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Parent versus child assessment of quality of life in children using cochlear implants

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ABSTRACT

Objective: Children with hearing loss who use cochlear implants have lower quality of life (QoL) in social situations and lower self-esteem than hearing peers. The child's QoL has been assessed primarily by asking the parent rather than asking the child. This poses a problem because parents have difficulty judging less observable aspects like self-esteem and socio-emotional functioning, the domains most affected by hearing loss.

Methods: This case-control study evaluated QoL in 50 preschoolers using a cochlear implant and their parents with the Kiddy KINDL®, an established QoL measure. Children's responses were compared to a hearing control group and correlated with demographic variables. We used a questionnaire for parents and a face-to-face interview with children. *T*-tests were used to compare (a) paired parent–child ratings and (b) children with cochlear implants versus normal hearing. Pearson rank correlations were used to compare QoL with demographic variables.

Results: Children using cochlear implants rated overall QoL significantly more positively than their parents ($M_{Difference} = 4.22$, $p = .03$). Child rating of QoL did not differ significantly by auditory status (cochlear implant (82.8) vs. hearing (80.8), $p = .42$). Overall QoL correlated inversely with cochlear implant experience and chronologic age, but did not correlate with implantation age.

Conclusions: Preschool children using cochlear implants can assess adequately their own QoL, but parents afford valuable complementary perspective on the child's socio-emotional and physical well-being. Preschool children using cochlear implants rate overall QoL measures similar to hearing peers. A constellation of QoL measures should be collected to yield a better understanding of general QoL as well as specific domains centered on hearing loss.

1. Introduction

Children with severe or profound sensorineural hearing loss experience well-documented improvements in communication skills after receiving a cochlear implant, but the broader impact of cochlear implantation on a child's physical, emotional, and social functioning [1] receives little attention [2–9]. Health-related quality of life (QoL), a uniquely personal perception of physical, mental, and social well-being in diverse situations and developmental activities [10–12], provides a mechanism to evaluate the multi-dimensional impact of a health-related condition such as hearing loss or cochlear implantation on a child's daily life [10–12]. The dearth of studies addressing the impact of cochlear implantation on QoL [2–9,13–15] is surprising in light of the documentation of lower QoL – particularly with respect to social participation, self-esteem, and school acceptance – for children with lesser degrees of hearing loss [16–20]. Difficulties in these domains may be exacerbated further in individuals with severe or profound hearing loss, resulting in slower emotional adjustment [21], fewer relationships and social activities [22] and feelings of isolation and depression [23]. Although some studies represent a pediatric cochlear implant user's overall well-being in a single value [5,13–15], only eleven studies to date yield quantifiable outcomes in QoL domains in children using cochlear implants [2–4,6–9,24–27].

QoL in children using cochlear implants relies consistently on parental perceptions of their child's quality of life [6,7,9,24,25,28]. Parents rate the QoL of their children who use a cochlear implant as moderately positive: a rating also associated with higher auditory perception skills, better communication outcomes, longer duration

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of cochlear implant use, and earlier age at implantation [6,7,24]. However, asking parents rather than asking children about health-related QoL unveils discrepancies in parent versus child ratings of a child's communicative and functional capacities [29–34]. Parents adeptly judge objective aspects of a child's behavior such as physical function but show less aptitude on less observable aspects such as self-esteem, emotional or social functioning [35,36], the domains likely to be most affected by hearing loss. Moreover, self-report of QoL maintains consistency with the definition of health-related QoL as an individual's self-perception [10,11]. Six studies to date query children with cochlear implants about QoL [2–4,8,26,27], but only two studies ask both parents and children to complete complementary surveys [2,3] to allow investigation of independent perspectives within parent–child dyads [1,7,37,38].

Chmiel et al. [3] administered a self-constructed instrument focused on benefits and problems associated with cochlear implant use with questions derived from the parent responses reported by Kelsay and Tyler [9] to 11 parent–child dyads. Participant age at time of testing ranged from 6 to 20 years (*M* = 11 years). Parents independently completed a 54-item questionnaire and cochlear implant recipients younger than 12 years of age completed an 18-item questionnaire presented in interview format. Parents reported improved communication as the greatest benefit of their child's cochlear implant, followed by the child's sense of safety, self-esteem, language skills, and family relationships [3]. Children using cochlear implants responded similarly, but they rated making new friends more positively than parents; peer acceptance less positively than parents; and overall problems less positively than parents [3]. Chmiel's [3] self-constructed measure included questions about QoL that have not been tested for reliability or validity in pediatric cochlear implant users, which creates difficulty in generalization of results.

Huber [2] used an established instrument, the KINDL® [39], to compare health-related QoL in 44, 8–16-year-old cochlear implant users to their parents and to hearing children of comparable ages. Results indicate children with cochlear implants in the 8–11-year-old group rate overall QoL significantly less positively than parental proxies, but adolescents with cochlear implants between the ages of 12 and 16 years achieve similar subscale and overall QoL levels compared to their parents [2]. The KINDL® [39] appears to be a reliable and valid measure evaluating general health-related QoL in cochlear implant users at least 8 years of age when child responses are compared to parental responses. However, it remains unclear if these measures are equally reliable and valid for cochlear implanted children younger than 8 years of age.

Although emerging evidence suggests children reliably describe themselves as young as 7 years of age [35,41] and possibly younger [42–46], only three studies [3,4,8] have queried cochlear implant users younger than 8 years regarding QoL issues. Schorr et al. [8] collected self-reported QoL measures in 37 cochlear implant users between the ages of 5 and 14 years (*M* = 9 years). Two other studies [3,4] included children younger than 8 years. However, the broad age range and limited sample size of children younger than 8 years complicate application of results to younger children who may experience different QoL than chronologically older peers due to differences in cognitive, emotional, and social development.

We highlight gaps in the QoL literature of children with cochlear implants with respect to parent versus child reports; and age at testing (i.e., children older vs. younger than 8 years of age). Previous studies of pediatric cochlear implant users, however, appear to agree regarding the relationship between QoL ratings and demographic variables such as age at identification of hearing loss, age at implantation, and duration of cochlear implant experience. Studies consistently show a direct relationship of QoL with duration of implant use [2] and communication outcomes [2,7] and an inverse relationship with age at implantation [2,6,7] and age at first amplification [8]. That is, more positive QoL scores are associated with younger age at intervention, longer duration of cochlear implant experience, and higher speech perception and speech production test scores. However, the relationship of these variables remains unexamined within a cohort of pediatric cochlear implant users younger than 8 years of age.

A paucity of information also exists about comparisons between pediatric cochlear implant users and their normal hearing peers. Huber [2] reports 8–11-year-old children who use a cochlear implant rate specific psychosocial domains and overall QoL significantly less positively than age-matched children with normal hearing. A reliable group difference is not evident for the 12–16-year-old cochlear implant users, who achieved similar subscale and overall QoL levels with normal hearing peers. Huber's [2] evaluation of QoL in children with cochlear implants versus children with normal hearing raises questions regarding the reliability of QoL differences related to chronologic age and maturation level of the children and highlights the uncertainty of QoL ratings by younger cochlear implant users compare with normal hearing peers.

In this report, we explore multi-dimensional aspects of health-related QoL in 50, 4–7-year-old children who use cochlear implants via child and parental (proxy) assessments. We also examine QoL relative to important demographic variables such as age at identification of hearing loss, age at implantation, duration of cochlear implant use, and chronologic age at time of testing. Finally, we compare the CI data to normal hearing peers. We expect congruence between parent–child ratings on overall QoL but differences between parent–child ratings on less observable domains. We hypothesize that a child's QoL derives from his or her developmental level and anticipate no difference in overall QoL between children with cochlear implants and children with normal hearing of the same chronologic age. Finally, we hypothesize that health-related QoL is negatively associated with age at identification of hearing loss and age at implantation and is positively associated with duration of cochlear implant use.

2. Methods

A case-control study was used to assess health-related QoL in preschool children who use cochlear implants. Comparisons were made between (1) parent versus child assessment of health-related QoL in preschool children using cochlear implants; and (2) child assessment of health-related QoL in preschoolers using cochlear implants versus preschoolers with normal hearing.

2.1. Participants

2.1.1. Children using cochlear implants

Sixty-eight families with children between 4 and 7 years of age who used a cochlear implant were contacted as a means of eliciting participation in the study. Fifty families responded positively for their child to participate. Forty-five of the fifty families also contributed parental assessments. Inclusion criteria for the children were (1) documented severe-profound hearing loss defined as a pure-tone average (0.5, 1, 2, and 4 kHz) greater than 75 dB HL (NHANES III, 1988–1994) prior to cochlear implantation; and (2) use of at least one cochlear implant device. Children were not excluded based on age at identification of hearing loss, etiology of hearing loss, age at cochlear implant activation, duration of cochlear implant experience, type of cochlear implant device (i.e., manufacturer or speech processing strategy), number of cochlear implants (i.e., unilateral vs. bilateral), or mode of communication (i.e., oral vs. oral + sign) in order to form the sample of preschool children using cochlear implants. The only exclusion criterion was