

Childhood Hearing Loss in the Developing World

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Abstract: Globally, unidentified hearing loss is the largest and most significant childhood disability impacting on development. Of the babies born annually with hearing loss, 90% come from developing countries. Less than 2.5% of these babies will get hearing aids and less than 10% will ever have access to early intervention.

With the dearth of services available to this largely marginalized paediatric community, the EHDI pathway has been established with significant buy in from the World Bank, WHO and UNESCO. This paper will explore the EHDI pathway and how it is currently being implemented in the developing world.

Keywords: Universal newborn hearing screening, paediatric hearing loss, early hearing detection and intervention, developing countries, early intervention.

Childhood hearing loss is the most prevalent sensory disorder [1] often referred to as the silent epidemic [2, 3] with more than 90% of these babies residing in the developing world [4-6]. 'Developing' is defined by indices such as gross national income (GNI), degree of integration into the global financial system, life expectancy and literacy among others with 150 countries currently on this list [7]. With an estimated 7 billion people on earth, the large majority are born into developing nations [8].

Of the approximately 123 million babies that are born annually in developing countries, 737 000 are born with a permanent congenital early-onset hearing loss (PCHL) [9, 10]. This translates into 6 per 1000 live births¹ in developing countries as opposed to 2 per 1000 live births in developed countries [9, 11], however higher rates have been noted in various developing countries during a review of worldwide infant screening in 2008 (see Table 1).

HEARING LOSS AND ITS IMPACT

Hearing loss is the most frequently occurring birth defect [12] and the World Health Organisation (WHO) estimates that it is among the 20 leading causes of the global burden of disease, one of only four non-fatal conditions [2]. Future projections indicate hearing loss will be increasing in these rankings, estimated to become the 7th leading cause of the global burden of disease in 2030, primarily due to a growing global

population with increasingly long life expectancies [2,13].

Children may be either born with a hearing loss (a congenital hearing loss) or acquire it after birth. There are more than 400 syndromes, sequences and associations that include hearing loss as a major feature [14] accounting for up to 50% of infant hearing losses [15] (see Table 2 for the aetiological and risk factors).

A disabling hearing loss is usually described as one above 30 or 40dB [2, 16], however research and experience has shown that if it remains undetected all hearing loss (including minimal and unilateral hearing losses) can have detrimental consequences [17-20]. These consequences include delays in language development, cognitive development and socio-emotional development [6, 21-24] which may result in persistent language delays of 2-4 years [25]. These delays then have far reaching ramifications for academic, employment and societal integration [25, 26], particularly in developing countries. In addition to the impact of hearing loss on the child, there is also an impact on the family [27-29] and larger community [30] with communities in developing countries attributing stigma for the hearing loss to supernatural causes [31] or ancestral punishment [16].

At a societal level Mohr *et al.* [32] have calculated that the economic impact of this burden of disease for the life span of a person with a hearing loss is \$1 million, highlighting the imperative to identify hearing losses as soon as possible.

EARLY HEARING SCREENING AND DETECTION

As early as the 1960's paediatric audiology and newborn screening were being pioneered in the USA,

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¹Some are reported as even higher e.g. 7.9/1000 births in Pakistan [47, 66].

Table 1: Rate of Permanent Congenital and early-onset Hearing Loss^a (PCEHL) in Developing Countries^b (adapted from Olusanya *et al.*, 2008)^c

Country	Rate of PCEHL/1000	Country	Rate of PCEHL/1000
Brazil	2.4 ^d	Pakistan	7.9
China	2.8	Philippines	22.1
Cyprus	1.19	Qatar	53.4
India	5.0 – 5.6	Saudi Arabia	1.8
Jordan	13.7	Slovakia	1.5
Kuwait	51.2	South Africa	1
Malaysia	4.4 – 12.5	Taiwan	1.3
Mexico	1.6	Thailand	67.1
Nigeria	5.3 - 28	Turkey	4.2
Oman	1.2		

^aMost of these studies included children with unilateral and mild hearing losses (although a detailed breakdown was not given), the community-based study from Nigeria may have included a significant number of infants with postnatal hearing loss and studies from Qatar and Kuwait were reported from populations with high rates of consanguinity.

^bThe current list of developing countries are published in the International Monetary Fund's World Economic Outlook Report, April 2012 [7].

^cThe data were collected from a systematic review of studies on infant hearing screening across the developing world since 1998.

^dOne study indicated a prevalence of as high as 102.1/1000.

Table 2: Aetiological and Risk Factors for Congenital and Early-Onset Hearing Loss (Adapted from Olusanya, 2012)

Aetiological and risk factors for congenital and early-onset hearing loss	
Prenatal	
Family history of deafness	<i>Genetic: Non-Syndromic</i>
Consanguinity	Connexin 26
<i>Genetic: Syndromic</i>	Connexin 31
Treacher-Collins syndrome	Others
Pendred syndrome	
Ushers syndrome	<i>Chromosomal</i>
Waardenburg Syndrome	Down Syndrome
Jervell Lange-Nielsen syndrome	Edward Syndrome
Alport Syndrome	Patau Syndrome
Hunter Syndrome	Turner Syndrome
Craniofacial anomalies associated with	
Crouzon disease, Flippel-Feil syndrome,	<i>Acquired Congenital Infections</i>
Goldenhar syndrome & Pierre Robin Sequence	Maternal Rubella
Branchio-Oto-Renal Syndrome	Cytomegalovirus (CMV)
Stickler Syndrome	Herpes Simplex
Marshall Syndrome	Toxoplasmosis
<i>Other</i>	Syphilis
Charge Association	Congenital Malaria
	Fetal Alcohol Syndrome
Natal	
Prolonged/obstructed labour	Hypoxia/ Birth Asphyxia
Lack of skilled birth attendant	Low Apgar scores
Mode of delivery	Prematurity/Low birth weight (<1500gr)
Maternal hypertensive disorders in pregnancy	NICU/ ventilation > 5 days
Maternal malnutrition in pregnancy	Trauma to the head
Birth trauma	Maternal HIV infection
Postnatal	
Neonatal sepsis	High fever (with or without convulsion)
Neonatal meningitis	Ototoxic medication
Neonatal jaundice (requiring exchange transfusion)	Under nutrition & Failure to thrive
Neonatal seizures	Hydrocephalus
Neonatal measles, mumps	Infant HIV/ Aids infection
	Parental concern

with the majority of the developed world following suite in the years to follow [33]. Internationally this has led to a strong move toward not only newborn screening, but universal newborn hearing screening (UNHS) where it is proposed that screening for hearing loss occur by no later than 1 month of age, diagnostics follow shortly thereafter to be finalized by three months of age and referral to early intervention to be in place by no later than six months of age [26]. This screening to intervention process is referred to as the 'early hearing detection and intervention' pathway (EHDI)

Screening protocols of the Joint Commission on Infant Hearing (JCIH) (used widely as a reference document) propose physiological measures using a 2-stage screening protocol: an initial screening using an OAE² (otoacoustic emissions test) followed by an automated ABR (automated brainstem response) if the first screen is not passed [26, 34, 35]. This is echoed by Olusanya [5] in a report on screening in Nigeria and McPherson and Olusanya [36] in discussion of screening in developing countries. In practice however, two studies in South Africa, one a national survey and the other a smaller geographically focused area, both reported on a one-stage screening protocol using predominantly OAE's alone with the rationale being one of ease and cost of screening [4, 37].

In the developed world the current protocol is that to a large extent they follow UNHS (Universal Newborn Hearing Screening) with a 95% screening rate in the USA [38] and 99% in the UK [39]. Yet more than 90% of babies born in South Africa do not have the prospect of either screening or early detection [40] with an even lower prospect of identification in most other developing countries.

Screening in the developed world usually takes place in the hospital or clinic within a few days of birth and often before the child is discharged from the hospital. Less than 60% of babies born in developing countries are born in hospital [10] with numbers dropping to as low as 35% in South Africa and Nigeria, and 15% in Somalia among others [9]. This has led to various recommendations for community-based screening programmes to be offered in immunization clinics or Maternal and Child community clinics [4, 41].

Historically, screening and diagnostics have been performed by Audiologists and Ear Nose and Throat

surgeons (ENTs), however a recent survey of services within hearing health care in Africa revealed a severe shortage (or total lack) of ENT surgeons and Audiologists [42]. As opposed to the average ratio of audiologists to people in developed countries (1/20 000), the ratio in developing countries ranges from 1/500 000 to as high as 1/6.25million [13, 43]. Due to this dearth of hearing healthcare professionals, recommendations have been made to consider using nurses [4, 37, 44, 45] and other paraprofessionals in the screening of hearing loss [5, 46]. More recently recommendations have been made to consider telehealth as offering opportunities to access the full spectrum of EHDI in underserved populations [13] without the on-site availability of an audiologist.

In addition to a lack of professionals in the field, developing countries have widespread resource constraints [45] that they are going to need to adapt to. Fagan & Jacobs (pg 7) propose a "lower technology, lower cost developing world medical practice" [42] and to this end the Joint Commission on Infant Hearing (JCIH) and Olusanya [5, 45] have recommended that rather than universal newborn hearing screening (NHS), developing countries implement targeted newborn hearing screening (TNHS). This would include many of the high risk factors noted in Table 2, as well as some sites also requiring a bilateral refer, thus excluding any unilateral refers at screening.

Ideally, those infants with unilateral refers or bilateral passes with risk factors for hearing loss should be monitored in terms of their language development and milestone achievements on a 6-monthly basis [4, 26] in order to identify the children who either acquire or have late onset hearing loss.

In terms of this first phase of the EHDI pathway there are currently no benchmarks for evaluating infant hearing screening in developing countries, though all the pilot studies that have been done to date have made use of the JCIH guidelines [47]. Proposals have been made for developing countries to make use of targeted screening [4, 5, 34, 45], and that despite cost effectiveness and resource constraints withholding newborn hearing screening could not be justified for any population, but rather that context specific strategies be sought [9].

Once identified the EHDI pathway leads toward intervention and Young and Tattersal [28] state that "early identification is of little importance if it is not combined with quality services that can realize for

²Protocols for equipment vary: TEOAEs were used in Nigeria while DPOAEs and AOAEs were used in the South African studies.

children and families the potential advantage of significantly earlier diagnosis than had previously been the case” (p 209).

EARLY INTERVENTION

The process of early intervention includes amplification, therapeutic intervention as well as holistic child and family-centred early intervention. As with screening and diagnosis, it is acknowledged that the referral to intervention also needs to occur as early and as swiftly as possible [26]. Based on current research in developing countries it appears that beyond the primary focus of preventing or detecting hearing loss early [48], this is the component of the EHDI pathway that is most lacking.

The benefits of early intervention are extolled internationally [49-52] though currently in the developing world the primary focus is on amplification [53].

The Convention on the Rights of Persons with Disabilities recognizes that access to assistive technology such as hearing aids is a basic right for persons with hearing impairment [54]. The World Health Organization estimates that fewer than 1 in every 40 people (less than 2.5%) who could benefit from hearing aids actually receive this device [2, 55]. This was confirmed through a survey of 18 African countries in which 9 reported that they had no access to hearing aids, 7 said their access was poor and only 2 said they had good access to hearing aid services [42]. In contrast one longitudinal study (n=615) found that 94.5% of the infants were amplified³. Some of the challenges that developing countries experience with amplification include: affordability of the hearing aids, earmoulds and batteries [53], a chronic shortage of professionals to either assess hearing or provide the rehabilitative services [43], lack of awareness and tropical climates that impact on life-term of the hearing aid [55].

In terms of affordability, the WHO has established a guideline of affordability to ensure that hearing aids don't cost more than 3% of gross national product (GNP) per capita [53]. Using this affordability guideline, this would translate to a costing range of 'equitable' prices from the USA (\$1390) to China (\$110) to Ethiopia (\$10) [55], however, this seems hard for the

manufacturers to reach, making hearing aids largely unaffordable to the developing world. Subsequently, local manufacturers are producing low-cost hearing aids in China and India for example [55] and where possible loaner hearing aid banks could be used [56]. In order to cut costs for earmoulds, Brouillette [53] proposes that in developing countries earmoulds need not only be custom made two-stage moulds, but that the stock ear canal tip be used (currently as many as 60% of hearing aid wearers in the least developed countries prefer these) or the one-stage 'instant' earmould (particularly for a severe to profound hearing loss). And finally the long-term cost of hearing aids batteries can be averted through either low-cost rechargeable batteries or using solar powered hearing aids (see discussion of Godisa in Brouillette, 2008). In order to overcome the shortage of access to professionals during the amplification process, Swanepoel *et al.* [13] propose making use of telehealth (see Table 3) which would make professional services more accessible through either synchronous or asynchronous support. Finally, awareness campaigns on hearing loss and the benefit of amplification need to be run [53] as well as an exploration of the possibility of weather proofing hearing aids for more tropical climates [55].

While effective amplification is an essential component of post identification intervention, Yoshinago-Itano & Thomson [56] (pg 20) urge the sector “not wait to provide intervention service until hearing aids have been acquired” and that the primary objective of early intervention is access to communication, whether auditory or visual. In addition to communication, early intervention has as its goal to “meet the developmental needs of the child and the needs of their family related to enhancing the child's development” [57]. Effective early intervention is holistic and multifaceted [25, 26, 34, 58] as well as family-centred [25, 59]. Internationally, early intervention is often home-based [59], is totally unbiased and embraces informed choice [60, 61] as it relates to the gamut of choices parents need to consider (from amplification to language to modality to schooling among others).

In two studies on this second phase of the EHDI pathway the average age of identification was 24 months (n=54) [62] and 31 months (n=20)⁴ with age of

³This research is from an unpublished annual report on an early intervention programme in South Africa [67].

⁴Venter, C & Viljoen, J. 2008. Children with hearing loss: Parental needs regarding diagnosis. Unpublished B.Communication Pathology research report, University of Pretoria, Pretoria.

Table 3: Scope of Application Possibilities for Telehealth in Early Intervention (Adapted from Swanepoel *et al.*, 2010)

Field of application	Scope of telehealth applications	
	Synchronous	Asynchronous
Intervention [65]		
Counseling [65]	Counseling and troubleshooting conducted via interactive videoconferencing	Counseling sessions via interactive videoconferencing may be preceded by questions and complaints emailed
Ear canal management	Ear canal management guided remotely by audiologist via videoconferencing	Internet-based audiological counseling programs Internet-based audiological treatment programs (i.e. tinnitus)
Hearing aid selection, fitting & verification	Hearing aids fitting guided and programmed via interactive videoconferencing and application sharing Verification of hearing aid via application sharing and interactive videoconferencing	Hearing aids may be pre-selected and pre-programmed based on audiological results
Cochlear implant mapping	Cochlear implant activation and mapping via application sharing and interactive videoconferencing	Internet-based auditory training programs
Early Intervention	Follow-up sessions via interactive videoconferencing Home-based early intervention services via interactive videoconferencing	Intervention for infants may be provided by recorded play/ child communication sessions at home sent through to interventionist for evaluation Home-visit sessions are preceded by questions emailed Internet-based early intervention topics

^aUsually involves a paraprofessional or trained volunteer to facilitate the telemedicine setup at the remote location whilst the health care provider (audiologist) is present remotely via interactive videoconferencing.

referral to centre-based early intervention at 31 months and 43 months respectively (indicating a referral to intervention gap of between 8-12 months). A third longitudinal study of 615 infants revealed an average age of diagnosis of 26 months and referral to a home-based early intervention programme at 40 months, indicating a gap of over 12 months from identification to intervention (see footnote c). No further early intervention programmes could be located in the developing country research, however this does not necessarily mean there are no large-scale early intervention programmes in the developing world, but that the programmes are not yet documented.

CONCLUSION

All children with significant hearing loss have the basic human right to have access to human communication, regardless of where they are born, of their race, ethnicity or national origin, of how much income their family makes, the level of education of their parents, or the type of occupation (pg 1) [56]. To this end, developing countries need to ensure that this basic human right is acknowledged and prioritized by linking the implementation of such EHDI programmes

to existing health, social and educational systems and where possible setting up private-public partnerships to enable the implementation [45].

There is widespread agreement that the golden standard to which developing countries should aspire in setting up EHDI processes is UNHS using physiological measures (OAE and ABR). Due to unique local challenges and resource constraints, however each small step toward the goal would be a valuable interim measure: whether starting with a geographical subset of infants (eg. a hospital or a clinic in a specific area) and working toward NICU, high risk and then national screening of babies or whether starting with family questionnaires and working toward behavioural and then physiological screening [63].

As the developing world looks ahead to putting national plans in place (WHA, 1995), time and energy needs to be invested into establishing national infrastructures that will ensure that each infant identified with a hearing loss (and their families) receives appropriate intervention services [56], as investing in early childhood will bring about important economic returns later in life [64].

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