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Disparities in Access to Pediatric Hearing Healthcare

Matthew L. Bush, M.D., Ph.D., Michael R. Kaufman, M.D., and Beth N. McNulty, M.D.

Department of Otolaryngology – Head and Neck Surgery, University of Kentucky Medical Center, Lexington, KY, USA

Abstract

Purpose of Review—There are significant disparities in care facing children with hearing loss. The objective of this review is to assess the current disparities in pediatric hearing healthcare delivery, describe the barriers of efficient and effective pediatric hearing healthcare, and explore the innovations to improve pediatric hearing healthcare delivery.

Recent findings—Children with hearing loss from certain geographic regions or ethnic background are significantly delayed in diagnosis and treatment. Multiple patient characteristics (presentation of hearing loss), parental factors (insurance status, socioeconomic status, educational status, and travel distance to providers), and provider barriers (specialist shortage and primary care provider challenges) prevent the delivery of timely hearing healthcare. Advances such as improved screening programs and the expansion of care through remote services may help to ameliorate these disparities.

Summary—Timely identification and treatment of pediatric hearing loss is critical to prevent lifelong language complications. Children from vulnerable populations, such as rural residents, face significant disparities in care. Careful assessment of these barriers and implementation of culturally-acceptable interventions are paramount to maximize communication outcomes of children with hearing loss.

Keywords

access to care; pediatric hearing loss; hearing aid; cochlear implant; rural; Health disparity

Introduction

Pediatric hearing loss constitutes a major public health and economic problem. As the most common neonatal sensory disorder in the United States, infant hearing loss occurs in 1.6 per 1000 births.¹ (GRANT) The US Preventive Services Task Force has recognized the significant effect that congenital hearing loss has on communication skills, psychosocial development, and educational progress, and has found that early detection of hearing loss improves language development.² Others also have confirmed that language skills are

Corresponding Author: Matthew L. Bush, M.D., Department of Otolaryngology – Head and Neck Surgery, University of Kentucky Medical Center, 800 Rose Street, Suite C-236, Lexington, KY 40536-0293, Telephone: 859-257-5097, Fax: 859-257-5096, matthew.bush@uky.edu.

Conflicts of Interest
None.

can develop sensorineural hearing loss (SNHL).²⁵ It is estimated that congenital CMV infection accounts for about 13–22% of all case of neonatal hearing loss making it the leading nonhereditary cause of congenital hearing loss.²⁶ Since the 1970s, we have known that the hearing loss can present bilaterally or unilaterally, be progressive or fluctuating in nature and range from mild to profound.²⁴ Importantly, it can also present late and be missed by neonatal hearing screening.^{27,28} It is vital that these children be identified and followed closely through childhood. Additionally, older children with hearing loss may not be identified in a timely manner as there is significant inconsistencies with school-based hearing screening.²⁹

Rehabilitation Services

The implementation of widespread infant hearing screening and rehabilitation services through state early hearing detection and intervention (EHDI) programs have expanded the access to hearing healthcare and has facilitated the timely identification of hearing loss in many children; however, there are still significant delays in treatment of pediatric hearing loss in various groups of children. Indigent children may face a delay of 3 months in receipt of their hearing aids after diagnosis of hearing loss, compared with a 1 month delay in non-indigent children.³⁰ Children from rural areas with congenital hearing loss are significantly delayed in receipt of hearing aids and cochlear implants, with many rural children being twice as old as their urban counterparts when they receive these devices.²² There is compelling evidence that suggests that with each year after birth that cochlear implantation in children is delayed there is a substantially greater financial burden for the family, educational system, and the healthcare system.³¹ Children with cochlear implants from healthcare inequity settings with public insurance also tend to have poorer sound recognition outcomes when controlling for other variables such as age of the child, timing of implantation, and frequency of speech rehabilitation services.³² There is also limited access to speech therapists in rural areas with expertise in treating children with hearing loss, which further complicated aural habilitation for children.^{33,34}

Barriers to Pediatric Hearing Healthcare Delivery

Patient and Parent Factors

Timely adherence to infant diagnostic testing and hearing loss treatment is a complex process and parents face many barriers. EHDI programs are coordinated by each state and the diagnostic and treatment process is complex. Despite multiple streamlining initiatives, many parents find the diagnostic and treatment difficult to navigate.³⁵ Risk of non-adherence is higher in families with greater travel distances, low levels of parental education, low socioeconomic status, and public insurance.^{22,36–38} A recent systematic review involving reports from multiple countries assessed barriers to follow-up after newborn hearing screening and found that educational disparities, travel distance, work constraints, unfavorable attitudes, and competing healthcare needs were the primary reasons for non-adherence.³⁹ Families of children with hearing loss report that they lack confidence and resources needed for healthcare decision-making for their child.⁴⁰ Many parents lack role models who have been through the complex process of hearing loss diagnosis and intervention⁴¹ because more than 90% of deaf children have hearing parents.⁴² Children

with hearing loss from culturally and linguistically diverse homes may poorer rehabilitation outcomes.³⁴ Many children may be delayed in cochlear implantation due to problems with insurance approval or medical comorbidities; however, missed appointments and parental reluctance continue to be prominent barriers.⁴³

Lack of parental knowledge and support to navigate the EHDI system may complicate hearing healthcare delivery. In quantitative and qualitative studies investigating parental knowledge, attitudes, and behaviors regarding the EHDI system, more than 20% of parents found the process of newborn hearing testing difficult, and many were unaware of the screening results and need for follow-up at the time of hospital discharge.⁴⁴ Misinformation from providers and difficulty coordinating appointments were prominent barriers to appropriate follow-up for infant hearing testing.⁴⁵

Provider Factors

Efforts to improve the hearing of the children in remote areas through the provision of hearing screening and rehabilitative services has been a challenge due a lack of experienced hearing healthcare providers and limited access to existing providers.⁴⁶ Developing countries also face shortages with some countries facing a ratio of over 1 million people per hearing healthcare specialist.⁴⁷ Some remote areas require extensive external financial and technical support.^{48,49} Delivery of rural hearing healthcare is significantly hampered by this disparity.^{50–52} Many primary care providers in rural areas feel that appointment wait times to see specialists, such as pediatric Otolaryngologists, are too long and feel that there is a shortage of hearing specialists.⁵³ Furthermore, primary care physicians face barriers to promote EHDI initiatives. In a cross-sectional survey of 93 rural physicians, many providers reported that they do not receive newborn hearing screening results consistently and they lack confidence in counseling parents through the EHDI process.⁵⁴

Innovations in Pediatric Hearing Healthcare Delivery

Advances in Screening

Universal newborn hearing screening was implemented over a decade ago for most states as well as many countries. Recent evidence that confirms the benefits of infant hearing screening on long-term literacy outcomes.⁵⁵ State EHDI programs continue to investigate methods to provide the most efficient and accurate screening by implementing double inpatient screening, using automated auditory brainstem response testing, and promoting hospital outpatient screening. Proposed methods for improving loss to follow-up for diagnostic testing in many countries throughout the world include the use of a database management system, increased parental education, telephone reminders, multidisciplinary team management, and flexibility in appointment scheduling.³⁹ There are also advances in screening for causes of pediatric hearing loss, such as cCMV. Screening for cCMV is typically completed within the first 3 weeks after birth and evidence of cCMV positivity can promote timely infant hearing testing after screening.^{56,57} Targeted cCMV saliva PCR testing is a valuable companion to hearing screening as it can contribute to the timely diagnosis of sensorineural hearing loss, lead to the identification of central nervous system manifestations of cCMV, and identify children who could benefit from antiviral therapy.⁵⁸

Improvement in Patient Support

There are no existing evidence-based approaches to decrease non-adherence to infant hearing testing and treatment. Prenatal educational modules⁵⁹ and social worker counseling⁶⁰ have not demonstrated significant benefit in promoting rescreening after failed infant hearing screening; however, parental contact after postnatal hospital discharge may promote rescreening.⁶¹ Parent-to-parent programs, such as *Guide By Your Side*,⁶² are available in many states and may reduce parental isolation and boost parental acceptance of the child's condition.⁶³ However, despite promising data from nearly 2 decades ago, these programs are not consistently integrated into state-funded EHDI services and diagnostic centers, and when provided they are under-utilized. Additionally, these programs typically require the parents to make initial contact to establish services, and they often are not utilized until after a diagnosis of hearing loss is made. Evidence regarding the effects and optimal implementation of these programs is lacking; in fact, a recent meta-analysis found no literature addressing the effectiveness or cost of initiatives designed to decrease non-adherence in follow-up after failed newborn hearing screening.⁶⁴

Implementation of Remote Services

The use of telemedicine has been increasing exponentially in recent years in multiple disciplines (rural outpatient settings for psychiatry and behavioral health, endocrinology, and dermatology, as well as emergency and critical care services) and there are promising applications in pediatric hearing healthcare. There are two different types of telemedicine, synchronous and asynchronous. Synchronous involves two videoconferencing units at separate locations, with simultaneous video and audio. Asynchronous involved the electronic transfer of images and/or video to be reviewed at a later time.⁶⁵ Several studies have demonstrated the use of telemedicine in the form of tele-audiology for pediatric and adult hearing evaluations.^{66–69} Dharmar et al reported on the feasibility of tele-audiology in twenty-two infants who failed the newborn hearing screen.⁷⁰ This remote evaluation included taking a history, visualization of external structures, video otoscopy, immittance (including high-frequency tympanometry and middle ear muscle reflexes), distortion product otoacoustic emissions, auditory brainstem response with air and bone conduction, and, when indicated, auditory steady-state response. None of the infants in this cohort were lost to follow-up compared with 22% of infants in the region prior to implementation of the program. Both parent and provider satisfaction were high in this program.

There is also evidence of rehabilitation services provided through telemedicine. Using “real world” scenarios with pediatric CI patients, Hughes et al⁷¹ reported the successful collection of clinical measures of cochlear implant function and conducted speech testing on cochlear implant recipients. The short commute time to the remote site was viewed favorably by the patients' families. This same group has investigated methods to maximize remote cochlear implant testing environment to obtain accurate measures of cochlear implant function in children.⁷² Telemedicine can also be utilized to address unmet need for speech therapy services.⁷³ Delivery of remote speech therapy is highly acceptable to parents,^{74,75} and the outcomes are comparable to in-person therapy.^{76,77} Important areas to be addressed with expanding delivery of remote speech therapy include maintenance of patient relationships,

interaction with parents and teachers, high fidelity technology, and ongoing training in telepractice for providers.⁷⁸

Conclusion

The delivery of hearing healthcare to underserved communities is complicated but a critical area of research. Multiple patient, family, and provider factors are barriers to timely care. Advances in screening protocols and remote services may address the NIH mandate to increase access to health care and enhancing delivery of care.⁷⁹

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Key Points

1. Children from rural areas are may be dramatically delayed in the diagnosis and treatment of hearing loss
2. Multiple factors are associated with delayed access to care, such as socioeconomic status, insurance status, parental educational level, travel distance.
3. Efficient and effective screening methods may improve timing on infant diagnostic services and telemedicine applications can expand access to care for patients from remote areas.