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Quality of life outcomes for children with hearing impairment in Singapore

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A B S T R A C T

Objectives: This study aimed to investigate the hearing-related quality of life (hearing-QOL) of children with hearing loss in Singapore using hearing aids (HAs) and/or cochlear implants (CIs). Their health-related QOL (health-QOL) as well as their families' health-QOL were compared with normally hearing (NH) children and their families.

Methods: This cross-sectional study recruited families (i.e., children aged 2–18 years and their parents) of NH children ($n = 44$), children wearing HAs ($n = 22$) and children wearing CIs ($n = 14$). Hearing-QOL was assessed using the parent-reported Children Using Hearing Devices QOL questionnaire. General health-QOL was assessed using parent and child-reported measures from the PedsQL inventory consisting of the Generic Core Scales, General Well-being Scale and Family Impact Module. The questionnaires were self-administered for children aged 8–18 years, and interviewer-administered for children aged 5–7 years.

Results: The NH children and their families had significantly higher general health-QOL scores compared to the children with hearing loss and their families. This indicates that hearing loss significantly impacts on the well-being of children and their families. Congruence between parent and child reports was only observed in the NH group. Parents of children wearing HAs rated their child's overall hearing-QOL significantly higher than parents of children wearing CIs. Family household income was the only significant predictor of child hearing-QOL scores with parents from the middle income families rating their child's hearing-QOL significantly poorer than parents from high income families.

Conclusion: Overall, NH children and their families have higher self-rated general health-QOL than children with hearing loss and their families, with children using HAs providing higher hearing-QOL than those using CIs. Evaluating both general health and hearing specific QOL from both the child and their parent/caregiver is worthwhile, allowing a more holistic measure of real-life outcomes and better individualised clinical care.

1. Introduction

Since the U.S. Food and Drug Administration (FDA) approved cochlear implant (CI) devices for children in 1990, the number of children being implanted worldwide has increased dramatically. In Singapore, cochlear implantation started in approximately 1997, with Government funding commencing in 2001. Universal Newborn Hearing Screening commenced in 2002, and data collected between 2002 and 2004 indicated a national incidence rate for hearing loss in newborns of 4 in 1000, with 1.7 per 1000 having a severe to profound loss [1]. According to the 2010 Singapore National Health Survey, the national birth rate increased by 7.6% from 39,654 in 2011 to 42,663 in 2012 [2], suggesting that the number of hearing impaired (HI) children in Singapore may also be rising.

Hearing is fundamental to the development of spoken communication and language. Initial delays in the development of speech and language lead to poorer communication, which can in turn result in lower levels of social interaction, poorer academic performance, feelings of isolation and/or low self-esteem. This may subsequently manifest into behavioural, socio-emotional or learning difficulties [3–5]. These issues may continue into adolescence and adulthood; hence job opportunities, relationships, and long-term quality of life (QOL) may be impacted if the hearing loss is not adequately managed at an early age.

Accordingly, evaluating the outcome of hearing aid (HA) and/or cochlear implant (CI) fittings, and monitoring progress over time is

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imperative. The most commonly used measures to ascertain these outcomes in Singapore include: (1) measures of hearing thresholds, (2) measures of speech perception skills, and (3) subjective parent-reported functional auditory assessment tools such as the Infant-Toddler Meaningful Auditory Integration Scale (IT-MAIS) [6]. However, these would only represent a small portion of the effect that a hearing intervention has on a child's life [7] and do not fully represent the real-world impact on the child's QOL and overall functioning [8–12].

Over more recent times, evaluating QOL has become an increasingly important outcome measure for healthcare services and treatment options, including hearing loss. However QOL is a broad concept and there is no consensus on its definition nor measurement [13,14]. In essence though, it is about the meaning that people derive from the important aspects of their life, and thus a highly individualised social construction. The World Health Organisation (WHO) defines QOL as an "Individuals' perceptions 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" [14] (p. 551). It is subjective and encompasses both an individual's life domains such as their physical, psychological, and social well-being, as well as broader domains such as economic, vocational, and family life considerations. Furthermore, cultural, social, and environmental factors may also have an impact [14].

Quality of life can be measured using generic and condition-specific instruments [15,16]. The strength of generic instruments lies in their ability to enable comparisons among children with different medical conditions, as well as make comparisons with healthy populations [17]. However, they lack precision and sensitivity, particularly when the assessor wants to target outcomes for a specific health condition [18,19]. In contrast, condition-specific (or disease-specific) QOL instruments are designed for application with a particular medical condition or sensory impairment. For this paper, the condition-specific QOL measures used will be referred to as hearing-related QOL (hearing-QOL) measures, and the generic measures as health-related QOL (health-QOL) measures. Both health and hearing-QOL assessments provide real-world information regarding the consequences and experiences resulting from hearing loss. In a paediatric population, this may be obtained from the child and/or their parent (or main caregiver), with the information guiding clinical decisions around the child's hearing intervention and habilitation needs. Furthermore, as the cost of healthcare is on the rise, there is an increasing need for clinicians to justify their choice of intervention(s) based on efficacy as well as cost-effectiveness [7]. For example, administering the same QOL measure(s) to hearing impaired (HI) and normally hearing (NH) children could enable a comparison of how children with hearing impairment function when compared to their NH peers. Warner-Czyz et al. [40] observed in their study that CI children reported significantly better physical functioning and comparable social functioning than their NH peers. They conducted a cross-sectional study to evaluate the health-QOL of children using CIs ($n = 50$, mean age: 9.1 years, age range: 8–11 years), with NH children ($n = 918$, mean age: 9.7 years) as the control group. The KINDLR (Kinder Lebensqualität Fragebogen) questionnaire was administered to both groups. When the two groups were compared, the children with CIs self-reported their physical well-being ($p = 0.03$) and self-esteem ($p = 0.03$) significantly higher than the NH children.

In keeping with the WHO's definition of QOL, and given that some children may be too young or ill to self-report, it would seem best practice for QOL ratings to be obtained from both the child and their parents/main caregivers if possible. Currently there are limited hearing-QOL measures that use both parent proxy-report and child self-reports; most studies have obtained ratings from one or the other. Several studies have used parent proxy-reports to assess the child's hearing-QOL [11,12,21–24]; however, by relying on one informant, we may not obtain a complete understanding of a child's hearing-QOL [19]. Concordance between parent and child ratings can be affected by various factors and identifying discrepancies between the two may help clinicians with their counselling and clinical decision-making [25]. Eiser and Varni [26] observed that HI children can present with 'internalising' and 'externalising' problems which can affect the parent–child concordance on hearing-QOL assessments. Externalising problems such as behavioural issues or refusing to go to school are often easier for parents to detect and note on a QOL measure. On the other hand, internalising issues such as emotional distress or low self-esteem may be less obvious to parents [26]. Both Upton et al. [25] and Eiser and Varni [26] observed that parents tend to report more externalising problems in their children whereas children tend to self-report more internalising problems.

Another factor that can affect parent and child concordance is the child's age [26,27]. A study by Chang and Yeh [28] to evaluate parent–child concordance in the children with cancer found stronger correlations for children younger than 12 than adolescents, possibly as parents may spend more time with a younger child than an adolescent. However, opposite findings were seen in a cross-sectional study by Jozefiak et al. [27] who evaluated the general health-QOL scores of 1997 Norwegian school children aged 8–16, and their parents, using the KINDLR questionnaire. Findings showed that correlations between parent and child reports were weaker for children younger than 12 years old ($r = 0.23$, $p < 0.01$, $n = 887$) compared to children above 12 years ($r = 0.37$, $p < 0.01$, $n = 856$). It may have been that older children's interpretation of questions and perspectives may be more adult-like than younger children.

In turning to children with hearing loss, improved technology, earlier identification and intervention, and increased awareness of the importance of habilitation has led to better outcomes and increased educational opportunities for children with hearing impairment. In addition, improved psychological well-being, better social integration and QOL are also reported as a result of early intervention and (re)habilitation [29,30]. However, along with this come increased expectations, time demands, pressure, and possibly costs. Further, parenting a child using HA(s) and/or a CI can make some of the common parenting demands more challenging, as well as create new demands. These may lead to parents feeling frustrated and/or with a diminished sense of competence and satisfaction [31]. In addition, parents are responsible for ensuring their child wears the device, maintenance, attending clinical appointments, and complying with habilitation plans. All of these factors may lead to parents experiencing psychological distress and increased stress, in turn reducing their QOL [32].

At present, there are no published studies on the QOL of children in Singapore using HAs or CIs. The need for research in this area, within a Singaporean context, is evident given that the incidence of hearing loss in Singaporean children is on the rise. Health and hearing-QOL outcomes provide valuable information to Governments, medical insurers, and other relevant agencies who may contribute to decisions over funding distribution and access to treatment. At a clinical level, hearing-QOL will aid clinicians in their decision-making process and also help parents make informed choices on their child's hearing interventions.

Accordingly, the aims of this study were: (i) to investigate hearing-QOL ratings for Singaporean children using HAs or CIs, and (ii) to investigate and compare health-QOL ratings for both NH and HI Singaporean children and their parents. It was hypothesised that: (i) the NH group will have better child health-QOL scores than the children with hearing impairment; (ii) there would be