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Evaluating the sinus and Nasal Quality of Life Survey in the pediatric cystic fibrosis patient population





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A R T I C L E I N F O

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ABSTRACT

Introduction: The Sinus and Nasal Quality of Life Survey (SN-5) is a validated quality of life (QOL) questionnaire for chronic rhinosinusitis in patients age 2–12. Its utility in the cystic fibrosis (CF) has been studied, but not yet validated. The purpose of this study is to determine the effectiveness of the SN-5 for evaluation of sinonasal symptoms in the pediatric CF population.

Methods: This retrospective study analyzed SN-5 surveys completed between 2012 and 2015 by pediatric CF patients and caregivers. Baseline and follow-up overall QOL scores and specific symptom scores were obtained from surveys completed in the three-year span. Non-parametric statistics were conducted to identify differences in survey data.

Results: A total of 165 patients completed baseline and follow-up surveys. The overall QOL of the patient cohort did not change over the duration of the study (p = 0.660). Thirty-seven patients indicated higher overall QOL, with all five symptom scores showing significant improvement. Analysis by age group showed that QOL was significantly correlated with all five symptoms for children ages 0–4. In patients 5 –12 years, overall QOL was only correlated with sinus infection (r = -0.3090, p = 0.01). QOL was significantly correlated with sinus infection (r = -0.2903, p = 0.04) and allergy symptoms (r = -0.5644, p < 0.01) in patients >12 years of age.

Conclusion: There remains a need for a validated CRS QOL tool for children with CF. Though the SN-5 has previously been described as a potential instrument, our data suggest that it may be more valuable in children ages 0–4.

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1. Introduction

Cystic fibrosis (CF) is an autosomal recessive disorder with mutations in the CF transmembrane conductance regulator gene. This mutation occurs most commonly as a deletion of F508 [1]. Chronic rhinosinusitis (CRS) is significantly prevalent in the CF population with 74%–100% of CF patients experiencing symptoms of severe chronic rhinosinusitis [2]. Chaaban et all suggested that sinus disease in these patients is both reflective and predictive of

pulmonary disease [2].

Health-related quality of life (QOL) instruments have previously been validated for adults with CRS [3-5]; however, there are no similar QOL instruments for pediatric CF patients with CRS. This lack of data makes it difficult for clinicians to determine how CRS affects QOL in pediatric CF patients, and further may complicate the selection of an appropriate and effective treatment plan.

Currently, the Sinonasal Outcome Test (SNOT-22) is commonly used to measure CRS symptoms in adults by evaluating various outcomes including physical problems, functional limitations, and emotional consequences [6,7]. However, the SNOT-22 has not yet been evaluated and validated for use in pediatric populations. The Sinus and Nasal Quality of Life Survey (SN-5), specific to the

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Table 1	
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Patient	charact	eristics
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	Ages 0-4 n = 34	Ages 5-12 n = 77	Ages 13-18 n = 54	Total n = 165
Age (years)*	1.50 ± 1.13	7.51 ± 2.19	14.93 ± 1.93	8.70 ± 5.28
Gender				
Male	20 (58.8)	37 (48.1)	26 (48.1)	83 (50.3)
Female	14 (41.1)	40 (51.9)	28 (51.9)	82 (49.7)
Race				
White	33 (97.1)	75 (97.4)	52 (96.3)	160 (97.0)
African American	1 (2.9)	2 (2.6)	2 (3.7)	5 (3.0)
Household income**	\$43,540	\$50,020	\$47,086	\$47,086
	(\$37,790-\$55962)	(\$38,046-\$60,196)	(\$40,204-\$63,896)	(\$38,341-\$61,486)
Insurance status				
Public	18 (52.9)	42 (54.5)	30 (55.6)	90 (54.5)
Private	14 (41.2)	31 (40.3)	22 (40.7)	67 (40.6)
Self-pay	1 (2.9)	0 (0)	0 (0)	1 (0.61)
Other (ie, military)	1 (2.9)	4 (5.2)	2 (3.7)	7 (4.2)

Data presented as n (%); *mean \pm SD, **median (IQR).

Bold indicates that the differences were statistically significant.

Table 2

Baseline and follow-up data.

	Baseline	Follow-up	p-value
Sinus infection	3 (2-4)	3 (1-4)	0.021
Nasal obstruction	3 (1-4)	2 (1-4)	0.049
Allergy symptoms	2(1-3)	2 (1-4)	0.562
Emotional distress	1 (1-2)	1 (1-2)	0.897
Activity limitations	1 (1-2)	1 (1-2)	0.026
Overall QOL	8 (7-10)	8 (7–10)	0.660

Higher symptom scores indicate symptoms are occurring more frequently. Higher overall QOL scores indicate an improved QOL. Data presented as median (IQR). Bold indicates that the differences were statistically significant.

pediatric population, asks caregivers to rate their children's CRS symptoms on a 7-point scale [8]. This survey evaluates 5 specific symptoms (sinus infection, nasal obstruction, allergy symptoms, emotional distress, and activity limitations). In addition to the symptomatic evaluation, caregivers evaluate the child's overall QOL on scale from 0 to 10. This survey has only been validated in children between the ages of 2–12, leaving those between the ages of 12–18 without a validated CRS QOL instrument.

The SN-5 was validated in a population of pediatric CRS patients but has not yet been formally evaluated in a CF population. There are recent papers looking at the use of SN-5 in CF patients [9–11]. When used to identify the CRS QOL burden for CF patients, Chan et al. showed that despite the high incidence of symptomatic CRS, the SN-5 results indicated that the disease impact was relatively low [9]. Wentzel et al. [10] similarly evaluated SN-5 for 50 patients with CF, and found that mean symptom frequency was negatively correlated with overall QOL score (r = -0.55, p = 0.00006). However, there does not exist a quality of life measurement that is specific to pediatric CF CRS. As such, there remains a need for a quality of life instrument that can be used to evaluate the overall impact of medical and surgical intervention in the short and long term. The goal of this study is to evaluate the SN-5 as a healthrelated QOL instrument for the pediatric CF patient population.

2. Methods

This retrospective study analyzed previously completed SN-5 surveys. Survey data between 2012 and 2015 from pediatric cystic fibrosis patients were collected and complemented with clinical and sociodemographic data. Overall QOL scores and specific symptom scores were obtained from surveys completed at the first, baseline, and last follow up clinic visit in the three-year span. Patients, or patient caregivers, of all ages were asked to complete the surveys and were later analyzed by age groups 0-4 years, 5-12 years, and 13 + years.

The SN-5 survey evaluates five CRS-related symptoms on a seven-point scale to indicate the frequency at which the symptoms affected the patient over the past 4 weeks, with higher scores indicating higher frequency. A final question asks, "How would you rate your child's quality of life as a result of nose or sinus problems?" on a scale from 0 to 10, with higher scores indicating the best possible QOL.

Wilcoxon matched-pairs signed rank tests were performed to identify differences present between baseline and follow-up scores. Mann-Whitney tests were used to conduct additional comparison analysis. Subgroup analysis was performed, within each age category, to assess symptom and QOL changes over time (improved, no change, and worsened). Spearman rank correlation coefficient was used to identify relationships between the change in the overall QOL score and each of the symptom scores. Statistical significance was set *a priori* at p < 0.05.

3. Results

A total of 266 patients completed surveys. Of these, 165 patients had both baseline and follow-up data. Mean age at baseline data collection was 8.70 ± 5.28 years. A majority of patients identified as Caucasian (97.0%) and non-Hispanic (98.2%). Additional demographic data are shown in Table 1. Mean baseline scores in the symptom domains ranged from 1.68 ± 1.34 for activity limitations to 3.08 ± 2.51 for sinus infections, where higher values indicate experiencing these symptoms more frequently (Table 2). Median time between obtaining baseline and follow-up data was 7 months (IQR 4–14). Comparing baseline and follow-up data, there were statistically significant symptom improvement in sinus infection (p = 0.021), nasal obstruction (p = 0.049), and activity limitations (p = 0.026). The overall quality of life of our patient cohort did not significantly change over the duration of the study (p = 0.660).

Of the 147 surveys with baseline and follow-up data on overall quality of life, 37 patients (25.2%) indicated an improved quality of life with a mean change of 3.19 ± 2.05 points. Based on a Wilcoxon matched-pairs signed rank test, these patients with improved overall QOL had statistically significant improvement in all 5 symptoms over time (Fig. 1). Approximately half (46.9%) of the patients showed no change in their quality of life. Of the 41 patients

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