Quality of Life and Health Status in Pediatric Tonsil and Adenoid Disease

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Objective: To assess the baseline global health status and quality of life (QOL) in children with tonsil and adenoid disease.

Design: Cross-sectional multicenter survey series.

Settings: A tertiary academic pediatric specialty hospital and a tertiary academic hospital in 2 different cities.

Patients and Other Participants: Consecutive series of 55 parents of children who were seen for tonsil and adenoid disease.


Main Outcome Measures: Quality-of-life subscale scores of affected children on the Child Health Questionnaire version PF28 (CHQ-PF28); comparisons of population data from healthy normal children and children with asthma and juvenile rheumatoid arthritis.

Results: The overall health status and QOL of children with tonsil and adenoid disease is significantly worse than those of healthy normal children, as demonstrated by lower mean scores on several CHQ-PF28 subscales, including general health, physical functioning, behavior, bodily pain, and parental impact (emotional). In addition, the general health perception of children with tonsil and adenoid disease is similar to the perceptions of children with asthma and juvenile rheumatoid arthritis, but several aspects of health status, as measured by CHQ-PF28 subscale scores, were significantly worse in children with tonsil and adenoid disease.

Conclusion: The health status impact of tonsil and adenoid disease appears to be quite significant, particularly in aspects related to the parental impact of the child’s disease.

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Tonsillectomy and adenoidectomy (adenotonsillectomy) remains one of the most commonly performed pediatric surgical procedures in the United States, although the frequency of adenotonsillectomy has decreased significantly from peak levels in the 1960s. Most of the literature on the effectiveness of adenotonsillectomy has focused on changes in objective measures of disease status (such as number of infections) and not on quality of life (QOL) or overall health status. In addition, most studies have examined only one aspect of tonsil and adenoid disease and have enrolled only severely affected children who met stringent entry criteria. Therefore, it is likely that the impact of tonsil and adenoid disease has been underestimated, since patients with mild or moderate disease were excluded from those studies.

The current accepted indications for adenotonsillectomy differ among authors. In addition, most authors do not suggest thresholds at which nonsurgical treatment, such as antibiotic therapy or watchful waiting, may be appropriate. Uncertainties concerning the indications for surgery are further compounded by the lack of studies that address the health status and QOL of children with tonsil and adenoid disease and by the lack of an instrument to assess tonsil-and-adenoid–specific health status in affected children.

There are literally hundreds of validated instruments available to measure health status and QOL in adults. However, the first validated instruments to assess health-related global QOL in the pediatric population have only recently been developed. Although global instruments are now available for the pediatric population, there is no disease-specific instrument for children with tonsil and adenoid disease. Disease-specific health status instruments are useful to health services researchers because they are often more sensitive than global instruments to subtle changes in health status that are nevertheless important to patients and providers.

We are currently in the process of developing and validating a disease-specific health status instrument for pediatric tonsil and adenoid disease. As part of the process, we surveyed a subgroup of children...
**PATIENTS AND METHODS**

As part of a larger, multisite ongoing study to develop and validate a disease-specific health status instrument for pediatric tonsil and adenoid disease, we have assessed the QOL of a group of children with tonsil and adenoid disease. A sample of consecutive children presenting with tonsil and adenoid disease was assessed from the Baylor College of Medicine Pediatric Otolaryngology Clinic (located at Texas Children’s Hospital, Houston) and the Duke University School of Medicine Pediatric Otolaryngology Clinic (located at Duke University Hospital, Durham, NC). Eligibility criteria, determined by attending physician assessment only, were age 2 to 16 years and any combination of the following diagnoses: recurrent tonsillitis, recurrent pharyngitis, chronic tonsillitis, at least 2 episodes of peritonsillar abscess, tonsil hypertrophy, upper airway obstruction, obstructive sleep pattern, obstructive sleep apnea, and/or sleep hypopnea. Exclusion criteria were any of the following: diagnosis of possible tonsil or adenoid malignant neoplasm, emergency surgery (eg, for peritonsillar abscess), adenoidecomy alone performed for treatment of otologic disease or obstruction, significant immunodeficiency (eg, human immunodeficiency virus infection, severe combined immunodeficiency disorder, or iatrogenic immunodeficiency from treatment of a malignant neoplasm), complete cleft of the secondary palate, and non–English-speaking parent (since the instruments have not been translated into other languages). Once the eligibility criteria were met, the primary caretaker parents of eligible children were asked to enroll in the study. If the parents agreed, after the office visit they completed a group of instruments, including a 23-item pilot version of the tonsil and adenoid health status instrument and the 28-item CHQ-PF28. The attending physician also completed a data sheet for each patient that contained items about the primary diagnosis and other medical problems.

All data were entered into spreadsheets and analyzed using SPSS version 7.0 (SPSS Inc, Chicago, Ill). The CHQ, released in 1997, is a valid, reliable, and responsive instrument designed to assess the physical and psychosocial well-being of pediatric patients. There are 4 different versions of the CHQ: 3 were designed for parental completion, and, of these, the version with the lowest respondent burden is the CHQ-PF28, which contains 28 items. The CHQ-PF28 contains 12 subscales that measure different constructs, or dimensions, of overall health status. These subscales are listed below.

**Physical Functioning**
- Role/social limitations due to emotional/behavioral problems
- Role/social limitations due to physical problems
- Bodily pain/discomfort
- Behavior
- Mental health
- Self-esteem
- General health perceptions
- Parental impact (emotional)
- Parental impact (time)
- Family activities
- Family cohesion

In this study, the CHQ-PF28 was scored and broken down into subscales (range, 0-100) using published algorithms. Comparisons between CHQ subscale scores in children with tonsil and adenoid disease and healthy children, as well as children with known systemic diseases, were made using published data. There are published tables of normal population data that were obtained from healthy volunteers (ie, parents of healthy children) using the CHQ-PF28 instrument. To date, there are no published data on scores of children with known diseases using the CHQ-PF28 version, but there are several reported databases from clinical trials that have used the CHQ-PF50 instrument, and these were reported by Landgraf et al. The 50-item instrument is merely an earlier version of the CHQ-PF28; the method of administration is identical, and every item on the 28-item instrument is found on the earlier version of the instrument. Subscales and scoring algorithms were not significantly changed between the 2 versions, and the published subscale means for the 2 instruments are virtually identical. Therefore, for the purposes of comparison, the CHQ-PF50 subscale scores were used, although the reader is cautioned that because the 2 instruments are not identical, mean scores may not be comparable.

Significance testing between groups was performed by calculating the means and 95% confidence intervals for the subjects in our sample and then comparing the confidence interval with the published means for other groups of children (healthy and with common diseases). If the 95% confidence interval for study group mean scores did not contain the published mean score from the comparison group, then the difference between the groups was statistically significant (ie, P<.05).

In total, 154 children participated in this part of the instrument validation study at the 2 sites. Global QOL and health status data from the CHQ-PF28 were available from a subset of 55 patients; 28 were from Duke and 27 from Baylor. In this subgroup, there were 67% male (n = 37) and 33% female (n = 18) patients, and the mean and median ages were 6.2 years and 6 years, respectively.

The mean subscale scores for children with tonsil and adenoid disease are shown in Table 1; for comparison, the mean subscale scores from a sample of healthy children are also shown. The mean scores of the children with tonsil and adenoid disease were significantly
lower (indicating poorer health status) on almost every subscale than the mean scores of healthy subjects. Mental health and self-esteem subscale scores were lower, but not significantly so, and family cohesion scores were actually significantly higher in the tonsil and adenoid group. In Table 2, mean subscale scores for children with tonsil and adenoid disease are also compared with the mean scores of groups of children with asthma and juvenile rheumatoid arthritis. Overall, general health perceptions for children with tonsil and adenoid disease were similar to general health perceptions for children with asthma and arthritis. However, for children with tonsil and adenoid disease, some subscale scores were lower (indicating poorer health status), including subscales related to emotional impact, behavior, and parental impact of the child's disease.

Subscale-to-subscale relationships on the CHQ-PF28 for children with tonsil and adenoid disease are shown in a correlation matrix in Table 3. Of note, the general health perception for these children was associated with behavior, physical functioning, and the impact on family activities.

Although several authors have studied the effects of adenotonsillectomy, most have studied only the impact of surgery on one aspect of tonsil and adenoid disease (eg, recurrent infection and sleep apnea) and have studied only small numbers of severely affected children. Tonsillectomy has been shown to be effective at decreasing the number of infections in children with severe recurrent throat infections. In addition, adenotonsillectomy for tonsil and adenoid hypertrophy has been shown to be effective in the treatment of obstructive sleep apnea and hypopnea in affected children. However, the impact of tonsil and adenoid disease on the QOL of the majority of affected children has been inadequately documented. In order to study the impact of tonsil and adenoid disease, the severity of tonsil and adenoid disease, and the effectiveness of different treatments for tonsil and adenoid disease, a disease-specific health status instrument is needed.

As discussed earlier, disease-specific instruments have distinct advantages for health services researchers. However, global (or generic) health status and QOL instruments allow benchmarking, comparability with other disease states, and the ability to compare treatment effects across diseases. Therefore, many authors recommend using both disease-specific and global instruments in outcomes studies.

This report concerns primarily the global QOL and health status of children with tonsil and adenoid disease seen in 2 pediatric otolaryngology clinics. As part
of the validation process for a disease-specific health status instrument, the QOL of affected children was assessed with a validated survey—the CHQ-PF28. We assessed health status and QOL by surveying the parents of affected children, which is a useful practice in pediatric QOL research. Much of the public health impact of tonsil and adenoid disease is caused by repeated utilization of health care services, from antibiotics to physician visits, and the impact of this utilization is felt by the caretaker parent. Therefore, caretaker opinions concerning QOL and health status are of critical importance in assessing treatment outcomes and satisfaction.

We found that the global QOL of children with tonsil and adenoid disease was significantly poorer in most areas than the QOL of healthy children, with the exception of mental health and self-esteem. Some subscale scores (for instance, general health perceptions, parental impact, and family activities) were markedly lower for the patients with tonsil and adenoid disease, indicating the significant impact of tonsil and adenoid disease on overall health status and QOL in affected children.

In addition, we compared the QOL scores of children with tonsil and adenoid disease with those of children with 2 other common childhood diseases, asthma and juvenile rheumatoid arthritis. In both cases, the general health perception score was approximately the same, but several other subscale scores were significantly lower for the children with tonsil and adenoid disease (behavior, role/social limitations [both emotional and physical], and parental impact [both emotional and time]). In addition, physical functioning and bodily pain were significantly worse for children with tonsil and adenoid disease than for children with asthma, but not significantly worse than for children with rheumatoid arthritis.

When subscale-subscale correlations on the CHQ-PF28 were assessed, general health perception was noted to correlate significantly with physical function and behavior, indicating that physical functioning and behavior were important predictors of general health status. The emotional aspect of parental impact on health status was correlated with role/social limitations caused by emotional problems, behavior, and bodily pain. The family activities subscale score for patients with tonsil and adenoid disease was also significantly lower than for healthy normal patients, again indicating the significant impact of the family of tonsil and adenoid disease in the child. In addition, this family activities construct was correlated with physical functioning, general health perception, behavior, and parental impact (emotional) and was correlated very strongly with parental impact (time).

In interpreting the results from this cross-sectional survey, 2 important caveats should be kept in mind. First, the children surveyed may also have suffered from other comorbid illnesses, such as diabetes or sinusitis. If so, then the changes in global health status and QOL measured in this study may not be entirely the result of tonsil and adenoid disease. Second, the children studied were being seen by specialists in tertiary referral centers and therefore may not be representative of all children with tonsil and adenoid disease.

In summary, the health status and QOL impact of tonsil and adenoid disease appears to be quite significant. Further research is needed to assess the natural history of untreated tonsil and adenoid disease and to measure the effects of treatments, such as adenotonsillectomy.

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