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“Development of Preschool Hearing Related Quality - Of - Life Measure”
RESEARCH GRANT 2016

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PUBLICATIONS:

Yu C, Jeffe DA, Kenna M, Germiller J, **Lieu JEC**. Validation of a Parent Proxy Quality-of-Life Measure for Young Children with Hearing Loss. Laryngoscope 2021; 131(3): 663-670. <http://dx.doi.org/10.1002/lary.28891>. PMID: 32668032

Zhang AL, Jeffe DB, **Lieu JEC**. Discriminant Validity of the Parent-Proxy Preschool HEAR-QL. Otology & Neurotology 43:e212–e219, 2022.. PMID: 34699398. DOI: 10.1097/MAO.0000000000003390.

Lindburg M, Ead B, Jeffe DB, **Lieu JEC**. Hearing-Loss-Related Issues Affecting Quality of Life in Preschool Children. Otolaryngology-Head and Neck Surgery 2021;164(6): 1322–1329. PMID: 33078995. <https://doi.org/10.1177/0194599820962475>

RESEARCH SUMMARY:

The Parent-Proxy Preschool HEAR-QL is a hearing-related quality-of-life instrument for children aged 2-6 years with hearing loss, developed through the support of the AOS grant. The work involved a qualitative study of parental concerns about their young children with hearing loss, creation of survey using the data gathered through the qualitative study, and then validation of the survey across multiple sites. This work was an extension of previous work to develop a hearing-related quality of life instrument for children aged 7-12 and 13-18 years, but with the added dimension of parent/caregiver-proxy concerns for their child’s quality of life.

OUTCOMES:

The validated Parent-proxy HEAR-QL instrument includes 23 items scored on a 5-point Likert scale. Because children with no hearing loss were included as the reference/control group, scores for children with hearing loss can be compared to normal/typical hearing children. The domains include Hearing Environments, Behavior and Attention, Communication, New Social Situations, and Social Interactions. This validated survey has been used in ongoing clinical studies that are investigating the use of gene therapy for children with otoferlin-related auditory neuropathy disorder, as well as other clinical and research sites.

The instructions for the Parent-proxy HEAR-QL are included as a screenshot below.

**Hearing-related Quality of Life (HEAR-QL™) in Preschool Children (2-6 years old):
Parent-proxy Questionnaire**

Instructions to the person administering the survey (read and review instructions with the participant before the participant completes the questionnaire):

The purpose of this survey is to learn about how your child’s hearing may be affecting aspects of his/her quality of life in different situations. Place an “x” in the box that best answers each question for him/her: Never, Almost Never, Sometimes, Often, or Almost Always. If your child uses a hearing aid or cochlear implant, please answer the way they hear with the hearing device.

LAY SUMMARY OF FINDINGS AND IMPLICATIONS OF THIS RESEARCH:

The creation and validation of the Parent-Proxy HEAR-QL survey enables caregivers, clinicians and researchers to measure the quality of life of children with hearing loss. This measurement can be used to show how children with hearing loss are functioning and when treatments are helping children with their hearing loss. It is being used in clinical and research applications throughout the world for young children aged 2-6 years.