Perception of Pulmonary Function in Children with Asthma and Cystic Fibrosis

Erick Forno, MD, MPH,^{1,2} Neethu Abraham, MD,¹ Daniel G. Winger, MS,³
Christian Rosas-Salazar, MD, MPH,⁴ Geoffrey Kurland, MD,^{1,2} and Daniel J. Weiner, MD^{1,2}

Background: Under-perception of pulmonary dysfunction may delay appropriate treatment, while over-perception may result in unnecessary treatments.

Objectives: To evaluate the ability of patients with asthma or cystic fibrosis and their subspecialty caregivers to assess changes in lung function based on their subjective clinical impressions.

Methods: Patients were asked to qualitatively describe how they felt compared to their prior visit (same/better/worse) and to quantitatively estimate their forced expiratory volume in 1 s (FEV₁) after being reminded of their FEV₁ at the prior visit. Providers made similar estimates based on history and physical examination and knowledge of prior FEV₁. After adjusting for relevant clinical covariates, lung function estimates were categorized as accurate ($\pm 5\%$ of measured FEV₁), overestimated ($>5\%$ above measured), and underestimated ($>5\%$ below measured).

Results: One hundred nine patients estimated FEV₁ on 179 occasions. Concordance between patient qualitative assessment and FEV₁-based categories was low ($\kappa = 0.08$); 44% of patients reported feeling better than the FEV₁-based category showed. Quantitatively, 56% of patient estimates were accurate, 18% were underestimated, and 26% overestimated; accuracy improved with age (odds ratio = 1.16, $P = 0.01$). Concordance between provider qualitative assessments and FEV₁-based category was moderate ($\kappa = 0.35$); about 19% said their patient looked better than the FEV₁-based category showed. Quantitatively, 65% of provider estimates were accurate, 16% were underestimated, and 19% were overestimated; accuracy improved with years of experience.

Conclusions: Patients' and providers' perceptions of lung function were low to moderately accurate. Relying on subjective impression may place patients at risk for unnecessary treatments or increased morbidity. These findings highlight the importance of objective lung function assessment.

Keywords: cystic fibrosis, asthma, lung function, lung function perception

Introduction

INACCURATE SYMPTOM PERCEPTION contributes to morbidity and mortality in children and adults with asthma,^{1–3} and therefore strategies to assess perceptual accuracy are necessary.^{1,4} Under-perception of lung function impairment can contribute to poor self-management and lead to disease exacerbations.⁵ Conversely, over-perception of pulmonary function decline can contribute to anxiety and medication overuse.^{2,4} Previous studies suggest that as many as 42% of children with asthma under-perceive their respiratory impairment.⁵

Research on lung function or impairment perception is scarce in other lung diseases, such as cystic fibrosis (CF).

Patient perception of the severity of their disease may influence their adherence.⁶ Moreover, poor lung function perception may delay identification and treatment of disease exacerbations.

We, and others, have observed that spirometry is infrequently used for monitoring patients with asthma in primary care settings as compared to subspecialty settings. In this study, we assess whether children with asthma or CF and their providers are able to estimate lung function and determine factors associated with perception accuracy. We hypothesized that providers and patients are equally accurate and that their estimates are affected by factors such as age, gender, race, diagnosis, interval between tests, and baseline lung function.

¹University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania.

²Division of Pulmonary Medicine, Department of Pediatrics, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania.

³Department of Statistics, Clinical and Translational Science Institute, University of Pittsburgh, Pittsburgh, Pennsylvania.

⁴Division of Pediatric Allergy, Immunology and Pulmonology, Department of Pediatrics, Vanderbilt University School of Medicine, Nashville, Tennessee.

Materials and Methods

Study population

Children 6–17 years, diagnosed with CF or asthma and followed at the Children's Hospital of Pittsburgh, were recruited during inpatient admissions or follow-up clinic visits in the Division of Pulmonology, Allergy and Immunology between May 2014 and February 2015. Spirometry was performed under the supervision of a respiratory therapist according to American Thoracic Society guidelines⁷ and using a rolling seal spirometer (SpiroAir LT; Morgan Scientific).

Data collection

Children were asked to *qualitatively* estimate their lung function at the visit in comparison to their prior visit (“Based on how I feel, when compared to my last visit, my lung function today is: better, the same, or worse”). After reviewing their forced expiratory volume in 1 s (FEV₁; as percent of predicted) at the prior visit, they were also asked to *quantitatively* estimate their current FEV₁ before performing spirometry. Providers were asked to *qualitatively* estimate the patient's lung function (“Based on history and physical examination, when compared to his/her last visit, I suspect my patient's lung function is: better, the same, worse”). Providers relied on their clinical assessments, rather than on a structured evaluation tool. Typical history questions for asthma would include rescue medication use and frequency, interim use of systemic steroids, Emergency Department visits or hospitalizations, and frequency of daytime or nighttime symptoms. Typical questions for CF patients would include frequency or change in cough, sputum production, hemoptysis, chest tightness, appetite, and activity level. After reviewing the patient's prior FEV₁, patients were also asked to *quantitatively* estimate the current FEV₁. Providers were blinded to the actual FEV₁ and to patient estimates. Children and their providers were invited to continue participating during subsequent encounters over the course of one year. Individual patients were assessed at all visits by the same provider who provided continuity of their clinical care. Additional data, including age, diagnosis, ethnicity, Asthma Control Test (ACT) scores (for asthma patients), and the patient's best FEV₁ in the prior year (“baseline FEV₁”) were abstracted.

Ethics statement

The study was approved by the University of Pittsburgh Institutional Review Board (PRO13100618). Written consent/assent was obtained from all participants before participation.

Data analysis

We compared the subjective assessments from participants and providers with objective ones based on measured FEV₁ (% of predicted). Qualitative assessments (better/same/worse) were compared to FEV₁ changes since the last visit (“better” = current FEV₁ > 5% higher than the prior FEV₁; “same” = FEV₁ within $\pm 5\%$ from prior; “worse” = FEV₁ > 5% lower than prior). We compared quantitative assessments, classifying participants' and providers' estimates as being

“accurate” (within $\pm 5\%$ of measured FEV₁), “overestimated” (>5% above measured FEV₁) or “underestimated” (>5% below measured FEV₁). Inter-rater agreement for categorical variables was assessed using Cohen's kappa coefficient (κ). To identify factors associated with accurate assessment, qualitative and quantitative assessments were grouped into a binary outcome of “accurate” versus “inaccurate” (combining overestimated and underestimated assessments) for some analyses. Bivariate analyses were performed using chi-square, *t*-tests or Pearson's correlation. Multivariable analyses were performed via logistic or linear regression. Covariates included age, sex, race, diagnosis, interval between visits, baseline lung function (best value in the prior 12 months), ACT (for subjects with asthma), and provider years of experience.

To account for patients who participated at more than 1 visit, we also performed adjusted longitudinal, random-effects, repeated-measures analyses. Finally, we performed a sensitivity analysis including only 1 measurement/estimate per participant. Analyses were conducted with STATA v.13 (STATA Corp., College Station, TX), SPSS v.21 (IBM Analytics, Armonk, NY), and R v.3.3.1.

Results

Study participants

Patients. One hundred nine patients were enrolled (asthma 54%, CF 46%) and provided lung function estimates during 179 encounters. Main characteristics are shown in Table 1. All patients participated on at least one occasion, 44 on two occasions, and 26 on 3–6 occasions. Mean “baseline” FEV₁ (the best FEV₁ obtained over the prior 12 months) was $100.2\% \pm 15.1\%$ of predicted (range 50%–134%). Mean ACT scores for asthma patients was 22.7 ± 2.6 (range 17–27) and did not correlate with FEV₁ (baseline, prior, or current; all $P > 0.20$).

Providers. Eleven healthcare providers provided lung function estimates during 172 encounters (7 visits were excluded when providers became unblinded to measured FEV₁ before making an estimate). Average experience of the providers was 22 ± 12 (range 4–38) years.

Patient perception of pulmonary function

Overall, 35% of patient felt “the same” as at the prior visit, 51% felt “better,” and 14% felt “worse” (Table 2). In contrast, measured FEV₁ was unchanged in 62% of patient estimates, better in 21%, and worse in 17%. Concordance between patient qualitative assessments and assessments based on FEV₁ was low (agreement = 40.2%, $\kappa = 0.08$; Supplementary Table S1; Supplementary Data are available online at www.liebertpub.com/ped); more than 44% of patient said they felt better than the FEV₁-based objective category indicated (eg, they felt “better” when FEV₁ was the same/worse, or they felt “the same” while FEV₁ was worse). Our adjusted analyses (Table 3, top) showed that patients' qualitative accuracy improved with age [odds ratio (OR) = 1.14, 95% confidence interval (CI) = 1.03–1.26, $P = 0.03$; results were similar for the repeated-measures longitudinal analysis], with a nonsignificant trend toward improved accuracy among patients with CF (OR = 2.23, 95% CI = 0.90–5.55, $P = 0.08$; results were similar in the longitudinal analysis) relative to patients with asthma.

TABLE 1. GENERAL CHARACTERISTICS

	<i>All</i>	<i>Asthma</i>	<i>CF</i>
<i>N</i>	179	72	107
Age (years)	12.0 (3.0) ^a	11.4 (3.1)	12.4 (2.8)
Sex (male), %	51.9	56.9	48.6
Race, %			
White	88.8 ^a	77.5	96.3
Black	11.2 ^a	22.5	3.7
ACT score	—	22.7 (2.6)	—
Interval (months)	3.4 (3.1) ^a	5.8 (3.3)	1.8 (1.7)
Physician experience (years)	21.9 (11.8) ^a	19.4 (11.2)	23.6 (11.9)
Baseline FEV ₁ (% predicted) ^b	100.2 (15.1)	99.8 (13.1)	100.4 (16.4)
Prior FEV ₁ (% predicted) ^c	93.7 (16.9) ^a	97.4 (13.2)	91.3 (18.6)
Current FEV ₁ (% predicted)	93.8 (16.6) ^a	98.6 (12.8)	90.6 (18.1)
Delta FEV ₁ (current-prior)	+0.05 (9.9)	1.2 (7.6)	−0.7 (11.1)
Patient estimate			
FEV ₁	95.6 (16.9) ^a	100.1 (15.4)	92.6 (17.3)
Error (patient-actual) [range]	+1.9 (9.5) [−20 to +57]	+1.6 (8.9) [−20 to +25]	+2.1 (10.0) [−20 to +57]
MD estimate			
FEV ₁	93.9 (15.4)	96.2 (11.5)	92.2 (17.6)
Error (MD-actual) [range]	+0.006 (8.5) ^a [−32 to +42]	−2.3 (6.8) [−20 to +11]	+1.7 (9.2) [−32 to +42]

Shown are mean (standard deviation) for continuous variables, and percentages for binary variables.

^a $P < 0.05$ for asthma versus CF comparison.

^bBest FEV₁ of the past 12 months.

^cFEV₁ at the last visit before the study.

ACT, Asthma Control Test; CF, cystic fibrosis; FEV₁, forced expiratory volume in 1 s.

When evaluating patient quantitative estimates versus measured FEV₁, 56% of patients were accurate (within $\pm 5\%$ of measured FEV₁), 18% underestimated their FEV₁, and 26% overestimated it (Fig. 1). Overestimators had a lower mean FEV₁ than did accurate estimators (89.2% versus 95.2%, $P = 0.037$); there was no difference between underestimators and accurate estimators ($P = 0.81$). Adjusted analysis (Table 3, bottom) showed that quantitative accuracy improved with age (OR = 1.16, $P = 0.01$). The absolute patient error (patient estimate − measured FEV₁) was smaller with older patients ($\beta = -0.54\%$, $P = 0.02$) and larger

with longer interval between visits ($\beta = +0.51\%$, $P = 0.006$), with no associations with sex, diagnosis, or baseline FEV₁. Findings remained unchanged in the longitudinal repeated-measures analysis (taking into account patients with more than one encounter) or sensitivity analysis (including only one encounter per patient; data not shown). Using a less stringent cut-off for accuracy (10% instead of 5%) increased the kappa coefficients as expected but did not change the significance of any of the covariates (Supplementary Tables S2 and S3).

Provider perception of patient pulmonary function

Providers reported that the patient looked “the same” in 62% of encounters, “better” in 21%, and “worse” in 17% (Table 1). Qualitative patient-provider concordance was low-to-moderate ($\kappa = 0.19$; Supplementary Table S4). Concordance between provider qualitative assessments and FEV₁-based category was moderate ($\kappa = 0.35$; Supplementary Table S5); about 19% of providers said their patient looked better than the FEV₁-based category would indicate. No factors were associated with provider qualitative accuracy in the regression analysis, but provider experience was significantly associated with improved concordance in the repeated measures longitudinal analysis (Table 3, top).

When evaluating provider quantitative estimates versus measured FEV₁, 65% of providers were accurate, 16% underestimated the FEV₁, and 19% overestimated it (Fig. 1). The FEV₁ of patients evaluated by underestimating providers was higher than the FEV₁ of patients evaluated by accurate providers (101.6% versus 94.6%, $P = 0.03$). In contrast, the FEV₁ of patients evaluated by overestimating providers was lower than the FEV₁ of patients evaluated by accurate providers

TABLE 2. QUALITATIVE AND QUANTITATIVE CATEGORIES

	<i>All</i>	<i>Asthma</i>	<i>CF</i>
Subjective, %			
Better	50.8	51.2	48.6
Same	35.2	31.9	37.4
Worse	14.0	13.9	14.0
Objective, %			
Better	21.2	19.4	22.4
Same	61.5	68.1	57.0
Worse	17.3	12.5	20.6
Patient category, %			
Underestimator	17.9	18.1	17.8
Accurate	56.4	51.4	59.8
Overestimator	25.7	30.5	22.4
MD category, %			
Underestimator	19.1 ^a	26.5	13.8
Accurate	64.8	64.7	64.9
Overestimator	16.1 ^a	8.8	21.3

^a $P < 0.05$ for asthma versus CF comparison.

TABLE 3. ADJUSTED ANALYSIS OF QUALITATIVE AND QUANTITATIVE ASSESSMENTS

	Patient			Provider		
	Bivariate	Adjusted	Longitudinal	Bivariate	Adjusted	Longitudinal
Qualitative assessments						
Age	1.14 (1.03–1.26) ^a	1.13 (1.01–1.26) ^a	1.15 (1.01–1.30) ^a	0.94 (0.85–1.04)	0.94 (0.94–1.05)	1.05 (0.93–1.19)
Sex (male)	1.16 (0.64–2.11)	1.10 (0.58–2.08)	1.12 (0.54–2.30)	1.09 (0.60–1.98)	1.04 (0.55–1.97)	1.26 (0.63–2.52)
Race (black)	0.60 (0.21–1.64)	0.84 (0.28–2.48)	0.86 (0.25–2.89)	0.63 (0.25–1.60)	0.76 (0.27–2.20)	0.73 (0.25–2.10)
Diagnosis (CF)	1.80 (0.96–3.36) ^b	2.23 (0.90–5.55) ^b	2.51 (0.88–7.15) ^b	0.95 (0.51–1.75)	1.70 (0.66–4.38)	1.10 (0.42–2.89)
Visit interval	1.01 (0.92–1.11)	1.09 (0.95–1.25)	1.10 (0.95–1.28)	1.09 (0.98–1.22)	1.16 (0.99–1.36) ^b	1.10 (0.92–1.30)
Baseline FEV ₁	1.01 (0.99–1.03)	1.01 (0.99–1.03)	1.01 (0.99–1.04)	1.02 (0.99–1.04)	1.01 (0.99–1.04)	1.00 (0.92–1.02)
Provider experience	—	—	—	1.01 (0.99–1.04)	1.01 (0.98–1.04)	1.04 (1.01–1.08) ^a
Quantitative assessments						
Age	1.15 (1.04–1.28) ^a	1.16 (1.04–1.30) ^a	1.31 (1.05–1.65) ^a	1.08 (0.97–1.21)	1.05 (0.93–1.19)	1.05 (0.93–1.19)
Sex (male)	0.87 (0.48–1.58)	0.80 (0.43–1.52)	0.59 (0.19–1.87)	1.24 (0.65–2.36)	1.26 (0.63–2.52)	1.26 (0.63–2.52)
Race (black)	1.19 (0.46–3.08)	1.60 (0.57–4.47)	1.76 (0.31–10.1)	0.5 (0.19–1.28)	0.73 (0.25–2.10)	0.73 (0.25–2.10)
Diagnosis (CF)	1.41 (0.77–2.57)	1.88 (0.77–4.57)	2.40 (0.55–10.4)	1.01 (0.52–1.94)	1.10 (0.42–2.89)	1.10 (0.42–2.89)
Visit interval	1.01 (0.92–1.11)	1.08 (0.94–1.25)	1.07 (0.87–1.32)	1.08 (0.96–1.22)	1.10 (0.92–1.30)	1.09 (0.92–1.30)
Baseline FEV ₁	1.00 (0.98–1.02)	1.01 (0.99–1.03)	1.01 (0.98–1.05)	0.99 (0.98–1.02)	1.00 (0.98–1.02)	1.00 (0.98–1.02)
Provider experience	—	—	—	1.05 (1.01–1.08) ^a	1.04 (1.01–1.08) ^a	1.04 (1.01–1.08) ^a

Shown are the adjusted odds ratios of being an accurate qualitative (top) or quantitative (bottom) estimator.

^a $P < 0.05$; ^b $P < 0.10$.

(81.6% versus 94.6%, $P < 0.001$). Regression analysis showed that provider accuracy improved with years of experience (OR = 1.04, 95% CI = 1.01–1.08; with similar results in the longitudinal analysis) (Table 3, bottom). Absolute provider error (provider estimate – measured FEV₁) showed no associations with any of the covariates. The distribution of provider and patient errors is shown in Supplementary Fig. S1. Using a less stringent cut-off for accuracy (10% instead of 5%) increased the kappa coefficients as expected, and provider experience was nonsignificant ($P = 0.08$) (Supplementary Tables S2 and S3).

High-risk categories

Based on the results from the quantitative agreement categories (Table 4), we identified two groups of “at-risk” patients: (A) those in whom both patient and provider overestimated lung function, and therefore patients are at risk of unnoticed deterioration; and (B) those in whom both underestimated lung function, and therefore patients are at risk of increased treatment burden. Each group included approximately 10% of patients. None of the assessed covariates was significantly different for those in Group A as compared to cases in which both patient and provider were accurate estimators. Those in Group B were younger ($P = 0.02$), more likely to be male ($P = 0.04$), and more likely to have asthma ($P = 0.03$) than were patients for whom both patient and provider were accurate. When using a 10% instead of a 5% cut-off, Group A comprised approximately 5% of patients and Group B comprised about 6% (Supplementary Table S6). There were no significant demographic differences with those groups in which both patient and provider were accurate estimators.

Effect modification by diagnosis

Given that patients with CF had better quantitative perception than those with asthma (Table 3, top), we performed an interaction analysis between diagnosis and all other covariates. Diagnosis (CF vs asthma) did not modify the associations between the outcomes and the following variables: age, sex, race, visit interval, baseline FEV₁, or provider experience (all interaction P values > 0.10 ; data not shown). For example, the association between age and quantitative perception was not significantly different between patients with CF or with asthma (Supplementary Tables S7 and S8).

Discussion

In this study, we found poor perception of pulmonary function by patients with CF and asthma. More than 44% of patients qualitatively overestimated their status compared with their last visit, and only 40% were accurate perceivers. Additionally, only 56% quantitatively estimated FEV₁ accurately. Thus, a sizable proportion of these children are at risk for respiratory deterioration due to disease under-perception or are at risk for medication overuse due to over-perception.^{2,4}

Very few studies have assessed lung function perception in children. Baker et al found that 46%–51% of children with asthma did not recognize bronchospasm after methacholine inhalation or bronchodilation after albuterol administration; the authors also found no differences in age, sex, or lung function between “perceivers” and “non-perceivers.”⁸ Among the latter, only age was associated with perceptual accuracy among patients in our study: for each year of age,

FIG. 1. Subjective estimate FEV₁ vs actual measurement. Red and green lines represent $\pm 5\%$ error margin. Values above the range (in red) indicate overestimators [ie, patient (A) or provider (B) estimate was $>5\%$ above actual FEV₁]; values below the range (in green) indicate underestimators ($>5\%$ below actual FEV₁). FEV₁, forced expiratory volume in 1 s.

the odds of qualitative accuracy (better/same/worse status) improved by approximately 13%, while the odds of quantitative accuracy (estimation of FEV₁) improved by about 16%. These results are consistent with reports that older children have greater perceptual accuracy.^{1–3} Gender was not related to perceptual accuracy in our analysis, in contrast to studies that found girls to be more likely to underestimate lung function.^{1,3} This accuracy difference could reflect differences in disease severity or underlying population characteristics. Among the modifiable factors, we found that the absolute error in FEV₁ estimate was approximately 0.5% higher with each additional month between visits.

Patients with CF showed a nonsignificant trend toward improved qualitative accuracy relative to patients with asthma possibly because patients with CF tend to have shorter intervals between visits than do patients with asthma. In one prior study, it was shown that increased frequency of visits for patients with CF resulted in improved lung function outcomes.⁹ Somewhat surprisingly, preliminary results from the Early Identification of Cystic Fibrosis Exacerbations (eICE) study, which randomized patients with CF to “usual care” or an intervention group that performed home spirometry twice weekly¹⁰, showed that, despite increased sick visits in the intervention group, there was no difference in lung function at the end of the study.¹¹

In our study, providers were somewhat more accurate than patients: approximately 65% had accurate qualitative estimates, and about 65% had accurate quantitative estimates. Still, more than one-third of the time, providers were unable to accurately estimate their patient’s lung function qualitatively or quantitatively, with 16%–19% overestimating the patient’s pulmonary function. For each year of work experi-

ence, providers had 4% higher odds of accurately estimating FEV₁; those with fewer than 10 years of experience were accurate about 50% of the time, while those with more than 30 years were about 80% accurate. As expected, when using less stringent criteria to define accuracy (10% instead of 5%), provider experience became less important. However, sample sizes for some providers were small, and these results should be interpreted with caution; indeed, provider experience was nonsignificant in our sensitivity analysis.

While patients tended to overestimate their lung function (Fig. 1), this was not related to their baseline FEV₁. Similarly, there was no association between provider accuracy and patient baseline FEV₁. This lack of association is consistent with prior studies of perceptual accuracy in asthma that have found FEV₁ to be unrelated to estimate accuracy.¹ However, a study in adults with CF found that a physician’s severity ratings increased in accordance with lung function decline, while a patient’s perceptions remained unchanged.⁴ Additionally, Ziegler et al found that CF patients reported only mild to moderate dyspnea during resistive loaded breathing despite significant impairment in pulmonary function, possibly suggesting a blunted perception of dyspnea.¹²

Among children with asthma, we found no association between ACT scores and estimation accuracy (not shown), nor between ACT and measured FEV₁. This suggests there is a discrepancy between the perception of asthma control, the perception of lung function, and measured FEV₁. This is in agreement with Steele et al who contrasted lung function with self-reported components of asthma control using a modified asthma risk grid scheme.³ This discrepancy between lung function and reported symptoms could be useful in identifying subgroups of asthma patients that are at particularly

TABLE 4. PATIENT VERSUS MD QUANTITATIVE CATEGORIES

Patient	Provider			Total
	Underestimator	Accurate	Overestimator	
Underestimator, <i>n</i> (%)	15 ^a (9.3)	9 (5.6)	2 (1.2)	26 (16.1)
Accurate, <i>n</i> (%)	12 (7.4)	74 (45.7)	8 (4.9)	94 (57.9)
Overestimator, <i>n</i> (%)	4 (2.5)	22 (13.6)	16 ^a (9.9)	42 (25.9)
Total, <i>n</i> (%)	31 (19.1)	105 (64.8)	26 (16.0)	162 (100)

Agreement = 64.8%, expected = 44.8%, $\kappa = 0.36$. Percentages may not add exactly up to 100.0% due to rounding.

^aHigh-risk categories in light grey shading: (1) both overestimators (9.9%); (2) both underestimators (9.3%).

high risk of asthma exacerbations. Of note, however, the majority of participants with asthma in our study had ACT scores >19, consistent with good asthma control.

Finally, quantitative assessments of providers and patients were found to have only a fair degree of agreement. This finding highlights the challenge for patients and providers alike in determining a mutually agreeable treatment plan and underscores the importance of further studies of pulmonary perception in children. Our results suggest that, in approximately 10% of cases, both provider and patient overestimated lung function, and in another 10%, both of them underestimated it. This places patients at increased risk for either pulmonary function deterioration or possibly unnecessary escalations of treatment if objective measures are not obtained. Further, Patient Reported Outcomes (PROs) are increasingly used by the FDA in approval decisions about the efficacy of medications in clinical trials. Our data demonstrate that subjective data (such as PROs) and objective data do not always align, and subjective impressions should not be used in isolation.

Childhood anxiety has been associated with over-perception of pulmonary compromise in asthma.¹³ Perceptions may be related more to the sensation of dyspnea, which may not necessarily be related to objective lung function; for example, in adults with interstitial lung disease, lung function correlates with 6-minute walk distance and oxygen desaturation but not with the feeling of breathlessness.¹⁴ Other factors that have been reported to affect perception include race, socioeconomic status, and intelligence.^{1,3} Additionally, feedback using objective measurements has been slow to improve perception accuracy and controller-medication compliance in patients with asthma.² We were not able to assess our patients for these other factors.

Some parents may assume erroneously that their child is able to assess his/her lung function accurately. This could, in theory, contribute to delayed recognition of exacerbations of asthma or CF and underscores the need for objective measurements of lung function on a regular basis. Although not directly addressed in this study, it would be quite interesting to know whether *parents'* subjective impression of their child's lung health is accurate and whether parental impression aligns with the impression of the child. This question clearly deserves further investigation, and we hope to include this in our future work.

Our study has several strengths. We performed bivariate, adjusted, and longitudinal analyses accounting for repeated measures in children who participated in more than one encounter. Including several demographic and other characteristics allowed us to identify older age and greater provider experience as factors that improve patient and provider perception, respectively. Furthermore, our study is novel due to the use of FEV₁ as a measure of lung function rather than using peak expiratory flow, the inclusion of both pediatric asthma and CF patients, and the assessment of both patient and provider lung function estimates. While peak expiratory flow measurements have been used in numerous studies of children with asthma, these measurements are extremely dependent on patient effort and technique,¹⁵⁻¹⁷ and can be nearly normal even in the presence of significant peripheral airway obstruction. As such, they have limited use in clinical pediatric practice.

There are also a number of limitations in our study. Our subjects came from a convenience sample from a single institution, and therefore extrapolating to other populations (or other lung diseases) may not be feasible. Additionally, disease

severity in our sample was mostly mild (both for CF and asthma patients); further research will be needed to determine whether the findings are replicated in more symptomatic subjects such as patients in our Severe Asthma cohort. Patients with CF had significantly better quantitative lung function perception, but our interaction analyses showed that diagnosis (CF versus asthma) did not modify the association of any covariate (e.g., the association between age and accuracy was similar regardless of diagnosis); larger sample sizes will be required to confirm these findings. We decided *a priori* not to evaluate other measures of lung function, such as FEV₁/FVC (forced vital capacity) or FEF₂₅₋₇₅ (forced expiratory flow), as our discussions with patients in clinic usually emphasize FEV₁. We chose to use an admittedly arbitrary 5% cut-off in large part because changes of this magnitude commonly caught the attention of clinicians in our group. While a variety of changes in lung function have been posited to be clinically significant for healthy adults,^{18,19} the minimal clinically meaningful change is less clear in pediatric patients, especially those with lung disease. Indeed, relatively small changes in FEV₁ (<5%) have been used to support approval of medications for CF.²⁰ Additionally, there are only limited and dated data describing day-to-day variability in spirometry in children with lung disease.^{21,22} Of note, our analysis, using a 10% cut-off, showed similar results, although, as expected, the magnitude or significance of some associations was attenuated. Finally, our ability to explore differences in providers (e.g., by experience level) was hampered by small numbers of providers and unequal distribution of responses.

In conclusion, patients' and providers' perceptions of lung function were low or moderately accurate at best. While objective measures of lung function are routinely obtained in subspecialist settings, they are less commonly obtained by primary care providers caring for children with asthma.²³ Less than 60% of patient estimates of their own lung function were accurate. Relying on subjective impression may place about 10% of patients at risk of unnecessary treatments, and approximately 10% of patients at high risk for increased morbidity. These findings highlight the importance of frequent and objective lung function assessment rather than solely relying on patients' or providers' subjective impressions.

Acknowledgments

The authors gratefully acknowledge the assistance of the respiratory therapists of the Pulmonary Function Laboratory at Children's Hospital of Pittsburgh of UPMC, without whom this study would have been impossible: Steve Walczak, RRT, CPFT (Lab Supervisor), Dane Stafford, RRT, Rebecca Mutich, RRT, Reid Masi, RRT, Jamie Donaldson, RRT, CPFT, Maria Lattanzi, RRT, Kristin Foulk, RRT, Shana Parr, RRT, and MaryBeth Lockwich, RRT. The project was supported by grant UL1-TR-001857 from the US National Institutes of Health (NIH). Dr. Forno's contribution was funded in part by grant HL125666 from the NIH.

Authors' Contributions

Study conception/design: D.J.W., N.A., G.K., E.F.; data acquisition: D.J.W., N.A., G.K.; data analysis/interpretation: D.J.W., N.A., D.G.W., C.R.-S., G.K., E.F.; manuscript

drafting: D.J.W., N.A., G.K., E.F.; critical manuscript revision: D.J.W., N.A., D.G.W., C.R.-S., G.K., E.F.; final manuscript approval: D.J.W., N.A., D.G.W., C.R.-S., G.K., E.F.

Author Disclosure Statement

No competing financial interests exist.

References

1. Fritz GK, McQuaid EL, Kopel SJ, Seifer R, Klein RB, Mitchell DK, Esteban CA, Rodriguez-Santana J, Colon A, Alvarez M, Canino G. Ethnic differences in perception of lung function: a factor in pediatric asthma disparities? *Am J Respir Crit Care Med* 2010; 182:12–18.
2. Feldman JM, Kutner H, Matte L, Lupkin M, Steinberg D, Sidora-Arcoleo K, Serebrisky D, Warman K. Prediction of peak flow values followed by feedback improves perception of lung function and adherence to inhaled corticosteroids in children with asthma. *Thorax* 2012; 67:1040–1045.
3. Steele AM, Meuret AE, Millard MW, Ritz T. Discrepancies between lung function and asthma control: asthma perception and association with demographics and anxiety. *Allergy Asthma Proc* 2012; 33:500–507.
4. Abbott J, Dodd M, Webb AK. Different perceptions of disease severity and self care between patients with cystic fibrosis, their close companions, and physician. *Thorax* 1995; 50:794–796.
5. Dalcin P de TR, Rampon G, Pasin LR, Becker SC, Ramon GM, Oliveira VZ. Perception of disease severity in adult patients with cystic fibrosis. *J Bras Pneumol* 2009; 35:27–34.
6. Abbott J, Dodd M, Webb AK. Health perceptions and treatment adherence in adults with cystic fibrosis. *Thorax* 1996; 51:1233–1238.
7. Miller MR, Hankinson J, Brusasco V, Burgos F, Casaburi R, Coates A, Crapo R, Enright P, van der Grinten CPM, Gustafsson P, Jensen R, Johnson DC, MacIntyre N, McKay R, Navajas D, Pedersen OF, Pellegrino R, Viegi G, Wanger J. Standardisation of spirometry. *Eur Respir J* 2005; 26:319–338.
8. Baker RR, Mishoe SC, Zaitoun FH, Arant CB, Lucas J, Rupp NT. Poor perception of airway obstruction in children with asthma. *J Asthma* 2000; 37:613–624.
9. Konstan MW, Butler SM, Schidlow DV, Morgan WJ, Julius JR, Johnson CA. Patterns of medical practice in cystic fibrosis: part I. Evaluation and monitoring of health status of patients. Investigators and Coordinators of the Epidemiologic Study of Cystic Fibrosis. *Pediatr Pulmonol* 1999; 28:242–247.
10. Lechtzin N, West N, Allgood S, Wilhelm E, Khan U, Mayer-Hamblett N, Aitken ML, Ramsey BW, Boyle MP, Mogayzel PJ, Jr., Goss CH. Rationale and design of a randomized trial of home electronic symptom and lung function monitoring to detect cystic fibrosis pulmonary exacerbations: the early intervention in cystic fibrosis exacerbation (eICE) trial. *Contemp Clin Trials* 2013; 36:460–469.
11. Goss C, West N, Allgood S, Wilhelm E, Khan U, Mayer-Hamblett N, Aitken M, Ramsey B, Boyle M, Mogayzel Jr P, Gibson R, Orenstein D, Milla C, Lechtzin N. Assessment of the effectiveness of home monitoring trial in CF to identify and treat acute pulmonary exacerbation, the eICE Study results. North American Cystic Fibrosis Conference. Phoenix, AZ: Wiley-Liss, 2015, 50, p. 342.
12. Ziegler B, Fernandes AK, Sanches PR, Silva Junior DP, Thome PR, Dalcin P de TR. Dyspnea perception in cystic fibrosis patients. *Braz J Med Biol Res* 2013; 46:897–903.
13. Feldman JM, Steinberg D, Kutner H, Eisenberg N, Hottinger K, Sidora-Arcoleo K, Warman K, Serebrisky D. Perception of pulmonary function and asthma control: the differential role of child versus caregiver anxiety and depression. *J Pediatr Psychol* 2013; 38:1091–1100.
14. Chetta A, Aiello M, Foresi A, Marangio E, D'Ippolito R, Castagnaro A, Olivieri D. Relationship between outcome measures of six-minute walk test and baseline lung function in patients with interstitial lung disease. *Sarcoidosis Vasc Diffuse Lung Dis* 2001; 18:170–175.
15. Miller MR. Potential problems in peak expiratory flow data used to diagnose occupational asthma. *Occup Med (Lond)* 1996; 46:239–241.
16. Brusasco V. Usefulness of peak expiratory flow measurements: is it just a matter of instrument accuracy? *Thorax* 2003; 58:375–376.
17. Ross S, Cochran DP. Method for manipulating peak flow measurements producing falsely raised readings. *Thorax* 2001; 56:500–501.
18. Crapo RO, Casaburi R, Coates AL, Enright PL, Hankinson JL, Irvin CG, MacIntyre NR, McKay RT, Wanger JS, Anderson SD, Cockcroft DW, Fish JE, Sterk PJ. Guidelines for methacholine and exercise challenge testing-1999. This official statement of the American Thoracic Society was adopted by the ATS Board of Directors, July 1999. *Am J Respir Crit Care Med* 2000; 161:309–329.
19. Parsons JP, Hallstrand TS, Mastrorade JG, Kaminsky DA, Rundell KW, Hull JH, Storms WW, Weiler JM, Cheek FM, Wilson KC, Anderson SD; American Thoracic Society Subcommittee on Exercise-induced Bronchoconstriction. An official American Thoracic Society clinical practice guideline: exercise-induced bronchoconstriction. *Am J Respir Crit Care Med* 2013; 187:1016–1027.
20. Wainwright CE, Elborn JS, Ramsey BW. Lumacaftor-ivacaftor in patients with cystic fibrosis homozygous for Phe508del CFTR. *N Engl J Med* 2015; 373:1783–1784.
21. Hutchison AA, Erben A, McLennan LA, Landau LI, Phelan PD. Intrasubject variability of pulmonary function testing in healthy children. *Thorax* 1981; 36:370–377.
22. Cooper PJ, Robertson CF, Hudson IL, Phelan PD. Variability of pulmonary function tests in cystic fibrosis. *Pediatr Pulmonol* 1990; 8:16–22.
23. Ayuk AC, Uwaezuoke SN, Ndukwu CI, Ndu IK, Iloh KK, Okoli CV. Spirometry in asthma care: a review of the trends and challenges in pediatric practice. *Clin Med Insights Pediatr* 2017; 11:1–6.

Address correspondence to:

Daniel J. Weiner, MD

Children's Hospital of Pittsburgh of UPMC
4401 Penn Avenue, 3rd Floor, AOB
Pittsburgh, PA 15224

E-mail: daniel.weiner@chp.edu

Received for publication April 12, 2018; accepted after revision May 30, 2018.