ISSN: 2083-389X
eISSN: 2084-3127

© J Hear Sci, 2022; 12(4): 9–15
DOI: 10.17430/JHS.2022.12.4.1

HEALTH-RELATED QUALITY OF LIFE IN CHILDREN HOSPITALISED DUE TO FOUR ENT ILLNESSES: A SELECTIVE REVIEW

Lechosław Paweł Chmielik[1,2A-F], Grażyna Mielnik-Niedzielska[3ABD-F], Artur Niedzielski[1,2ACEF]

[1] Department of Pediatric Otolaryngology, Centre of Postgraduate Medical Education, Dziekanow Lesny, Poland
[2] Department of Pediatric ENT, Children's Hospital in Dziekanow Lesny, Poland
[3] Department of Pediatric Otolaryngology, Medical University of Lublin, Poland

Corresponding author: Lechosław Chmielik, Department of Pediatric Otolaryngology, Centre of Postgraduate Medical Education, Konopnickiej 65, 05-096, Dziekanow Lesny, Poland; email: l.p.chmielik@chmielik.pl

Contributions:
A Study design/planning
B Data collection/entry
C Data analysis/statistics
D Data interpretation
E Preparation of manuscript
F Literature analysis/search
G Funds collection

Abstract

Introduction: The concept of health-related quality of life (HRQOL) is nowadays increasingly and more broadly used for evaluating the effectiveness of medical treatment, superseding the earlier 'quality of life'. The reason is that subjective parameters have now been added – such as health, freedom, and happiness – to previous objective parameters such as social development and material wellbeing. The HRQOL concept applies equally well to otolaryngology and this selective review of the literature focuses on HRQOL outcomes in four childhood ENT diseases. Study aim is to retrospectively evaluate the literature on HRQOL in children hospitalised for chronic sinusitis, nasal septum deviation, adenoid hypertrophy, or hearing disease.

Material and methods: Published studies and case reports were searched in Medline/PubMed, Web of Science, Scopus, and ORCID on quality of life based on paediatric patient questionnaires, whether completed by the subjects themselves or their parents. As well as confining results to the four selected illnesses, the following key words were used: health quality of life, otolaryngology/ENT, pediatrics/paediatrics. The review is selective, not comprehensive, with total results limited to 25 studies. Studies before 1999 were omitted because before then 'quality of life' was imprecisely defined.

Results: HRQOL scores and well-being were found to significantly deteriorate in pediatric patients suffering from chronic sinusitis, nasal septum deviation, adenoid hypertrophy, or hearing disease. The main problems found were infection, inflammation, disruption to family life and child–parent interaction, fitness-related issues, reduced ENT patencies, and apnea.

Conclusions: HRQOL significantly deteriorates in children suffering from the defined ENT diseases. Further studies are needed to cover all ENT diseases.

Key words: otolaryngology • pediatrics • health quality of life

JAKOŚĆ ŻYCIA ZWIĄZANA ZE STANEM ZDROWIA DZIECI Z WYBRANYMI CHOROBAMI OTORYNOLARYNGOLOGICZNYMI: PRZEGLĄD LITERATURY

Streszczenie

Wprowadzenie: Koncepcja jakości życia związanej ze zdrowiem (HRQOL) jest współcześnie coraz częściej stosowana do oceny skuteczności leczenia i zastępuje wcześniejszą definicję. Powodem jest dodanie parametrów subiektywnych, takich jak zdrowie, wolność i szczęście, do wcześniej stosowanych parametrów obiektywnych, takich jak rozwój społeczny i dobrobyt materialny. Koncepcję HRQOL można równie dobrze zastosować w otolaryngologii. Niniejszy wybiórczy przegląd literatury skupia się na wynikach HRQOL w czterech dziecięcych chorobach ORL. Celem badania jest retrospektywna ocena literatury na temat HRQOL dzieci hospitalizowanych z powodu przewlekłego zapalenia zatok, skrzywienia przegrody nosowej, przerostu migdałków lub zaburzeń słuchu.

Materiał i metody: Opublikowane badania i opisy przypadków wyszukane w bazach Medline/PubMed, Web of Science, Scopus i ORCID, dotyczące jakości życia w oparciu o pediatryczne kwestionariusze pacjentów, wypełniane przez pacjentów samodzielnie lub przez rodziców pacjentów. Poza ograniczeniem wyników wyszukiwania do czterech wybranych chorób, zastosowano następujące słowa kluczowe: jakość życia związana ze zdrowiem, otolaryngologia/ORL, pediatria. Przegląd jest wybiórczy, niewyczerpujący, ostateczne wyniki są ograniczone do 25 opublikowanych badań. Badania opublikowane przed rokiem 1999 zostały pominięte ponieważ przed tym rokiem pojęcie jakości życia było zdefiniowane nieprecyzyjnie.

Wyniki: Wyniki badania wskazują, że poziom HRQOL i dobrostan ulegają znaczącemu pogorszeniu u pacjentów pediatrycznych ciepiących z powodu przewlekłego zapalenia zatok, skrzywienia przegrody nosowej, przerostu migdałków lub zaburzeń słuchu. Najważniejszymi problemami były infekcje, stany zapalne, zakłócenie życia rodziny i interakcji dziecko–rodzic, problemy związane z kondycją fizyczną, pogorszona drożność uszu, nosa i gardła oraz bezdech.

Wnioski: HRQOL ulega znaczącemu pogorszeniu u dzieci cierpiących na określone choroby ORL. Konieczne są dalsze badania obejmujące wszystkie choroby ORL.

Słowa kluczowe: otolaryngologia • pediatria • jakość życia związana ze zdrowiem

Introduction

Numerous attempts have been made to find a uniform definition for the quality of life, but none have as yet met with general acceptance [1–3]. The 'quality of life' issue only began being addressed in the latter half of the 20th century. Criteria used for its assessment were initially those measuring levels of social development in the USA and Western Europe. At first, only objective parameters were considered, such as material well-being and social development; however, subjective and non-material parameters were later added – like health, freedom, and happiness – leading to the HRQOL concept. Indeed, the subjective parameters have attracted increasing attention recently. This is also the case in the otolaryngology field where assessing a patient's HRQOL has become important.

Quality of life definition

Quality of life can be simply defined as the area of human life that directly concerns a person and which is important to them [5]. The World Health Organization (WHO) defines 'quality of life' as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. The following can be included in the concept of 'quality of life': levels of freedom/independence; mental health; physical health; social belonging; the environment; and religious beliefs, convictions, and views [1,3,6]. Allowing for the wide range of subjects covered when defining 'quality of life', the medical field has introduced the term 'health-related quality of life' (HRQOL) [1,6].

Relationship between quality of life and health status

In the 1940s, WHO defined 'health' as not only the absence of illness, but also including physical and mental well-being and social belonging [4]. Quality of life includes those areas of life directly concerned with patient health. Other factors not included are freedom, income level, or quality of the natural environment [7,8]. In the 1970s, the holistic approach became embraced in medicine which generated interest in the HRQOL concept. Any therapeutic process should make a patient's life active and, as far as possible, return it to that of a healthy person [1,2,6]. Assessing HRQOL has also found application in pediatric otolaryngology.

There are specific difficulties in testing HRQOL in children, and it is necessary to use separate questionnaires that are adapted to children's developmental changes [9,11]. It is also necessary to account for the differences in perception of various aspects of life between children and adults. Questionnaires used in pediatrics should assess family relationships, active spending of time, self-esteem, external appearance of the child, and contacts with peers [9–11]. Engaging in sports and physical fitness also affects the quality of life in children [11]. Although both parents (or guardians) and children can make an assessment of their HRQOL, their ratings do not always coincide. However, both are important when evaluating a child's overall HRQOL [10]. The reason is that parents will inevitably have some effect on their child's diagnosis and therapy; in addition, any physical or mental impairment of the child, or their immaturity, can prevent the child from completing the questionnaire on their own [10]. Parental assessment of HRQOL that covers a long follow-up period may be more reliable because inconsistencies in the child's viewpoint, perhaps caused by immaturity, are removed [9,11]. Greater agreement between parents and offspring on HRQOL measures has been found when children have a chronic disease, compared to HRQOL measures between healthy children and their parents [9–11].

Study aim

Our aim was to retrospectively evaluate HRQOL measures in children hospitalized due to one of four otolaryngological/ENT illnesses by conducting a review of the available literature in this area.

Material and methods

We reviewed published studies on HRQOL which measured children's well-being during treatment in four otolaryngological diseases: chronic sinusitis, nasal septum deviation, adenoid hypertrophy, and hearing disease. Generally, the questionnaires for measuring HRQOL needed to meet certain criteria, principally *responsiveness* (the ability to detect a minimal change during testing), *reliability* (the ability to obtain reproducible results for consecutive measurements), and *validity* (the ability to measure intended parameters) [7,9,10]. Questionnaires were either completed by the child themselves or, to avoid any misunderstandings, in most cases by their parents. The review consisted in searching PubMed, Web of Science, and Scopus. The ORCID digital ID search engine was also used as a safeguard to identify any possible publications of relevance that might have been missed by the other search engines. The following key words were used: health quality of life, otolaryngology/ENT, pediatrics/paediatrics, nasal septum deviation, nasal quality, chronic sinusitis, adenoid/tonsil hypertrophy, adenoidectomy, adenotonsillectomy, chronic otitis media, hearing disorders, and cochlear implant.

Table 1. Ten randomly selected HRQOL studies on tonsil hypertrophy

First author's name and reference number	Whether validated questionnaires were used	Whether general questionnaires were used	Whether specific questionnaires were used	Whether treatment efficacy was studied	Whether questionnaires were adapted to a given language	Number of subjects
Stewart [25]	+	+	–	–	+	55
Michell [26]	+	–	+	+	+	60
Ericsson [27]	+	–	+	+	+	67
Franco [28]	+	–	+	+	+	61
Garetz [47]	+	–	+	+	+	453
Stepan [19]	+	–	+	+	+	146
Fehrm [20]	+	–	+	+	+	60
Lee [21]	+	–	+	+	+	144
Lushington [22]	+	–	+	+	+	64
Türkoğlu [23]	+	+	–	+	+	64

Table 2. Seven selected HRQOL studies on chronic sinusitis

First author's name and reference number	Whether validated questionnaires were used	Whether general questionnaires were used	Whether specific questionnaires were used	Whether treatment efficacy was studied	Whether questionnaires were adapted to a given language	Number of subjects
Rudnick [41]	+	–	+	+	+	22
Ahmed [30]	+	–	+	–	+	163
Makary [31]	+	–	+	+	+	80
Lai [32]	+	–	+	+	+	85
Calvo-Henriquez [33]	+	–	+	+	+	81
Calvo-Henriquez [34]	+	–	+	+	+	137
Sethi [35]	+	–	+	+	+	35

Studies prior to 1999 were omitted because 'quality of life' had until then been imprecisely and variously defined. Only HRQOL-based studies were considered in this review.

Inclusion criteria consisted of selecting quality of life studies in pediatric otolaryngology written in English, with > 50 subjects, and using validated questionnaires. Exclusion criteria were studies not in English, ENT subjects aged > 18 years, insufficient numbers of subjects, non-validated questionnaires, and any studies prior to 1999. If there were more than 10 studies found eligible per condition, then 10 were randomly selected to constitute the analyzed group. The criterion of having > 50 subjects was however waived in the case of chronic sinusitis, where a threshold of $n \geq 20$ was adopted because of the small numbers of studies meeting the original criterion. We recognise that the Evidence Based Medicine (EBM) power of these studies may have been thereby compromised.

Results

In terms of tonsil hypertrophy, we found 164 eligible studies out of 12,354 studies on HRQOL. Of these, 10 were randomly entered into the study group as presented in **Table 1**. For chronic sinusitis, there were 7 eligible studies out of 2,248 studies on HRQOL. These papers constituting the study group are presented in **Table 2**. There were 4 eligible studies out of 10,128 studies on HRQOL in papers with nasal septum deviation; these papers are listed in **Table 3**. Finally, there were 4 eligible studies out of 4,355 studies on HRQOL in papers with hearing disease that constituted the study group as presented in **Table 4**. This meant that, in total, 25 studies were selected for our study group.

Some of the reasons for rejecting studies for **Table 4** were insufficient numbers of subjects (in one study, only 7 subjects were finally analyzed out of 53 patients), the use of non-randomized procedures, published in a non-English language, or based on adults.

Table 3. Four selected HRQOL studies on nasal septum deviation

First author's name and reference number	Whether validated questionnaires were used	Whether general questionnaires were used	Whether specific questionnaires were used	Whether treatment efficacy was studied	Whether questionnaires were adapted to a given language	Number of subjects
Valsamidis [43]	+	–	+	+	+	60
Gary [44]	+	–	+	+	+	65
Saniasiaya [45] (study with a literature review)	+	+	+	+	+	267 (28–136)
Manteghi [46]	+	–	+	+	+	136

Table 4. Four selected HRQOL studies on hearing disease

First author's name and reference number	Whether validated questionnaires were used	Whether general questionnaires were used	Whether specific questionnaires were used	Whether treatment efficacy was studied	Whether questionnaires were adapted to a given language	Number of subjects
Smit [52]	+	+	+	–	+	161
Chow [53]	+	–	+	+	+	53
Lameiras [51]	+	–	+	+	+	169
Zhumabayev [54]	+	–	+	+	+	53

Many problems and complications were found and are considered further in the next section, but mainly include: family and physical activity/function, general health, social behaviour, pain discomfort, mental and emotional health, impaired nasal and other ENT patencies, breathing and speech problems, apnea, disturbed sleep, fatigue, and dysphagia. Some appeared in the short term and others in the long term.

We found that 23 of the 25 studies selected for analysis (i.e., 92%) had used specific HRQOL questionnaires, whereas general ones had been used 4 times (8%). The effect of treatment on HRQOL had also been evaluated in 23 studies.

The vast majority of HRQOL studies on ENT are focused on HRQOL before and after treatment using a very specific test. However, no studies were found comparing the HRQOL of sick with healthy children, nor studies comparing the HRQOL in children with ENT diseases with each other or with children suffering from other diseases [12].

The general-purpose questionnaires used for the studies selected as eligible were: the Pediatric Quality of Life Inventory (PedsQL), the Child Health Questionnaire (CHQ-PF28 and CHQ-PF50) along with the Glasgow Children's Benefit Inventory (GCBI), D15, D16, D17, SF36, Visual Analogue Score (VAS), EuroQol 5-Dimension Health Assessment (EQ5D), and the General quality of life as measured by the Dutch version of the Kidscreen-27 [12–17]. Specific questionnaires from those ENT studies found were as follows: the Obstructive Sleep Apnea-18 (OSA-18), Obstructive Sleep Disorders-6, Pediatric Throat Disorders Outcome Test (T-14), Tonsil and Adenoid Health Status Instrument (TAHSI), Sinus and Nasal QoL (SN-5), Nasal Obstruction Symptom Evaluation (NOSE), Otitis Media 6-item (OM-6), Speech Spatial and Qualities of Hearing Scale (SSQ), and Children with Cochlear Implants: Parental Perspectives (CCIPP) [12–17].

Discussion

The aim of any quality of life study dictates which questionnaire is appropriate [13–17]. General purpose questionnaires are used for studying large populations suffering from various pathologies, allowing comparisons to be made between studies – regardless of whether patients are in good health or suffering an illness [4,13–17]. It is worth underlining that general purpose questionnaires are not applicable for assessing slight changes in a single patient [11–17]. If these changes are to be investigated, a special HRQOL research questionnaire is needed. Such questionnaires are more sensitive in detecting changes which occur over time, and so they can provide information about the effectiveness of treatment or the evolution of a disease. However, they are not suited for evaluating individuals with comorbidities [15–17].

Only single studies have compared the quality of life in healthy children to those with chronic diseases and ones investigating differences in the quality of life for particular diseases relative to each other.

Assessing quality of life is increasingly being recognized as a component of a patient's clinical condition and is one measure of the effectiveness of therapy, including on pediatric patients. It is therefore desirable to establish a baseline for quality of life in healthy children. Studies have mainly investigated children's health status before and after an applied treatment by using detailed questionnaires. In many

countries, recurrent tonsillitis and tonsil hypertrophy (and its complications) are recognized as reducing the quality of life of affected children [19–29]. These studies emphasize that limitations in a child's health affect joint family activities, physical activity, general health, behaviour, and family emotions. A very strong correlation has also been found between such constraints and limitations on the parents' free time. As an aside, and beyond the scope of this review, it should be noted that studies on patients suffering from sleep apnea syndrome are the focus of many articles looking at the quality of life in ENT patients [23–25].

Chronic sinusitis. Our work has taken into account studies on HRQOL in relation to chronic sinusitis, where quality of life becomes limited in areas such as general health, pain, discomfort, the influence of a child's condition/well-being on parents' emotions, physical fitness, limitations in social functioning, limitations in parents' free time, and mental health. Study tools used were designed to survey longitudinal changes in the HRQOL (such as SN-15 or OSA-18) [26–29]. However, this disease does not apparently reduce self-esteem or change behaviour [26,27]. Long-term impaired nasal patency is observed in patients with chronic rhinitis and paranasal sinusitis, where ENT examination shows discharge into the nasal cavities or at the back of the throat. Such children experience pain, a feeling of fullness in the face and have an impaired sense of smell [30–42]. Having a worse nasal patency usually leads to infection of the paranasal sinuses and ears. Parents' free time may become limited, while also reducing the quality of child–parent contact due to long-term inflammatory changes and the related problems in organising how family life functions (e.g. reconciling parents' work commitments to fit in with check-ups at pediatric or ENT clinics, or in providing a sick child with care during the parents' working hours).

Nasal septum deviation. Patients with nasal septum deviation report chronic obstruction of the nasal cavities, thereby reducing the efficiency in how the upper respiratory tract operates [43–46]. A disturbed breathing pattern in children may cause their abnormal physical and mental development. Indeed, any causes of abnormal child development may deteriorate the patient's physical fitness (one of the determinants of peer-group position), which will also probably reduce the self-esteem of the sick child. A significantly deteriorating quality of life includes the following general symptoms: nervousness, fatigue, sweating, concentration disorders, and excessive daytime sleepiness.

Enlarged adenoid. Whenever obstruction of the nasal cavities occurs, particularly in adenoid hypertrophy [34–36], then the local symptoms reported include: changes in breathing pattern to mouth breathing (adenoid faces/long face syndrome), malocclusion, altered voice timbre, night snoring, and night apnea. Furthermore, an enlarged adenoid may impair the patency of the Eustachian tube which, inter alia, can lead to exudative otitis media, that may lead to hearing loss [49–55]. Symptoms of tonsil hypertrophy are snoring, obstructive sleep apnea syndrome, speech disorders such as slurred speech, and dysphagia (especially with solid foods) [19–35,51,55].

Ear disease. The remainder of our chosen studies record HRQOL in patients with ear disease. One study showed a small deterioration in the education and social functioning aspects of HRQOL for children suffering from a one-sided (unilateral) hearing loss/deafness. It also found that HRQOL was more limited in children with bilateral hearing loss than those with unilateral hearing loss. It has been stressed in other studies that children having cochlear implants were found to have similar HRQOL to healthy children [51–55]. Changes in hearing threshold and tinnitus severity after stapes surgery have also been found to be important to quality of life in adult patients [56].

Conclusions

All these aforementioned ailments can be expected to directly lead to a deteriorating HRQOL, when assessed either by the patients themselves or their parents. Parental concerns may be about their child suffering from frequent upper respiratory tract infections, decreased well-being, or poorer marks at school (the latter being partly due to more frequent absenteeism). The children's environment can signal changes in their character as manifested by more frequent bouts of anger or conflicts with schoolmates or teachers. Such disorders may arise from ENT-related or other conditions such as hypoxia of the central nervous system, poisoning by bacterial toxins during chronic diseases of the upper respiratory tract and ears, poorer hearing caused by a blocked Eustachian tube, and chronic infections of the middle ear.

The health-related quality of life has been found to significantly deteriorate in many areas when children are suffering from one of the four otolaryngological diseases reviewed. Further studies on HRQOL thus also appear advisable on children being treated for other diseases of the ear, nose, and larynx/throat. Making use of standardized HRQOL questionnaires, tailored to specific issues, is important across studies. The child's quality of life should be routinely measured as an element of their clinical examination.

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