

A systematic review of patient-reported outcome measures in paediatric otolaryngology

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Abstract

Background: Recently, there has been increased emphasis on the development and application of patient-reported outcome measures. This drive to assess the impact of illness or interventions, from the patient's perspective, has resulted in a greater number of available questionnaires. The importance of selecting an appropriate patient-reported outcome measure is specifically emphasised in the paediatric population. The literature on patient-reported outcome measures used in paediatric otolaryngology was reviewed.

Methods: A comprehensive literature search was conducted using the databases Medline, Embase, Cumulative Index to Nursing and Allied Health Literature, and PsycInfo, using the terms: 'health assessment questionnaire', 'structured questionnaire', 'questionnaire', 'patient reported outcome measures', 'PROM', 'quality of life' or 'survey', and 'children' or 'otolaryngology'. The search was limited to English-language articles published between 1996 and 2016.

Results: The search yielded 656 articles, of which 63 were considered relevant. This included general paediatric patient-reported outcome measures applied to otolaryngology, and paediatric otolaryngology disease-specific patient-reported outcome measures.

Conclusion: A large collection of patient-reported outcome measures are described in the paediatric otolaryngology literature. Greater standardisation of the patient-reported outcome measures used in paediatric otolaryngology would assist in pooling of data and increase the validation of tools used.

Key words: Outcome Assessment (Health Care); Health Impact Assessment; Surveys And Questionnaires; Patient Reported Outcome Measures; Quality Of Life; Children

Introduction

Over recent years, there has been an increased emphasis on the development and application of patient-reported outcome measures.¹ This drive to assess the impact of illness or interventions, from the patient's perspective, has resulted in a large expansion of available questionnaires.² Patient-reported outcome measures are usually designed to measure one of two broad themes, either patients' perceptions of their general health, or their perceptions of their health in relation to specific diseases or conditions.

The selection of a patient-reported outcome measure requires careful consideration regarding the content of the questionnaire and its relevance to the intended patient group. An appropriate measure is one that is supported by published evidence demonstrating that it is: acceptable to patients, reliable, valid and responsive (sensitive to change).³ In addition, evidence for these

properties needs to have been obtained in a similar context, and on similar types of patients (in terms of age range, gender, and diagnostic or surgical category) to those whom the patient-reported outcome measure is to be applied.

The importance of selecting an appropriate patient-reported outcome measure is specifically emphasised in the paediatric population. Many adult-designed patient-reported outcome measures may contain items that are irrelevant to children (e.g. driving, financial outcomes), or use language and response categories that are not age-appropriate.

We therefore reviewed the current literature on patient-reported outcome measures used in paediatric otolaryngology. This included general paediatric patient-reported outcome measures applied to otolaryngology patients, and otolaryngology disease-specific patient-reported outcome measures.

Materials and methods

A comprehensive literature search was conducted on 14 December 2016 using the databases Medline, Embase, Cumulative Index to Nursing and Allied Health Literature, and PsycInfo. The search terms used were: ‘health assessment questionnaire’, ‘structured questionnaire’, ‘questionnaire’, ‘patient reported outcome measures’, ‘PROM’, ‘quality of life’ or ‘survey’, and ‘children’ or ‘otolaryngology’.

Results

The search yielded 656 articles. The results were limited to English-language articles published from 1996 to 2016; this yielded 562 articles. Removal of duplicates returned 395 articles. Of these, 82 article abstracts were screened; this yielded a total of 63 relevant articles. Searching the bibliographies of these articles identified further articles that were reviewed.

Disease-specific patient-reported outcome measures

A large number of questionnaires were identified related to the conditions of otitis media,^{4–14} hearing loss,^{15–18} obstructive sleep apnoea,^{19–30} voice disorders,^{31,32} and sore throat and tonsillitis.^{33–38} A number of other questionnaires were infrequently described, related to other specific otolaryngology conditions (Table I).^{39,40} Each tool was of a varying length and underwent variable degrees of validation (Table I). We also identified multiple institutional designed questionnaires, which underwent little or no validation.^{41–43}

General patient-reported outcome measures

The paediatric otolaryngology literature describes a large number of general patient-reported outcome measures that have been utilised.^{8,20,21,38,44–64} Overall, these are extensively validated tools from a non-otolaryngology origin that have been applied to otolaryngology conditions or procedures (Table II).

Discussion

We identified a large number of both disease-specific and general patient-reported outcome measures that have been used in the paediatric otolaryngology literature. Many publications used a mixture of a disease-specific patient-reported outcome measures and general patient-reported outcome measures. Disease-specific patient-reported outcome measures are usually more sensitive to differences in one organ system, compared with generic instruments. For otolaryngology, this may be particularly important to detect improvements with treatment. Nevertheless, general tools are important to patients and healthcare commissioners, as they measure more global changes in health status and allow comparison with other conditions.^{1–3}

A large number of disease-specific patient-reported outcome measures were identified for the five conditions of otitis media, hearing loss, obstructive sleep apnoea, voice disorders, and sore throat and tonsillitis, which not unsurprisingly are the more common paediatric otolaryngology presentations.

In cases of otitis media, the Otitis Media-6 (‘OM-6’) questionnaire was by far the most extensively validated

TABLE I
DISEASE-SPECIFIC PATIENT-REPORTED OUTCOME MEASURES USED IN PAEDIATRIC OTOLARYNGOLOGY*

Condition	Patient-reported outcome measure	Number of items	Completed by:	Ease of scoring
Otitis media	Otitis Media-6 questionnaire ^{4,6–11}	6	Caregiver	Easy
	Otitis Media Outcome-22 questionnaire ^{10,12}	22	Caregiver	Easy
	Chronic Otitis Media-5 survey ^{13,14}	5	Caregiver	Easy
Hearing loss	Hearing Environments & Reflection on Quality of Life questionnaire ¹⁵	26	Adolescents aged 13–18 years	Easy
	Youth Quality of Life Instrument – Deaf & Hard of Hearing module ¹⁶	32	Adolescents aged 11–18 years	Easy
	Paediatric Hearing Impairment Caregiver Experience questionnaire ^{17,18}	68	Caregiver	Easy
Obstructive sleep apnoea	Obstructive Sleep Apnea-18 questionnaire ^{19–25}	18	Caregiver	Easy
	Clinical Assessment Score-15 ^{26,27}	15 (10 history, 5 physical signs)	Clinician	Moderate
	Rutter Children’s Behavior Questionnaire ²⁸	18	Caregiver	Moderate
	Children’s Sleep Habits Questionnaire ²⁸	45	Caregiver	Moderate
	Child Health Questionnaire Parent Form 28 ²⁹	28	Caregiver	Moderate
Voice disorders	OSD-6 instrument ³⁰	6	Caregiver	Easy
	Pediatric Voice-Related Quality of Life survey ^{31,32}	10	Caregiver	Easy
	Paediatric Vocal Handicap Index ^{32,65}	23	Caregiver	Moderate
	Pediatric Voice Outcomes Survey ^{31,66,67}	4	Caregiver	Easy
Sore throat & tonsillitis	Paediatric Throat Disorders Outcome Test ^{33–37}	14	Caregiver	Easy
	Tonsil & Adenoid Health Status Instrument ³⁸	18	Caregiver	Easy
Other tools	Pediatric Tracheotomy Health Status Instrument ³⁹	34	Caregiver	Moderate
	Post-Operative Pinnaplasty Questionnaire ⁴⁰	7	Caregiver or child	Easy

*Identified from the literature review.

TABLE II
GENERAL PATIENT-REPORTED OUTCOME MEASURES USED IN PAEDIATRIC OTOLARYNGOLOGY*

Patient-reported outcome measure	Number of items	Completed by:	Ease of scoring
Glasgow Children's Benefit Inventory ^{44–48}	24	Caregiver	Easy
Pediatric Quality of Life Inventory ^{49–51}	23	Caregiver or older children	Easy
Pediatric Quality of Life Inventory Family Impact survey ^{52,53}	36	Caregiver	Easy
Child Health Questionnaire ^{38,54–56}	28, 50 or 87	Caregiver or child aged 5–18 years	Easy to moderate
TNO-AZL Preschool Quality of Life Questionnaire ^{8,58,59}	43	Caregiver	Easy
KINDL-R questionnaire ^{60,61}	Various	Various versions for different age groups	Easy
Child Behavior Checklist ⁶²	Various	Various versions for different age groups	Moderate
Parenting Stress Index Short Form ⁶³	18	Caregiver	Easy
Caregiver Impact Questionnaire ⁶⁴	6	Caregiver	Easy

*Identified from the literature review.

tool.^{4–11} The Otitis Media Outcome-22 ('OMO-22') questionnaire was another prominent tool.^{10,12} These tools were principally discriminated by their number of questions, providing a trade-off between response rate and sensitivity to change (lower in longer tools), versus the collection of what may be important information (easier in longer tools). A specific chronic suppurative otitis media tool was also identified, the Chronic Otitis Media-5 ('COM-5') survey.^{13,14}

For hearing loss, more frequently generic quality of life (QoL) measures were used. However, disease-specific tools were also described; these included the adolescent-completed Hearing Environments and Reflection on Quality of Life ('HEAR-QL') questionnaire,¹⁵ the Youth Quality of Life Instrument – Deaf and Hard of Hearing ('YQOL-DHH') module,¹⁶ and the caregiver-reported Paediatric Hearing Impairment Caregiver Experience ('PHICE') questionnaire.^{17,18} All of these are fairly lengthy questionnaires related to hearing and general QoL.

A number of obstructive sleep apnoea specific health-related QoL measure were identified. Of these, the Obstructive Sleep Apnea-18 ('OSA-18') questionnaire, which was first described by Franco *et al.*,¹⁹ was the most widely used and validated QoL survey for the assessment of paediatric obstructive sleep apnoea.^{20–25} A number of other validated tools have also been described.^{26–30} Once again, the greatest discriminator was the length and form of the tool. The Clinical Assessment Score-15 ('CAS-15') stood out as the only clinic-completed tool identified, which included clinical and examination findings.

The literature concerning paediatric voice specific questionnaires was dominated by three frequently used tools, adapted from previously validated adult forms: the Pediatric Voice-Related Quality-of-Life ('PVRQOL') survey,^{31,32} the Paediatric Vocal Handicap Index ('pVHI')⁶⁵ and the Pediatric Voice Outcomes Survey ('PVOS').^{31,66,67}

Paediatric throat health related QoL was almost entirely reported on using the Paediatric Throat

Disorders Outcome Test ('T-14').^{33–37} Designed by Hopkins *et al.*,³⁴ this 14-item disease-specific questionnaire has been extensively validated and reported upon in children. The only other identified measure was the infrequently used Tonsil and Adenoid Health Status Instrument ('TAHSI'), from which the Paediatric Throat Disorders Outcome Test derives many question items.³⁸ A number of other questionnaires were infrequently described, including the Pediatric Tracheotomy Health Status Instrument ('PHTSI')³⁹ and the Post-Operative Pinnaplasty Questionnaire ('POPQ').⁴⁰

A number of general patient-reported outcome measures are described in the paediatric otolaryngology literature. The Glasgow Children's Benefit Inventory ('GCBi') was developed by Kubba *et al.*⁴⁴ to assess health-related QoL pre- and post-intervention, and has been extensively validated and used in a number of otolaryngology interventions.^{45–48} The less widespread use of this tool outside otolaryngology limits the global comparability of its findings with other non-otolaryngology interventions, which may be of importance to certain groups such as commissioners.

Tools such as the Pediatric Quality of Life Inventory ('PedsQL') have also been extensively used in otolaryngology, and in other specialties. It gives a global health overview, and usefully has two forms: the parent proxy report form and the age-specific child self-report form.^{49–51}

Similarly, the KINDL-R questionnaire for measuring health-related QoL in children and adolescents,^{60,61} the Child Health Questionnaire ('CHQ')^{38,54–56} and the Child Behavior Checklist ('CBCL')^{20,21,62} are general patient-reported outcome measures that have different forms for various age groups. These tools have the benefit of age-appropriate questions, but their use would potentially limit comparison of the findings outside of that age group.

Other generic tools have been used in otolaryngology and are completed by the caregiver, such as the TNO-AZL (Netherlands Organisation for Applied Scientific Research Academic Medical Centre)

Preschool Quality of Life Questionnaire ('TAPQOL'), specifically designed for pre-school children.^{8,58,59} Several generic tools have been described to specifically assess the impact of a disease on the family or caregiver, such as the Pediatric Quality of Life Inventory Family Impact survey,^{52,53} the Parenting Stress Index Short Form ('PSI-SF')⁶³ and the Caregiver Impact Questionnaire ('CIQ').⁶⁴

There were several incidences of patient-reported outcome measures being used inappropriately in the paediatric otolaryngology literature. We found instances where the wording of questionnaires was changed. It is important to note that the wording of a validated patient-reported outcome measure should not be changed because even relatively small alterations can make a considerable difference to the meaning of the questions and consequently to the measurement properties of a questionnaire.^{2,3}

We also identified numerous cases where patient-reported outcome measures were applied to very different groups or situations to those on which they were validated; for example, the use of adult patient-reported outcome measures, completed by caregivers on the child's behalf, or the use of adult patient-reported outcome measures in adolescents. The term 'paediatric' covers a broad range, and while many of the general patient-reported outcome measures had multiple age-appropriate questions, many of the disease-specific questionnaires were only validated for specific age ranges. Furthermore, patient-reported outcome measures data need to be obtained from relevant patients at the same point in time relative to the date of an intervention or event of interest.^{2,3}

It should also be noted that a number of the patient-reported outcome measures, particularly the general patient-reported outcome measures, had different versions available, and this needs to be considered when comparing to previously published studies using older versions.

We also identified a distinct lack of consistency regarding the methods for the development of patient-reported outcome measures in paediatric otolaryngology. The methods of validation contained many similarities, but were not universal; statistical methods and validation samples sizes varied radically.

The availability of multiple disease-specific and general patient-reported outcome measures is useful to the paediatric otolaryngologist. However, more consistent use of a smaller number of tools would allow for greater standardisation, and would assist in the pooling of data from multiple institutions and studies.

Selecting the appropriate patient-reported outcome measure can be challenging. This is emphasised in the otolaryngology literature from the extensive number of tools used for certain conditions; for example, otitis media.^{4–14}

When assessing a patient-reported outcome measure, it is crucial to review the six key areas of: validity, test–retest reliability, precision, responsiveness,

acceptance and response rate, and feasibility.^{1–3} Regarding validity, one should consider whether the patient-reported outcome measure assesses what it is supposed to. Changes in patient-reported outcome measure scores can be caused by a multitude of factors, not just the intervention that is being measured. With regard to test–retest reliability, do respondents score similarly on different occasions? Precision is epitomised by the disease-specific or general patient-reported outcome measure debate; can the patient-reported outcome measure discriminate a disease or intervention from a control group? Linking in with precision, responsiveness refers to the ability to measure change after an intervention or change in disease state. Acceptance and response rate are particularly important in paediatric questionnaires. Are the questions appropriate for children (e.g. do they contain questions about employment)? Linking in with acceptance and response rate, a long questionnaire may not be feasible in many clinic settings.

It is also crucial to review the literature on the previous use of any patient-reported outcome measure, considering particularly the age groups that it is appropriate for and whether there are reference data for the comparison group.

It is impossible to have one patient-reported outcome measure that covers all potential research or clinical questions posed in paediatric otolaryngology. For example, the 22-item Otitis Media Outcome-22 questionnaire provides more information than the 6-item Otitis Media-6 questionnaire, but may have a reduced response rate given its length and reduced sensitivity to change.⁴

Researchers and clinicians should aim to use the most appropriate patient-reported outcome measure for their question, but also consider the comparability with previous studies on that condition. We would advocate, whenever possible, using a disease-specific and/or general patient-reported outcome measure that is frequently cited for the condition of interest, and ensure it is suitably validated, with relevant reference data.

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