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Are validated patient-reported outcomes used on children in pediatric otolaryngology? A systematic review



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ABSTRACT

Objectives: Review the pediatric otolaryngology literature to 1) identify studies in which children completed patient-reported outcome (PRO) measures and 2) appraise the psychometric quality and validity of these PROs as they apply to pediatrics.

Methods: In October 2016, a systematic review was performed by two reviewers on PubMed/MEDLINE and EMBASE for all otolaryngology-related studies that utilized PROs in children. Inclusion criteria included articles that required children (age < 18) to complete PROs. Exclusion criteria included validation studies, reviews, and abstracts. Interreviewer agreement was determined using Cohen's kappa. Quality and rigor of validation testing for included PROs was determined using the COnsensus-based Standards for selection of health status Measurement Instruments.

Results: Interrater agreement was very good ($\kappa = 0.91$; 95% CI, 0.85–0.98). Out of 316 articles retrieved, 11 met inclusion criteria. Eight PROs were identified. Six PROs were tested for validity and three of these PROs were tested for validity specifically within children. The most frequently utilized PRO was the Pediatric Rhinoconjunctivitis Quality of Life Questionnaire. Two studies (18.2%) utilized PROs within the scope of their validation. Seven studies (63.6%) used PROs outside the scope of their validation. Two studies (18.2%) used non-validated PROs.

Conclusions: Patient-reported outcomes have become an integral part of research and quality improvement. There is a relative paucity of PROs directed towards children in pediatric otolaryngology and some studies utilized PROs that were not validated or not validated for use in this age group. Future efforts to design and validate more instruments may be warranted.

1. Introduction

As quality improvement and patient-centered care become central tenets of modern healthcare [1,2], patient-reported outcome (PRO) measures have become important tools to help physicians assess the quality and effectiveness of care [3]. Patient-reported outcome measures allow patients to directly convey the impact of their disease on their own health and quality of life [4]. This can provide deeper insight into a patient's subjective experience beyond traditional metrics such as lab values, vitals, or imaging. A variety of Otolaryngology-related conditions have previously shown to benefit from PROs, which provide an additional way to assess disease impact on health status and quality

of life [5–8]. With increasing attention placed on accurate measures of health impact, validating outcome measurements has become a pertinent and ever-important movement to advance clinical evaluation and treatment.

Non-validated PROs and PROs created for use in adults are sometimes used in children due to a lack of suitable alternatives [9,10]. This can be problematic for several reasons. First, regardless of age, using validated PROs is important to ensure that a given instrument is measuring what it is supposed to. Careful design and psychometric analysis also ensures that a PRO can provide consistent and reliable outcome measures [11,12]. Unfortunately, validation of a PRO in adults does not necessarily translate to validity in children [13]. Examining PROs that

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are designed for adults can reveal ways in which they can be “lost in translation” in the pediatric population. For example, many items may not address concepts that children value or understand, such as the impact of disease on driving or buying groceries [14]. Children also have vastly different language and cognitive abilities – not only compared to adults, but even amongst each other across different age groups [15]. This can decrease the readability and comprehensibility of PROs, making them too difficult for some children to complete. In short, a complex interplay of differences between children and adults can influence a child's ability to complete traditional PROs.

Despite these limitations, previous studies have shown that PRO measures that have not been validated in children are sometimes used to draw conclusions in pediatric research [10,16]. No study has investigated this topic in pediatric otolaryngology. We sought to fill this gap in knowledge by reviewing the otolaryngology literature for studies that administered PROs to children. Our goal was to 1) identify all PROs completed by children and 2) evaluate the psychometric performance and quality of these PROs as they relate to pediatric otolaryngology. We hypothesized that few PROs would be specific to pediatric otolaryngology. Among studies that administered PROs to children, we predicted that few would use instruments that were previously validated in this age group.

2. Materials and methods

This study was exempt by the Boston Medical Center institutional review board (H35712). We performed a review of the otolaryngology literature that followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

2.1. Search strategy

On October 26, 2016 a search was performed on PubMed/MEDLINE and EMBASE without limitations in publication date. The objective of this search was to identify all PROs completed by children in the otolaryngology literature. Search terms and controlled vocabulary were determined by an expert research librarian (A.P.L.) at the Boston University Alumni Medical Library (Boston, MA), and key concepts included surveys, questionnaires, and patient-reported outcome measures. The following 2 search strategies were combined: [“infant” OR “toddler” OR “children*” OR “teenager*” OR “adolescent*” OR “childhood” OR “pediatric*”] AND [“PROM*” OR “patient reported outcome measures*” OR “quality of life*” OR “QOL” OR “questionnaire” OR “survey” OR “instrument”]. For terms marked with *, an unlimited clipping strategy was used (e.g., *child* from *children*) and all variations of certain terms were captured (e.g., *pediatric* from *pediatric*). Results were exported onto Mendeley citation manager and duplicates were removed.

2.2. Article selection

Inclusion criteria included studies published by journals in the “Otorhinolaryngology” category of the Scimago Journal and Country Rank (Appendix) and articles that required children (age < 18 years old) to complete PROs. Exclusion criteria included validation studies, review articles, and abstracts without full-length articles. Full-text articles were obtained for 1) abstracts that met inclusion criteria 2) abstracts that did not provide sufficient information to make a screening decision, and 3) abstracts with reviewer disagreement. A secondary literature search was performed by reviewing the reference lists for all full-text articles to identify any additional articles that met our criteria. All search results were independently reviewed by two authors (K.W. and A.S.). Cohen's kappa statistic was run to determine interrater

Table 1
Psychometric grading rubric.

Property	Scoring System
Reliability	+ : test-retest between 0.70 and 0.90, Cronbach α between 0.70 and 0.90, or ICC between 0.60 and 0.75 + + : test-retest score \geq 0.90, Cronbach $\alpha \geq$ 0.90, or ICC \geq 0.75
Validity	+ + : correlation with other standardized concept measures \geq 0.70
Floor and Ceiling Effect	+ + : < 15% of respondents receive highest or lowest score
Acceptability	+ : < 15% of incomplete data or missing responses + + : < 5% incomplete data or missing responses
Feasibility	+ : < 10 min and reasonably limited required resources + + : < 5 min and easy to record and analyze measures

“+” = minimal acceptable rating; “+ +” = better than minimal acceptable rating.

Abbreviation key: ICC = Intraclass correlation coefficient.

agreement in article eligibility using the above-mentioned criteria. The senior author (J.R.L.) confirmed all articles for inclusion and exclusion criteria.

2.3. Data collection

Information recorded from each article included study title, authorship, publication year, journal, study type, sample size, subject age range, study outcomes, and PRO(s) used. For each PRO, instrument properties were recorded using an *a priori* template that included the following descriptions: concept measured, intended age, number of domains, number of items, and scoring system.

2.4. Quality assessment

The psychometric performance of each PRO was evaluated using the COSMIN-based Standards for selection of health status Measurement INstruments (COSMIN) guidelines [17]. To this end, performance in the areas of reliability, validity, and feasibility were graded for each PRO according to minimal acceptable quality recommendations that have been previously described [18] and outlined in Table 1.

The COSMIN checklist is a standardized approach for evaluating the methodological rigor of studies analyzing the psychometric properties of PROs. We chose this guideline because it delineates a comprehensive set of criteria including internal consistency, content validity, construct validity, and reliability. Previous studies have successfully assessed the validity of Otolaryngology-related PROs in other areas using these guidelines [19–21].

3. Results

3.1. Search results

Fig. 1 displays the flow chart of results from our search. In total, 316 unique abstracts were identified through our search strategy and 51 full-text articles were reviewed for eligibility. Interrater agreement for article selection was very good ($\kappa = 0.91$; 95% CI, 0.85–0.98). Forty articles were excluded after review of the full-text article, leaving 11 studies ultimately fulfilling all inclusion and exclusion criteria. A summary of included studies is provided in Table 2 [22–32].

3.2. Instrument descriptions

Eight PROs were identified from the eleven studies. Three instruments were intended for use in adults (37.5%), three were intended for

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