Parent cough-specific quality of life: Development and validation of a short form

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Background: Cough is a distressing symptom and has a significant effect on many children and their families. Quality-of-life (QOL) measures provide important outcome indicators for clinicians and aid in evaluating the efficacy of interventions.
Objective: The aim of this study was to develop and validate a short cough-specific QOL questionnaire for pediatric use.
Method: Two sources provided data to establish a shortened version of the Parent Cough-specific Quality of Life (PC-QOL) questionnaire. The first (n = 240, 137 boys; median age, 29 months [interquartile range, 14-64 months]) was used for development and cross-validation. Stepwise regression was used to select the reduced set of items, and analyses of reliability, validity, and minimally important differences determined psychometric strength and sensitivity to change. The second independent dataset (n = 320, 190 boys; median age, 39.5 months [interquartile range, 16-77 months]) was used as a confirmatory sample.
Results: Forward-step regression identified 8 items that accounted for 95% of the variance in the full-scale PC-QOL questionnaire. This shortened version (PC-QOL-8) was internally consistent (Cronbach α = 0.84), had good test-retest reliability (intraclass correlation coefficient = 0.66), and demonstrated strong validity (significant correlations with a cough verbal category descriptor score, cough visual analog scale, and subscales of the Short Form-12 General Health scale, the Pediatric Quality of Life Inventory, and the Depression, Anxiety, and Stress Scale). The reduced scale was responsive to change, and a minimally important difference of 0.9 was suggested. These findings were confirmed with the second dataset.
Conclusion: The PC-QOL-8 questionnaire is a short, reliable, and valid instrument for assessing the effect of a child's chronic cough. It demonstrated sensitivity to change, and its length and psychometric properties should enhance its potential uptake and routine use in clinical practice and research. (J Allergy Clin Immunol 2013;131:1069-74.)

Key words: *Quality of life, pediatric cough, psychometrics, minimally important difference*

Cough is a widespread and distressing symptom representing a significant health problem for many children[1] and influencing theirs and their families' lives in substantial and important ways.[2] It is associated with significant physical, social, and psychological effects[1] and therefore warrants further investigation. Health-related quality of life (QOL) is a multidimensional construct referring to a person's physical, psychological, and social well-being and functioning.[3] Measuring QOL is important in understanding the burden of disease and evaluating health care interventions and as an outcome indicator in epidemiologic and interventional studies.[4] It can be evaluated by using generic (eg, Pediatric Quality of Life Inventory 4.0 [PedsQL][5]) or disease-specific (eg, Asthma Quality of Life Questionnaire[6]) instruments. However, disease-specific QOLs have shown enhanced specificity and sensitivity over generic QOLs,[7] and this includes cough-specific QOL instruments for children and adults.[8]

A number of validated questionnaires designed to examine the effect of adult chronic cough on QOL have been developed (eg, the Leicester Cough Questionnaire[9]), and these have been shown to be reliable and valid and cover a range of dimensions (eg, physical, psychosocial, and emotional). However, the importance of pediatric-specific QOL instruments has been increasingly recognized because QOL tools designed for adults are inappropriate for pediatric use.[5] Thus we developed the 27-item Parent Cough-specific Quality of Life (PC-QOL) questionnarie.[10,11] The 27-item PC-QOL questionnaire has been shown to be reliable and valid[10,11] and provide an accurate measure in determining the effect of treatments and clinical trials.[12]

Although many QOL instruments, including the cough-specific measures, have proved useful for a variety of clinical and research purposes, they are often believed to be too long by both clinicians for inclusion in their interventions and by parents juggling the many demands on their time. Empirical work in other domains, such as general health[13] and chronic obstructive pulmonary disease,[14] have shown that shortened instruments can retain strong psychometric properties without loss of information, thus enhancing their routine uptake in research and, more importantly, clinical care. Use of simple and short instruments could substantially enhance routine clinical assessments.

In light of this, the aim of the present research was to develop a short, reliable, and validated parent-completed child's chronic cough QOL instrument that would be simple, easy to complete, and not time demanding. This brief tool would need to show sensitivity to change and be easy to interpret so that it might be readily incorporated into routine clinical practice and research. Using an exploratory and confirmatory sample set, we determined whether a shorter form has similar psychometric properties and

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Abbreviations used
DASS: Depression, Anxiety, and Stress Scale
ICC: Intraclass correlation coefficient
MID: Minimally important difference
PC-QOL: Parent Cough-Specific Quality of Life
PedsQL: Pediatric Quality of Life Inventory
QOL: Quality of life
SF-12: Short Form 12-item health survey
VAS: Visual analog scale
VCD: Verbal categorical descriptive

reproduces scores that would be sensitive to change without loss of information compared with the long version of our PC-QOL questionnaire.

METHODS

Data sources

Data for the present study came from 2 sources (Fig 1). The first was an expanded dataset (from the original set of n = 170) that led to the initial development and validation of the PC-QOL questionnaire (PCS dataset).[10] Two hundred forty-two children (137 boys and 105 girls; median age, 29 months [interquartile range, 14-64 months]) and 1 parent of each child were recruited after an initial presentation to the Royal Children's Hospital, Brisbane, Australia, for newly referred chronic cough.

The second source originated from a prospective multicenter cohort study called the Multicentre Study on Chronic Cough Assessment and Pathway Evaluation (MSCAPE) conducted in 5 major city hospitals and 3 rural-remote clinics in Australia (MSCAPE dataset).[15] Although 346 children were in this dataset, complete PedsQL questionnaires in the final assessment were only available for 320 children (190 boys and 130 girls; median age, 39.5 months [interquartile range, 16-77 months]). In this dataset the inclusion criteria were children who were newly referred with chronic cough to any of the participating sites. All were referred either from primary care or general pediatricians or were parent initiated.

The exclusion criteria for both studies were similar: children were excluded if they had a known chronic respiratory illness previously diagnosed by a respiratory physician or had diagnoses confirmed on objective tests (eg, cystic fibrosis and bronchiectasis) before referral. In both studies parents provided written consent, and the studies were approved at each participating site by the respective ethics committees.

Data collection

Both datasets provided 2 data collection points. For the PCS dataset, parents completed a range of measures, including the PC-QOL questionnaire,[10] the Short Form 12-item health survey (SF-12) version 2,[13] the PedsQL4.0,[5] and the Depression, Anxiety, and Stress Scale (DASS),[16] along with 2 measures aimed to quantify the severity of the child's cough: a cough verbal categorical descriptive (VCD) score and a cough visual analog scale (VAS). Parents repeated all questionnaires at a follow-up visit 2 to 3 weeks after the initial visit. Parents in the MSCAPE study completed the PC-QOL questionnaire and PedsQL together with the cough VCD and VAS severity measures at an initial visit and then again at follow-up approximately 6 weeks later or at cough resolution.

Materials

Cough measure. The severity of the child's current cough was operationalized by using 2 measures: the VCD and the VAS. For the VCD, parents rated their child's cough on a 6-point scale (0 = no cough to 5 = severe cough and cannot perform activities), with increasing scores reflecting greater interference with usual activities. This rating (a cough scoring diary) has been previously validated against an objective cough meter, with changes in this subjective cough rating reflective of changes in cough counts.[17] For the cough VAS, parents rated how troublesome their child's cough was on a 10-point scale (1 = no trouble to 10 = troublesome all the time).

PC-QOL questionnaire.[10] The PC-QOL questionnaire is a previously validated 27-item questionnaire designed to assess the level of parents' frequency of feelings (15 items) and worry (12 items) related to their child's cough. Participants respond on a 7-point Likert-type scale, with higher scores reflecting a greater QOL (ie, less frequent and fewer worry concerns). Research indicates that the PC-QOL questionnaire is both reliable and valid and taps 3 domains of functioning: psychological (11 items), physical (11 items), and social (5 items).[11] To simplify the presentation, this PC-QOL questionnaire will be referred to as the PC-QOL-27 questionnaire.

SF-12 version 2.[13] The SF-12, a shortened version of the SF-36, provides a measure of health functioning and computes to 8 subscales: physical functioning, role limitations as a result of physical health problems, role limitations because of emotional problems, mental health, bodily pain, general health perceptions, vitality, and social functioning. The 8 scales have reported satisfactory reliability estimates, ranging from 0.73 to 0.87.[18] For all scales, higher scores reflect better health status.

PedsQL.[5] This generic multidimensional questionnaire is designed for parental reports of the child's QOL. Each of the 23 items has a 5-point Likert-type scale (0 = never a problem to 4 = almost always a problem), which were reverse scored so that higher scores reflected more positive functioning. Five dimensions of functioning have been identified: psychosocial, physical, emotional, social, and school functioning. The inventory caters to 4 age groups (2-4, 5-7, 8-12, and 13-18 years) and has been used to validate disease-specific and symptom-specific QOL scores.[19] The PedsQL Generic Core Scales have demonstrated reliability and validity and are reported to be applicable across a variety of settings, including clinical trials and research.[20]

DASS-21.[16] The DASS-21 measures the domains of depression, anxiety, and stress. Seven items explore each of the domains, and participants respond on a 4-point severity scale from 0 (did not apply to me) to 3 (applied to me very much or most of the time), with the past week as the referent period. Higher scores reflect greater severity. The DASS-21 has been shown to be a reliable and valid measure.[21]

Statistical analysis

The aim of the statistical analyses was to arrive at a short form (reduced item set) of the PC-QOL-27 questionnaire and to ensure this shortened version remained a reliable and valid instrument. Forward-step regression of the PC-QOL questionnaire items on the total score was first used to identify the best subset of items. This method begins with an empty model and adds items one at a time if they meet an entry statistical criteria (eg, $P = .05$). Those items with the highest correlation are entered into the equation first, and the process continues until the remaining items do not satisfy the entry criteria. This method of item reduction is useful in developing a subset of items predicting an outcome while eliminating those items that do not provide any additional prediction.[22] It is a method commonly used in creating short-form versions of questionnaires (eg, the SF-12[13]).

Once the subset of items was finalized, the psychometric properties of reliability and validity were investigated (Fig 1). Reliability is concerned with whether an instrument is internally consistent or reproducible. Internal consistency refers to the extent to which items within a scale measure the same concept and is assessed with the Cronbach α value. Test-retest reliability takes account of variation over time and is usually assessed with intraclass correlation coefficients (ICCs). Validity refers to whether an instrument measures what it intends to measure and is assessed in multiple ways. In this study we have concentrated on construct and discriminant validity. Evidence of construct validity is shown through patterns of strong correlations with variables with which that it should be correlated (ie, convergent validity). Evidence of discriminant validity (known groups validity) is demonstrated when scores on the instrument differentiate between groups of participants with different health status or illness severity levels. In the present study this was investigated