

Assessment of health status and quality of life outcomes for children with asthma

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Increasing interest has been directed to understanding health outcomes associated with pediatric disease processes, including asthma. Salient areas of interest to health outcomes research include the child's and parent's subjective experience with the disease, a concept most often identified as quality of life. Quality of life reports fit within a broader scope of outcome measures embodied in the concept of children's health status. This article provides a description for how a child's health status can be understood theoretically, from a research perspective and in clinical practice. Emphasis is directed to how information obtained from both the child and parent is critical to outcomes research and clinical practice. Unique methodologic problems in assessing child health outcomes such as the challenge of understanding how the child's changing cognitive development may have an impact on responses to outcome measures and the role of contextual variables such as family characteristics are discussed. A variety of subjective and objective outcome measures currently exist that may be used in research on children with asthma. Practical guidelines for implementing outcomes research for children with asthma are presented. Clinical researchers must use multiple outcome measures for assessing asthma characteristics, including psychosocial characteristics, which have an impact on adherence and treatment regimens. (*J Allergy Clin Immunol* 2001;107: S473-81.)

Key words: Asthma management behaviors, health outcomes, quality of life

Increasing interest has been directed to understanding health outcomes associated with children's disease processes, including asthma. One of the most salient areas of interest to health outcomes research is the child's and parent's subjective experience with the disease, most often identified as quality of life. With a complex disease such as asthma, the impact of treatment on quality of life becomes important in shaping therapies used in managing the disease. Developmental and research problems arise in the assessment of health outcomes in pediatric asthma, including quality of life. This article will identify and present the major methodologic issues related to

Abbreviations used

CAQ: Childhood Asthma Questionnaire

PAQLQ: Pediatric Asthma Quality of Life Questionnaire

the assessment of health outcomes in young children. In addition, specific methods used in outcomes research will be described. It is important to recognize that measuring health outcomes in children is distinct from tracking self-reported health behaviors over time, such as daily diary cards completed by children or parents.^{1,2} The distinction between measuring health outcomes and self-reported health behaviors is principally the frequency of the measurement, self-report data being gathered more frequently than health outcomes data.

HEALTH STATUS OUTCOMES: A CONCEPTUAL MODEL

To assess quality of life outcomes, it is necessary to place the research concerns within a model of understanding health outcomes. The pediatric health status outcomes model³ provides a comprehensive model that can assess the consequences of chronic childhood illnesses and be adapted to the study of pediatric asthma. Although quality of life outcomes were not specifically addressed within this framework, this model has been adapted to include quality of life measurement (Fig 1). In addition, this model has significant clinical relevance to outcomes research in that it allows for the multiple influences affecting treatment adherence to be examined, resulting in interventions that address and modify the sources of different health status conditions. Also within this model, quality of life measures capture a patient's subjective experiences with asthma, as expressed in the parent's and child's subjective experiences with symptoms, functional capabilities such as activity limitations, and emotional experiences related to asthma.

The current adaptation of pediatric health status outcomes comprises 2 underlying principles. The first of these is that health outcomes research with children must include perceptions of symptoms by both parent and child and their perspectives of functional capabilities and psychologic characteristics (eg, family functioning) so that such perceptions can be targeted to meaningful treatment interventions. Parent and child perceptions of illness are not precisely correlated⁴ and thus merit separate attention. The perceptions and psychologic characteris-

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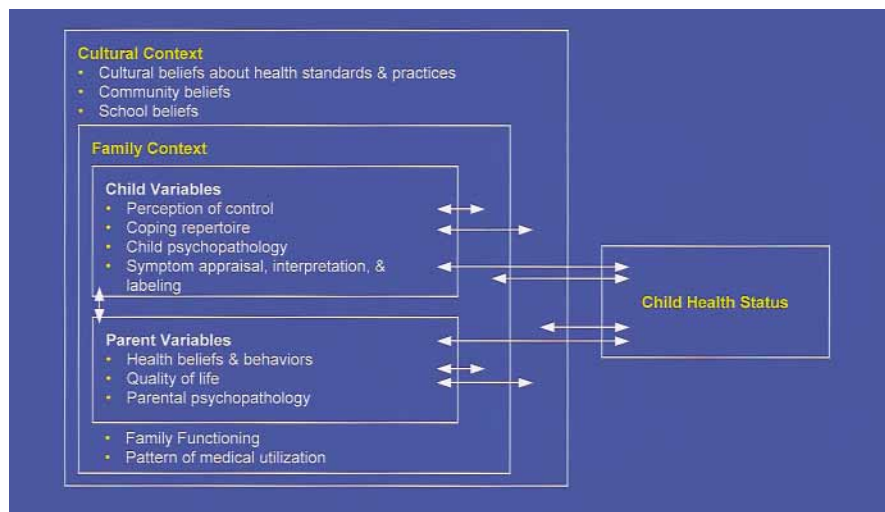


FIG 1. Pediatric health status outcomes.

tics of both parent and child also must be assessed so that the context of symptom appraisal can be understood and directed toward treatment interventions. No single measure of these variables can competently measure the impact of the illness for the child and family.

A second major principle of this model is that potentially severe and deadly consequences of ineffective symptom appraisal can occur. These consequences include inadequate treatment, additional family burden, and poor adherence. In the case of pediatric asthma, ineffective symptom appraisal can result in an increased number of missed school days, decreased job productivity for parents, increased family stress, increased use of health care services, and increased mortality.

Fig 1 presents the adaptation of pediatric health status outcomes that are used within our Pediatric Pulmonary Center. Specific domains within this model merit explanation because they provide insight into what measures may capture the relevant concepts of health status. Our model targets 4 child variables including the child's perceptions of control, coping repertoire, the presence of child psychopathology, and symptom appraisal, interpretation, and labeling. It is this last concept that merits discussion within this presentation because it most directly pertains to research in quality of life outcomes.

Symptom appraisal has proven to be a challenge in pediatric asthma research because children, especially younger children, may not be as aware of asthma symptoms as older children or adults, or they may have symptoms only in association with behavioral markers (eg, fatigue and irritability). Parents (or the child) may then not understand these behavioral markers as asthma-related symptoms. In fact, children may not be aware of asthma symptoms because they are intermittent, and a child may not be taught how to recognize them.⁵ Severity or chronicity of illness,⁶ psychologic variables such as denial or defensive style,⁷ parent-child variables,⁸ and intelligence may affect appraisal and interpretation of

symptoms.⁹ These challenges become particularly salient with younger children, because they may have greater difficulty detecting differences in resistive load than older children.¹⁰ Psychologic characteristics of the child, particularly the presence of childhood psychopathologic conditions, also influence the process of symptom appraisal and labeling.⁶ When younger children are the subjects of study, it is not at all uncommon to find that psychologic and asthma symptoms may be intimately intertwined in the child's understanding of the illness, resulting in a confusing picture where anxiety symptoms and asthma symptoms may be inseparable. A well-recognized clinical finding is that children with poorer psychologic adjustment are at risk for difficulties with asthma symptom appraisal and interpretation, although little empirical data supports this idea.¹¹

Intelligence may influence symptom appraisal and quality of life. In a small group of 8- to 15-year-old-children, overusers of β -agonist metered-dose inhalers scored lower than patients in a control group on the measure of intelligence.⁹ Overusers had a mean IQ of 84 versus the control group IQ of 99, indicating that overusers were approximately 1 SD below the normative data, whereas the members of the control group were within the normal range of intelligence. A similar finding indicating a relationship between intelligence and symptom appraisal has been found by other investigators.¹²

Quality of life is included in the list of variables in Fig 1 to help in understanding the influence parents play in educating children about symptom appraisal and interpretation. In our conceptualization of health status outcomes, parents have a primary responsibility for socializing and educating the child about asthma symptoms, and within this context, it is the parents' health beliefs and their interpretation of their child's symptoms that contribute to their reported quality of life. In fact, the perception of asthma symptoms and the burden of the illness as experienced by the parent possibly contribute to both

health behaviors (such as taking the child to the pediatrician's office when an exacerbation of symptoms is recognized) and the child's quality of life as perceived by the parent. Studies to date have recognized a variety of ineffective asthma management behaviors that may contribute directly to reduced parent-reported quality of life.¹³ Such behaviors include the parent failing to prevent asthma symptoms, failure to manage the child's asthma symptoms appropriately, ineffective use of medical resources, poor communication among the adults responsible for management of the child's asthma, and psychosocial stresses within the family.

Another element that increases the understanding of health status outcomes in childhood asthma is the acknowledgment that genetic and biologic factors play an important role in the expression of diseases such as asthma. A biologic predisposition to asthma may result from exposure to severe viral illness in early childhood,¹⁴ and there is a strong genetic component to allergies and asthma.¹⁵ These issues are not discussed within the scope of this article, but it is important to recognize that both biologic and psychologic components affect the management of pediatric asthma. The emphasis of research must be directed simultaneously at these biologic and psychologic variables influencing health status.

Health status outcomes are the end product of the variables previously identified and include changes in perception of symptoms, control of disease, improved adherence, and overall improvement in subjective quality of life identified by asthmatic children and their parents. Our model represents the integration of clinical research and practice, directing research findings to practical applications for improving the health status of the child with asthma. Bidirectional effects of the variables are identified in Fig 1; changes in health status outcomes can also affect child and parent variables. Changes occurring in the child's health status can have a direct effect on the family context, such as a decreased burden of the illness and improved family adjustment.

METHODOLOGIC CONCERNS WITH YOUNGER CHILDREN

Unique methodologic problems in assessing health outcomes occur when the child's experiences with illness are a focus of study. The child's changing cognitive development is thought to have an impact on his or her responses to quality of life measures. Rapid changes in cognitive development are most dramatic from birth to school age, making this a challenging time for directly assessing the child's experiences with asthma and perceptions of quality of life. In studying populations of preschool-aged children, researchers have developed different scales to assess younger and older children. For example, in the Rand Health Insurance Study,¹⁶ different scales were developed to assess the functional status of children under and over age 5 years. Likewise, quality of life researchers have also recognized developmental differences among children.¹⁷

Child cognitions about illness also change during this period of development. Younger children tend to conceptualize symptoms as static characteristics, not realizing that their health could improve with time.¹⁸⁻²⁰ As a child's cognitive development progresses into middle childhood (school age), she or he develops an increased ability to interpret physiologic cues as indicators of illness or well-being.²¹ In addition, the acquisition of increasingly sophisticated language skills during the preschool years plays an important role in a child's capabilities for symptom rating and ability to express feelings associated with his or her illness.

Accurate and reliable reporting of asthma symptoms and quality of life is challenging to accomplish with children because of difficulties in their ability to accurately recall this information during the time intervals typically used (eg, 1 to 2 weeks). Contextual factors, such as the parent's presence when the child is questioned, are also likely to contribute to what the child can recall. One way to promote a clear understanding of the child's perceptions of asthma symptoms and quality of life is to use a trained interviewer. Understanding the role of the interviewer contributes to how well the child responds to questions, particularly those about quality of life. Children, and particularly younger children, may be influenced by previous experiences with adults and attempt to respond in a manner they feel will please the interviewer. The child thereby assumes a "response set," which could affect findings, because responses may not accurately reflect past behaviors or symptoms over the time frame of interest.²² A response set develops for many children when they are required to complete a measure that consistently uses the same scaling system. This is typically seen when a child's initial response is then repeatedly used throughout remaining items. In the case of the child seeking to please an adult interviewer, extreme responses may be provided throughout the measure. Techniques for minimizing this problem include using different measures or scales to ascertain the child's perceptions to selected items, using a trained interviewer who employs minimal cues in administering the measure to the child, and avoiding lengthy measures.

In health status measures that assess disease characteristics, questions about symptom perception may be influenced by several important neuropsychologic factors.²³ Perhaps foremost of these is the child's awareness of sensory information associated with symptoms. Clinical experience indicates that the sensory threshold for changes in forced expiratory volume in 1 second is probably quite different in younger and older children, although little research has systematically examined these differences.²⁴

Sensory awareness and registration are intimately linked to attention and the capabilities of memory. The cognitive development of preschool-aged children is typically characterized as "preoperational,"²⁵ meaning that their problem-solving processes are not well organized and their memory processes may not conform to adult logic. Thus their attention may not be directed clearly at

asthma symptoms unless there are persistent efforts on the part of the parents to socialize and educate the child about symptom expression. Children's ability to recall symptoms and impressions of quality of life accurately is time- and experience-limited, meaning that events occurring in the time directly before clinical examination are perhaps most salient to younger children, whereas the parents are probably best at reporting patterns of symptoms over time. This has proven to be true with other aspects of child symptom reporting where children have been found to be accurate reporters of their state and parents more accurate reporters of behavior over an extended time frame.²⁶ With children in the preoperational stage of neurocognitive development, the child may also have difficulty distinguishing between emotional and physical symptoms. If the parent is aware of asthma symptoms, the child's perception of asthma symptoms will be modified. Yet, where the parent may not be closely attuned, anxiety symptoms (eg, chest tightness, difficulty breathing) and asthma symptoms may be confused, with the result that these can influence the child's motivation to respond to symptoms and influence the parental expression of concern with symptoms. In some instances, adaptive anxiety may increase vigilance and enhance motivation to seek treatment.

SPECIFIC METHODS

The 2 most common methods currently used in health status outcomes research are the "absolute health status" and "change in health status" outcomes procedures. When absolute health status is measured, a variety of outcome measures are used. Given the conceptualization of health status outcomes previously described, research procedures typically use a battery of outcome questionnaires assessing the domains of influence proposed to interact with disease characteristics, including symptom control. Multivariate statistical procedures that examine causal relationships among variables are then used to examine multiple contributing influences to the health status variable(s) of interest. Researchers using a change model of health status outcomes typically use an approach where a single measure is used at different points in time and "change scores" are examined for their clinical meaningfulness.²⁷ Within this procedure, participants in the research study are used as their own controls. Both modeling procedures provide useful and different types of information to researchers, although this topic has been discussed more completely in other publications.²⁸

Several important principles are suggested when health status outcome methods for pediatric asthma research and clinical practice are being developed:

1. The use of psychometrically sound measures is important for drawing valid and meaningful conclusions. That is, measures with proven reliability and validity are critical when change in health status is assessed over time. When questionnaires are being used, reliability data for the age group of children being studied are critical to understanding the meaning of change.
2. Complex problems such as pediatric asthma require multiple outcome measures. These measures should be selected based on research hypotheses for the aims of the study and with respect for participant and staff burden. A battery of questionnaires for parents and children is preferable to a single outcome questionnaire, particularly when the battery is used in a change in health status research model.³⁰
3. It is important to include both subjective and objective measures within health status outcomes research. Subjective measures include the participant's experience with asthma symptoms, coping, quality of life, and burden of the illness associated with asthma. Objective measures are ones where normative data exist and can include measures of social competence, frequency of physical activity, and psychosocial adjustment.
4. When outcomes with children are assessed, and especially when subjective experiences with asthma symptom management and control are assessed, it is imperative that questions about these issues be addressed separately with the child and parent so that undue influence on the child is minimized. Asthma-related research indicates the parents and children have different perspectives on asthma.³¹ It is also strongly recommended that these procedures occur before other objective measurements of disease status are obtained. For example, measurement of subjective experience with asthma should take place before the child completes spirometry or methacholine challenge testing.
5. The time interval for assessing health status variables becomes an important consideration when outcome measures are selected. For example, quality of life scores examined within the context of brief intervals may change as a result of repeated measurement rather than as an indicator of change, an issue that has been addressed in other publications.³² When children are respondents, change may occur as a function of neurocognitive development in concert with changes in symptoms and asthma management. Separating these factors can prove to be challenging, although the inclusion of objective measures such as norm-referenced measures with known reliability over time can be helpful.
6. In a clinical setting the use of a norm-referenced behavioral questionnaire can help promote practitioner awareness of behavioral and emotional difficulties that may contribute to adherence with a treatment regimen. Completion of such a questionnaire

The same can be said for parent-completed measures. Without information about the reliability of the measure, change scores may prove to be uninterpretable because findings may be confounded by regression to an unknown mean. In addition, measures with known psychometric properties will have been normed with populations where there has been a systematic stratification of sampling and other procedures to ensure that the statistical integrity of the measure has been instituted during its development.²⁹

before the child's clinical examination can allow the practitioner to determine whether additional time and effort must be directed to counseling strategies targeted at adherence or the need to involve behavioral specialists in the management of the child's asthma.

MEASUREMENT STRATEGIES WITH CHILDREN AND THEIR PARENTS

A variety of subjective and objective measures currently exists that may be used in research on children with asthma. Critical for each of these measures is (1) their ability to provide critical information about variables that may mediate the control of asthma symptoms and (2) how the measure can explain differences in health outcomes, an issue that has not been widely addressed in the research literature. Each of the measures described, however, offers a unique perspective for outcomes research and, in the case of the initial set of measures presented, may be administered to children by a trained examiner.

When research is being conducted with very young children, such as those 4 to 7 years of age, few measures are available for obtaining comprehensive information directly from the child. With young children, investigators also need to rely on reports from the parent about symptoms, quality of life, and child psychosocial functioning. This is not to say that a child's perceptions cannot be measured, but a child's perceptions of illness and quality of life are likely to be associated with different predictor variables than the perceptions of parents.

From the perspective of the health status outcomes model previously described, the following provides a brief overview of measures that can be used within the domains of interest, beginning with those measures that may be completed by children. The list of measures presented is not intended to be all-inclusive but rather represents a sample of how each domain within the health status model can be examined. A summary of the measurement characteristics is presented in Table I.

Pediatric Asthma Quality of Life Questionnaire

This 28-item disease-specific questionnaire is designed for children age 7 years and older who have asthma. The Pediatric Asthma Quality of Life Questionnaire (PAQLQ) was derived from a quality of life questionnaire for adults with asthma and can be self-administered or administered by a trained interviewer.³³ The first 3 items require children to identify activities that they believe have been affected by their asthma in the past week. They are then asked how much they have been "bothered" or how "often" an asthma symptom (eg, wheezing) has occurred in the past week with the use of a 7-point categorical scale (ie, "extremely bothered" to "not bothered"). The PAQLQ includes a total score and 3 primary domains: how asthma interferes with activities (4 questions), asthma symptoms (15 questions), and emotional reactions to asthma (9 questions). Reliability and concurrent validity for the PAQLQ have been reported.³⁴

Childhood Asthma Questionnaire

The Childhood Asthma Questionnaire (CAQ) measure has been developed with 3 age groups of children (Form A: ages 4 to 7 years; Form B: ages 8 to 11 years; Form C: ages 12 to 16 years) and uses both simple categorical responses (eg, "Yes" or "No") and ordinal categorical scales with "smiley faces" to assess children's perceptions of asthma symptoms and functional capabilities.¹⁷ It is important to note that the CAQ includes questions about general activities (eg, "How do you feel about going to the swimming pool?") and asthma-related items (eg, "How much have you been waking up at night with your asthma?") that would allow for comparisons with children without asthma. Statistical analyses have examined the CAQ's reliability, with findings indicating greater reliability coefficients for symptom items in contrast to questions asking about activities.³⁵

Brown Visual Analogue Scale

Unique to the Brown Visual Analogue Scale is its use of a visual analog scale to report on the global rating of selected asthma symptoms, specifically coughing, wheezing, and shortness of breath. The authors found that by using a visual analog scale anchored with pictures above the line, there was an increase in the range of symptom severity reported by children aged 9 to 14 years. The use of a visual analog scale is believed to provide a glimpse of the child's "gut feeling" about these aspects of asthma that is hypothesized to result in asthma self-management actions or inaction.²² These authors have also reported sex-related differences in studies with children, with girls reporting more asthma symptoms than boys.³⁶

KidCope

Although not a measure specific to childhood asthma, this instrument has been developed to examine coping strategies in children older than 7 years with a chronic illness.³⁷ Younger children use a 15-item version where they are asked to either (1) describe a problem that has occurred during the past month or (2) read a "standard problem" related to their illness and developed by the research team. Children are then asked to identify whether they used a particular coping strategy in the situation, and if so, they are asked to rate the extent to which their strategy helped. Domains of coping that have been identified include coping with common problems, coping with hospital problems, and coping with a chronic illness.³⁸

Revised Children's Manifest Anxiety Scale

The Revised Children's Manifest Anxiety Scale is a 37-item questionnaire where children aged 6 to 19 years respond to a simple statement (eg, "I get mad easily.") in a true-false format. Normative data are available for all of these age groups and include separate information for boys and girls and for different ethnic populations. Dimensions of anxiety encompassed by the measure

TABLE I. Summary of outcome measures characteristics

Measure	Type of measure	Age range	Length	Reliability/ validity source	Strength	Weakness
PAQLQ	Subjective	7-17 years	28 items	Juniper 1996	Quality of life domains identified	Unknown statistical structure of the questionnaire
CAQ	Subjective	4-16 years	14-41 items depending on age of child	French 1994	Items ask about general activities and asthma-related activities	Small correlation with asthma severity; modest correlation with night awakening
B-VAS	Subjective	8-15 years	3 items	Unknown	Uses VAS to assess coughing, wheezing, shortness of breath	Unknown statistical properties
KidCope	Subjective	Over 7 years	10 items	Spirito 1988	Measure of child-reported coping	Untested in children with asthma
RCMAS	Norm-referenced	6-19 years	37 items	Reynolds 1985	Measure of child-reported anxiety including a measure of social conformity	Weak statistical support for 3 subscales
CBCL	Norm-referenced	4-18 years	8 social competence items; 113 behavior problem items	Achenbach 1991	Large national representation in normative data	Limited evaluation of social competence
PARS-III	Norm-referenced	5-18 years	28 items	Stein 1990; Walker 1990	Developed to assess psychosocial adjustment of children with chronic illness; large number of children with respiratory diseases included in development	Normative data not nationally representative
C-PAQLQ	Subjective	7-17 years	13 items	Juniper 1996	Parent report of child quality of life	Unknown statistical structure of the questionnaire
CAQ	Subjective	????	6 items	Christie 1993	Parent report on school days missed, nighttime awakenings, asthma severity, control of symptoms, effect of asthma on family functioning	Little available information on the statistical properties of these items
BSI	Norm-referenced	13-Adult	53 items	Derogatis 1993	Self-report symptom inventory and global indices of distress	Limited national norms for both adolescents and adults
PSS	Subjective	Adults	14 items	Cohen 1991	Measure of stress that has been related to health outcomes	Unknown statistical properties
FRI	Norm-referenced	Adults	30 items	Moos 1981	Brief measure of family functioning	Small scope of family characteristics assessed
FAD	Norm-referenced	Adults	60 items	Epstein 1983; Kabacoff 1990	Evaluation of current family functioning	Limited normative information; scales highly correlated with each other
TAS-PV	Subjective	Adults/teens	7 items	Gavin 1999	Evaluates parent and teen sense of shared treatment goals	Relatively new measure

PAQLQ, Pediatric Asthma Quality of Life Questionnaire; CAQ, Childhood Asthma Questionnaire; B-VAS, Brown Visual Analogue Scale; RCMAS, Revised Children's Manifest Anxiety Scale; CBCL, Child Behavior Checklist; PARS-III, Personal Adjustment and Role Skills Scale; C-PAQLQ, Caregiver's Pediatric Asthma Quality of Life Questionnaire; BSI, Brief Symptom Inventory; PSS, Perceived Stress Scale; FRI, Family Relations Inventory; FAD, Family Assessment Device; TAS-PV, Treatment Alliance Scale, Parent Version.

include physiological anxiety, worry and oversensitivity, and social concerns and concentration. In addition, there is a measure of social conformity that may be useful to researchers seeking to understand the role of response set

in outcomes measurement. Reliability and validity have been documented with the Revised Children's Manifest Anxiety Scale,³⁹ and it has been used in childhood asthma studies.^{22,40}

In addition to the items completed by the child, there are several measures that parents can complete to describe the child's psychosocial adaptation, including the challenges associated with child psychopathology and a chronic illness.

Child Behavior Checklist

The Child Behavior Checklist provides a norm-referenced measure of psychosocial competence and parent report of behavior problems with children over a wide age range (2 to 18 years).⁴¹ Psychometric properties of this measure are well understood, because the measure has been used with a variety of chronic illnesses including asthma,^{22,42} and there are strong national norms for children's physical, social, and school competencies, and behavior problems scales for internalizing (withdrawn, somatic complaints, anxious, and depressed), externalizing (delinquent and aggressive), and total problems.

Personal Adjustment and Role Skills Scale

The Personal Adjustment and Role Skills Scale comprises 28 items including 6 subscales (peer relations, dependency, hostility, productivity, anxiety/depression, and withdrawal) and a Total Score for children aged 5 to 18 years.⁴³ Item content does not include somatic concerns, because these were believed to contribute adversely to the total adjustment score. Although much shorter and less time-consuming than the Child Behavior Checklist, this measure was designed specifically for children with a chronic illness and has sound psychometric characteristics despite its limited normative data.^{43,44}

Within the Bonner and Finney³ model of health status outcomes, another of the major domains for assessment is parent variables (Fig 1). Several measures that hold promise for assessing parent perceptions of quality of life and parent characteristics that may affect perceptions of quality of life include the following.

Caregiver's Pediatric Asthma Quality of Life Questionnaire

This measure is the counterpart to the PAQLQ and includes 13 items completed by the parent of a child with asthma.³³ Items are oriented to parent perceptions during the past week, asking them about 3 domains of quality of life: activity limitation, symptoms, and emotional function. Like the PAQLQ, responses to individual items are on a 7-point scale, ranging from "all of the time" to "none of the time."

Childhood Asthma Questionnaire

This is the parent-completed section of the CAQ, which asks them to report on several specific aspects of their child's behavior including school days missed, nighttime awakenings, asthma severity rating (mild, moderate, and severe), how well controlled asthma symptoms appear to be, and the effect of asthma symptoms on family functioning.⁴⁵

Brief Symptom Inventory

The Brief Symptom Inventory is a 53-item measure of self-reported symptoms including anxiety, depression, and hostility.⁴⁶ These variables have been strongly associated with physical health status in adults. Psychologic characteristics such as anxiety and depression are known to influence symptom perception, with increased reports of anxiety and depression associated with higher rates of symptom reporting. These psychologic characteristics have been associated with health care use in primary care settings.⁴⁷

Perceived Stress Scale

Including a measure of stress as part of a health status outcomes study is important for understanding one of the potential barriers to treatment adherence.⁴⁸ This measure includes 14 items used to assess the degree to which life situations are perceived as stressful. This specific measure has been linked to clinical rate of upper respiratory infections.⁴⁹ Reliability coefficients are excellent ($r^2 = 0.85$).

MEASUREMENT STRATEGIES FOR FAMILY AND CULTURAL CONTEXT

Contextual variables such as family characteristics and cultural beliefs and values are believed to play a central role in health status outcomes including treatment compliance. Although a comprehensive review of measurement strategies for assessing these variables is not possible within the scope of this article, several of these measures are presented to guide researchers. Critical to all of these measures are their known psychometric characteristics and particularly their reliability coefficients.

Family Relations Inventory

The Family Relations Inventory is a 30-item short form of the Family Environment Scale that measures dimensions of family cohesion, expressiveness, and conflict.⁵⁰ The Family Relations Inventory has excellent reliability coefficients for both intervals from 2 months (cohesion = 0.86, expressiveness = 0.73, conflict = 0.85) to 12 months (cohesion = 0.63, expressiveness = 0.69, conflict = 0.76).

Family Assessment Device

The Family Assessment Device is a 60-item report of family functioning with dimensions assessing family problem-solving, communication, roles, affective responsiveness, affective involvement, and behavioral control. Reliability coefficients range from 0.71 to 0.92.^{51,52}

Treatment Alliance Scale, Parent Version

This is a 7-item scale assessing the parent's perception of shared goals with the treating physician. Reliability has been reported as 0.93 for parents of adolescents with asthma.⁵³

RECOMMENDATIONS

A variety of recommendations addressing methodologic problems confronting researchers in pediatric asthma in younger children can be drawn from clinical experience and the preceding information. Although not meant to be exhaustive, these points must be considered when outcome studies are being developed.

1. For younger children with asthma, limited outcome measures are available to directly assess the child's perceptions of illness, including quality of life. It is valuable to ascertain the child's perspective of his or her illness, although this will require additional effort to truly understand the young child's perspective. Investigators will continue to need to rely on parents for another perspective of asthma symptoms, functional capabilities, and overall psychosocial adaptation.
2. Based on knowledge of child neurocognitive development, it is reasonable to consider a child as young as 4 years of age to be able to provide some information about his or her illness. Information obtained from the child need not require the completion of a large number of questions, rather, a few questions about how the child perceives the asthma symptoms and interference of these symptoms for activities within the past few days before a clinic visit may be sufficient. Given that the younger child's conceptualization of time is different from that of adults, it is probably best to ask the child about symptoms occurring within a limited period of time (eg, 24 hours) directly preceding the clinic visit.
3. Complementary methods for assessing individual changes in asthma symptoms should be included within a research protocol. Specifically, daily monitoring strategies, such as those used with diary card ratings of asthma symptoms and peak flow values, may provide additional useful information about the variable course of asthma symptoms. Such daily assessments have been suggested not only to provide symptom assessment data but also to be useful in directing intervention efforts.²
4. If information from the child is sought, it is imperative that a trained interviewer meet with the child to elicit this information in a reliable manner. Children younger than 11 years of age cannot be expected to complete questionnaires independently, and even those older than 11 years of age who have learning problems may not be able to reliably complete questionnaires. It is not advised to have a known investigator or coordinator interview the child, because the child's previous relationship with the interviewer may confound results as a result of some children's interest in pleasing a known adult. In addition, parents should not be used to ask the child about asthma symptoms and quality of life.
5. Measurement strategies that use simple response formats for the domain being measured are likely to make it easier for the child to respond to questions about his or her illness. Approaches such as visual

analog scales offer much promise without the inherent problems of a Likert scale, particularly with younger children. Individual items within the interviewer-administered questionnaire should be short and simple.

6. Health status outcomes, including quality of life, deserve the same care and attention to measurement that is given to physiologic data, because both contribute to our understanding of treatment outcomes and have substantial implications for treatment adherence.

CONCLUSIONS

An awareness of psychosocial variables mediating asthma awareness and control is vital for clinical care and research investigations of pediatric asthma. Contributions to understanding health outcomes for pediatric patients with asthma will require that both subjective and objective measures be obtained from the parent and child. Quality of life measures provide information on the child and parent's subjective experience with asthma, which can be very useful in developing or changing a clinical treatment plan and in understanding clinical outcomes. The most useful information for management of pediatric asthma, however, will be derived from multiple measures carefully chosen to address the outcomes of concern. A variety of outcome measures exist that can capture multiple contributing psychologic factors for adherence with pediatric asthma treatment regimens. These measures offer practical information for researchers and clinicians and range from measures completed by the child to those completed by the parent about the child or about other contributing factors that may affect asthma treatment.

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