linked with emotionally sensitive stimuli. While the previous category deals more specifically with functional health status, emotional sensitivity encompasses broader anxiety-inducing questions or settings. There were some instances where participant children exhibited sensitivities with respect to the interview process or other questions surrounding school participation, friends and family relations. Here, some participant children would exhibit behavioural signs of anxiety including fidgeting, shifting, restlessness, hesitation or becoming very quiet. One useful strategy that parents employed was reassuring their child that it's okay to answer based on how they feel and if they feel too uncomfortable, they do not have to answer. Another was positive reinforcement, as seen in the following example:

Interviewer: Overall how would you rate your health during the past week?
Excellent, very good, good, fair or poor?

Child: Good.

Interviewer: Okay.

Child: [inaudible whispering]

Parent: I know, I agree with you. I agree.

The interview guide builds on the power of positive reinforcement and validates feelings of discomfort that a child might have. As with issues surrounding past, present and future health states, the guide offers, “It’s okay to feel uncomfortable. Some of these questions might be hard to answer. But we want to know if something is making you uncomfortable, it helps us better understand how you think and feel about your health”.

Parent as advocate and parent as enabler

As constant comparison and theoretical development proceeded, the related concepts of parent as advocate and parent as enabler became apparent. Parent as advocate included sub-categories such as providing relevant information about the child to the interviewer, ensuring that the child was comfortable with the interview process and ensuring that the child’s learning and other needs were met. Parent as enabler included behaviours and strategies the parent used to aid the child. These included encouraging the child to answer based on their own feelings and perceptions; providing the child with specific examples of the past week’s events to facilitate the child’s understanding of the question; providing their child with positive feedback; translating questions into words that the parent knows the child understands; repetition and discussion and guiding their child through the questionnaire response options. Specific strategies that parents employed were encouraging the child to say if they were uncomfortable at any point; informing interviewers of the child’s learning needs, thereby alerting interviewers to difficulties that needed to be accommodated and enabling the child to answer questions; and telling their child not to look at them for the answer, but rather to answer based on their own thoughts and feelings.

Parent: Is it possible to stop the tape for a minute?

Interviewer: Sure.

Parent: ‘Cause I want to explain something about his learning and communication needs.

The interview guide includes a prompt that encourages parents to advocate on their child’s behalf. This prompt is used at the beginning of the interview and states: “To begin, we need to ask if there are any other conditions that impact on [child’s name]’s quality of life. As well, are there any special considerations that we need to make in terms of learning needs?”

Comprehension

Comprehension was an issue in many instances. Although all instruments claim to be valid for use in children as young as 8-years-old, some of the language and abstractions used in the standardized instruments were not easily understood by the children, particularly among

the 8–10 age range. Words such as “irritable” or abstract concepts such as “getting along” posed some difficulty. Subcategories of comprehension were developed and included not understanding the content of the question or statement and not understanding the meaning of a particular word. Strategies that parents employed were encouraging their child to ask questions for clarification; helping by explaining the meaning of a question, word or phrase; and encouraging their child to ask interviewers to repeat the question. The following example of where comprehension was an issue and the parent helped by defining a word for their child is taken from the administration of the HUI:

Child: What’s ‘interested’?

Parent: What’s ‘interested’? Means you care about what’s going on around you. You wanna know about what’s happening around you.

To encourage parents in helping their child understand the questions that are being asked, the interview guide includes prompts for both parent and child. Specifically, “[Child Name], do you want to ask your Mom/Dad for help?” or, “[Parent Name], can you help [Child name] understand that question?”

While some categories were observed relatively infrequently, such as psychic discomfort for past, present and future health states, frustration, coercion, emotional sensitivity and inter-relational conflict, there were others that occurred often. These included comprehension, recall difficulty, parent as enabler and respondent bias. To acknowledge the possibility of these and pre-empt their occurrence, the interview guide begins with an introductory script directed at both parent and child. It states:

To Mom or Dad & Child: Before we start the questionnaires, there are a few things we wanted to let you know.

To Child: [Child Name], there are no right or wrong answers. We want to hear all about what you really think and feel about how asthma affects your life. But, if there are times where you don’t understand or are not sure of the meaning of the question, phrase or word, or if you can’t remember what you did in the last week, we would like it if you asked Mom or Dad for their help.

To Mom or Dad: [Parent Name], while our questions are primarily directed to [child name], we want to hear from you as well. If there are instances where you think you might be able to assist your child because s/he doesn’t understand or is unsure of the meaning of a question, we would like it if you helped clarify things for them. This might include providing examples of last week’s events, their description, any use of medications, exposure to allergens and other triggers, and providing definitions or repeating questions.

An overarching finding among all categories was that their occurrence depended upon the child’s age. Children under the age of 10 were more likely to have problems with recall and comprehension than children aged 10–15 years. They were also more prone to being coerced or influenced by their parent. Parent participation in the interview (i.e. providing information and helping their child) did not seem to vary according to age. Irrespective of the child’s age, parents were largely willing participants. For those parents who were less involved,

their participation seemed to be a function of the pre-existing dynamic between parent and child. While mothers and fathers may have different concerns regarding their child's health as well as varying degrees of knowledge of events in their child's life, gender differences in parents' level of concern, type of concern or in the awareness of events were not apparent in this study.

Questionnaire analysis

The phenomena described in each of the categories were observed in all three HRQOL instruments. For each questionnaire, the frequency of occurrence of these phenomena depended on the type of domains present and the number of items within each domain. The observations for each of the HUI, PAQLQ and PedsQLTM are described below.

Health Utilities Index Mark II/III

The most significant categories that emerged were parent as enabler and comprehension. These two categories were closely related and interwoven. Difficulty with comprehension showed itself in more than one way. Sometimes children would report not understanding, but often parents would intuitively know their child might have difficulty or would interpret their child's non-verbal cues expressed in the form of body language and eye contact. Children's difficulties with comprehension were with the meanings of questions and statements, as well as with words and sometimes with response options. As a result, parents offered several strategies that enabled their child to report on their HRQOL from their own perspective. The following sub-categories of Parent as an Enabler were apparent for the HUI: (d) interpreting question/statement for child in words the child understands, (e) repeating question and (f) discussing and negotiating answer with child. Sometimes all three strategies were used for the same question. Items pertaining to the attribute of Emotion, followed by Cognition, appeared to most frequently evoke strategies by parents that enabled their child to answer. Items pertaining to the attribute of Emotion were also the most significant for the category of comprehension. Although one cannot be certain that these children always need help, it did appear that parents were able to anticipate the possibility and provided the appropriate strategies.

Pediatric Asthma Quality of Life Questionnaire

The two main categories that emerged from the analysis were parent as enabler and coercion/parental influence. As described above for the HUI, the category of parent as enabler includes sub-categories that describe strategies that parents used to help their child report on HRQOL. The following strategies were demonstrated by parents during PAQLQ administration: (d) interpreting question/statement for child in words the child understands, (e) repeating question and (f) discussing and negotiating answer with child. Discussing and negotiating the answer often involved a dialogue between parent and child. Such strategies were utilized for some of the activities domain questions, as well as the emotions domain. These strategies were used together. The second category that was observed with the PAQLQ was coercion/parental influence. Some questions in the activities and symptoms domains displayed the following sub-categories: (a) strong parental opinion, and (c) answering for child. This informed the interviewers that sometimes children and parents may not share the same perspective and that parents have the power to influence their child's

responses. To mitigate these effects, interviewers repeated questions for the child and, similarly to parents, tried to clarify what the child's final response was. In the interview guide, to handle parental influence, the interviewer is directed to repeat and/or redirect the question and probe the child to answer on their own:

To Child: [Child Name], Do you want to look at the response options again and then let me know what you want to answer?

or

To Child: [Child Name], given what your Mom/Dad said, and what you think, what do you think the answer should be?

PedsQL™ quality of life inventory

Limited experience with the PedsQL™ Core Scales revealed the relevance of three categories for the administration of this questionnaire: recall difficulty, especially sub-category (a) recall of events, parent as enabler, especially sub-category (f) discussing and negotiating answer with child, and comprehension, especially the sub-category (b) difficulty understanding the meaning of a question or statement.

For the PedsQL™ Asthma Module, the three most prominent categories and their corresponding sub-categories were recall difficulty (a) recall of events; parent as enabler (d) interpreting question/statement for child in words the child understands; and comprehension (b) difficulty understanding the meaning of a question or statement.

In summary, the most prevalent categories to emerge throughout the questionnaires that were administered were recall difficulty, parent as enabler and comprehension. Domains related to emotion within the HUI and the PAQLQ appeared to be the most sensitive, and required parental strategies most frequently. This was often a response to children's difficulties understanding the meaning of questions about their emotions. Recall difficulty appeared in different domains in the various instruments. The interview guide includes an appendix that outlines the observations pertaining to specific instruments and directs the interviewer regarding how to handle specific issues by providing cues and statements appropriate for use during dyad administration.

Discussion

A dyad approach provides children with access to their parent as an important information resource, as an enabler and as an extension of the child's cognitive skills. Parents used a number of strategies to enable their child to answer questionnaire items as accurately as possible. Specifically, parents were a valuable resource in overcoming problems associated with inaccurate recall, respondent bias, frustration, discomfort, anxiety and comprehension. This resource role was characterized by encouragement, advocacy, providing positive feedback, giving examples of past events, supplying definitions and ensuring a comfortable environment for their child. In some interviews, however, the opposite was true. Coercion and inter-relational conflict occurred in some dyads, as evidenced through verbal and non-verbal cues.

Consistent with the notion that the meaning of children's answers to questions about their own health status changes as a function of their experiences and developmental levels (Korfmacher, 2003; Riley, 2004), recall and comprehension problems were dependant upon the child's age, with problems arising predominantly among children 10 years and younger. Children are not usually the best possible reporters for medical history information or the timing of past events (Riley, 2004), while parents' reports of medical conditions (Daly, Lindgren & Giebink, 1994; Pless & Pless, 1995) and use of health services by children (Canino et al., 2002) are reasonably accurate. The age dependency of recall and comprehension suggests that the dyad interview may be more helpful among younger children where limited recall and comprehension abilities preclude them from completing the questionnaire alone.

Few studies have compared the parent's and child's assessment of HRQOL. However, studies in child psychology that compared parent and child reports obtained separately have found low to moderate agreement between child and parent in reports of relationships at home, at school and with peers, somatic symptoms, psychiatric problems and school performance (Herjanic, Herjanic, Brown & Wheatt, 1975; Herjanic & Reich, 1997), ratings of incidence, severity and duration of depression (Kashani, Orvaschel, Burk & Reid, 1985; Kazdin, French, Unis & Esveltd-Dawson, 1983) and psychotic symptoms and affective disturbances (Edelbrock, Costello, Dulcan, Conover & Kala, 1986). In general, these researchers found good agreement between child and parent for items that were concrete, observable and unambiguous, with poor agreement on items where a judgment was required. Jacobson and Fried (1998) suggest that parents may provide valuable information on the behavioural and external context of a child's HRQOL while the child can contribute information on his/her emotional state (Jacobson & Fried, 1998). They suggest that both perceptions taken together can enrich understanding of a child's HRQOL.

Study data describing the parent-child dyad interaction have resulted in the hypothesis that the dyad may be more likely to capture multi-factorial aspects of paediatric HRQOL than independent, structured assessments of parent or child alone. By bringing parent and child together, the dyad provides a forum for discussion and elaboration of perceptions of HRQOL. Through skilled interviewer facilitation, parent and child may learn from each other's judgments and the child may be enabled to provide more reliable responses to structured HRQOL questionnaire items.

A number of study limitations were present. Culture, race and income influence how parents and children perceive health and health status. The study sample was limited in terms of cultural, racial and socio-economic representation. There were no Asian participants and non-Canadian participants were small in number. As such, the generalization of the dyad approach to paediatric HRQOL measurement needs further assessment. Perhaps the biggest limitation of the dyad approach is the potential for coercion and parental influence over a child's answers. The interview guide helps mitigate this effect by providing interviewers with cues to redirect the question to the child and reassure them that we are interested in how *they* want to answer.

Another limitation to the findings of this study is the wide age range of child participants. Children aged 8–10 years had more difficulty understanding some of the questionnaire items and were generally more susceptible to recall and comprehension difficulties and coercion. Children 11–15 had overall less difficulty in understanding questionnaire items, were less susceptible to coercive parental influence and required little help from their parent. As such, the interview guide may have more applicability to children under the age of 11. As a first investigation into this question, no children younger than the lowest age limit recommended for the questionnaires were enrolled. Future research must test the dyad approach in younger children. This may serve to extend the applicability of these HRQOL questionnaires.

In addition to HRQOL assessment, further study is indicated to determine the value of the dyad approach in more common clinical scenarios. The need to rely on parent proxies for obtaining information on children's health is a recognized challenge in everyday healthcare practice. Practitioners require guidance on how to interpret the interaction between parent and child and how to make the most of contributions from both parent and child. Studies of the value of patient communication and process utility (Salkeld, 1998) need to be expanded to consider the parent–child–practitioner interface. A general interview guide may have value for facilitating discussions of health matters of children with a wide variety of conditions in diverse healthcare settings.

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Table 1

Participant demographics

Characteristic	<i>n</i>	%
Sex of child		
Male	9	56
Female	7	44
Age of child		
8–10	11	69
11–15	5	31
Mean, standard deviation	10.7, 2.2	
Primary ethnic affiliation		
Hindu	1	6
Mennonite	1	6
Mohawk	1	6
West Indian	1	6
English	1	6
Canadian	11	69
Language at home		
English	15	94
Hindi	1	6
Parent born in Canada		
Yes	13	81
No	3	19
Marital status		
Married/common law	13	81
Single	1	6
Widow or widower	1	6
Separated or divorced	1	6
Parent education		
Completed secondary/high school	2	13
Some post-secondary	1	6
Completed university or college	13	81
Parent occupation		
Full-time employed	7	44
Part-time employed	5	31
Homemaker	2	13
Disability pensioner	1	6
Unemployed	1	6
Household income (\$CDN)		
\$10,000–14,999	1	6
\$30,000–39,999	3	19
\$50,000–59,999	1	6

Characteristic	<i>n</i>	%
\$70,000–79,999	1	6
\$80,000 or more	9	56
Do not know	1	6

Table 2

Category	Sub-category
1. Recall difficulty	<ul style="list-style-type: none"> a. Recall of events b. Recall of frequency of asthma-related difficulties c. Recall of severity of asthma-related difficulties d. Recall of frequency of medication use
2. Respondent bias	<ul style="list-style-type: none"> a. Social desirability b. Embarrassment c. Lying to appear truthful or honest d. Lying to hide illness severity from parent e. Fear of punishment
3. Interviewer bias	<ul style="list-style-type: none"> a. Cultural bias b. A priori expectations/hypotheses c. Judgment
4. Frustration	<ul style="list-style-type: none"> a. Irrelevant questions b. Respondent burden
5. Coercion/parental influence	<ul style="list-style-type: none"> a. Strong parental opinion b. Overriding child's answers c. Answering for child
6. Inter-relational conflict	<ul style="list-style-type: none"> a. Conflict avoidance b. Conflict aversion c. Laying blame
7. Psychic discomfort for health states	<ul style="list-style-type: none"> a. Concerns about past, present and future health and ability
8. Emotional sensitivity	<ul style="list-style-type: none"> a. Anxiety induction b. Physical burden of illness c. Psychological burden of illness
9. Parent as advocate	<ul style="list-style-type: none"> a. Providing interviewer with additional relevant information about child b. Checking with child to ensure comfort with the interview process
10. Parent as enabler	<ul style="list-style-type: none"> a. Ensuring child's learning and other needs are met by disclosing them to interviewer b. Encouraging child to answer based on their own feelings and perceptions c. Providing child with examples of past events and activities to enable them to answer standardized questions d. Providing child with positive feed back e. Interpreting question/statement for child in words the child understands f. Repeating question g. Discussing and negotiating answer with child h. Providing child with examples that help put the question into context

Category	Sub-category	
11. Comprehension	a.	Difficulty understanding the meaning of a particular word
	b.	Difficulty understanding the meaning of a question or statement