INFANT HEARING LOSS IN DEVELOPING COUNTRIES - EXPOSING A SILENT EPIDEMIC

SOUND FOUNDATION THROUGH EARLY AMPLIFICATION

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De Wet Swanepoel, Ph.D University of Pretoria, South Africa University of Texas at Dallas, USA
CHANGE THE WAY WE LOOK AT THE WORLD
THE WORLD AS WE KNOW IT...
"Out of every 100 persons added to the population in the coming decade, 97 will live in developing countries." Hania Zlotnik, 2005
POPULATION 2015
"If we are the future and we’re dying, there is no future." Mary Phiri, 2001
"... I brought my little girl to the health center in my district in the south of Bujumbura. But the nurse wouldn’t see us as I didn’t have any money to pay for the consultation." Simeon, 2004
The human poverty index uses indicators that capture non-financial elements of poverty, such as life expectancy, adult literacy, water quality, and children that are underweight.
CHILDREN WITH HEARING LOSS
WHO ARE SCREENED AT BIRTH?

*Estimated
CHILDREN WITH HEARING LOSS IDENTIFIED BEFORE 3 YEARS OF AGE?

*Estimated
CHILDREN WITH HEARING LOSS WHO RECEIVE HEARING AIDS?

*Estimated*
CHILDREN WITH HEARING LOSS WHO LEARN SPOKEN LANGUAGE?

*Estimated
CHILDREN WITH HEARING LOSS WHO LEARN TO READ AND WRITE?
CHILDREN WITH HEARING LOSS
WHO BECOME ACTIVE CONTRIBUTING MEMBERS OF THEIR ECONOMIES?

*Estimated
WHO ARE THESE COUNTRIES?

- 164 Developing countries
- 31 Developed countries
- Heterogeneous group

<table>
<thead>
<tr>
<th>REGION</th>
<th>NUMBER OF COUNTRIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-Saharan Africa (SSA)</td>
<td>46</td>
</tr>
<tr>
<td>Middle East &amp; North Africa (MEN)</td>
<td>21</td>
</tr>
<tr>
<td>South Asia (SOA)</td>
<td>8</td>
</tr>
<tr>
<td>East Asia &amp; Pacific (EAP)</td>
<td>29</td>
</tr>
<tr>
<td>Latin America &amp; Caribbean (LAC)</td>
<td>33</td>
</tr>
<tr>
<td>Central/Eastern Europe &amp; Baltic State Countries (CEE)</td>
<td>27</td>
</tr>
</tbody>
</table>
WHO IS THE DEVELOPING WORLD?

• 5+ billion people

• Global population: >80%

• 90% of children under 5 live in Developing world

• Classified by indicators of development (e.g.)

(UNICEF, 2008; Alberti, 1999)
WHO IS THE DEVELOPING WORLD?

- Globally 20% live on less than $1 per day
- <1% in developed countries
- SSA: 43% of live on less than $1 per day
- 225 richest control wealth equivalent to annual income of poorest 2.5 billion

(UNICEF, 2008)
WHO IS THE DEVELOPING WORLD?

Proportion of people living under $1/day
WHO IS THE DEVELOPING WORLD?

- Mortality: 0.6 vs 8 & 14%
- Developing world (>80% of pop) spend 13% of global healthcare
- Life expectancy:
  - 79 Developed
  - 66 Developing
  - 55 Least developed

(UNICEF, 2008)
PREVALENCE OF INFANT HL

4-6/1000 bilateral HL
(>40 dB HL)

+ mild losses more

2-5% in high risk
PREVALENCE OF INFANT HL

- Disabling HL (>40dB) prevalence:
  - 120 mil in 1995
  - 278 mil in 2005
  - 642 mil in 2005*
    *(including mild HL, 26-40dB)

- 25% from childhood

- More than 62 million children younger than 15 years

- Mild and greater – 160 million children

(WHO, 2006; Olusanya & Newton, 2007)
PREVALENCE OF INFANT HL

- **120 million** annual births in developing world

- **798 000** - permanent bilateral HL (25% from SSA)

- **53 150** - permanent bilateral HL in all developed countries (Ratio 1:14)

(UNICEF, 2008; Olusanya & Newton, 2007; Olusanya et al. 2008; Smith et al. 2005)
PREVALENCE OF INFANT HL

Global Situation

• Everyday 2,118 born with significant permanent SNHL:
  – 1,972 born in developing world (6/1000)
  – 146 born in developed countries (4/1000)

• >90% born in developing world
CAUSES OF HEARING LOSS

Developed countries

- 54% of HL genetic at 4 years

Developing countries

- Risks abundant, complex & varied
- Poor maternal-child health care
- Adverse peri- & postnatal conditions
- Consanguinity
- Infectious disease burden

(Morton & Nance, 2006; Morzaria et al. 2007; Davis et al. 1997; Olusanya & Okolo, 2006)
APPENDIX 2: RISK INDICATORS ASSOCIATED WITH PERMANENT CONGENITAL, DELAYED-ONSET, OR PROGRESSIVE HEARING LOSS IN CHILDHOOD

Risk indicators that are marked with a “§” are of greater concern for delayed-onset hearing loss.

1. Caregiver concern§ regarding hearing, speech, language, or developmental delay.62
2. Family history§ of permanent childhood hearing loss.24,140
3. Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO,§ assisted ventilation, exposure to ototoxic medications (gentamicin and tobramycin) or loop diuretics (furosemide/Lasix), and hyperbilirubinemia that requires exchange transfusion.64,131
4. In utero infections, such as CMV,§ herpes, rubella, syphilis, and toxoplasmosis.64–67,125,126
5. Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies.24
6. Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.24
7. Syndromes associated with hearing loss or progressive or late-onset hearing loss,§ such as neurofibromatosis, osteopetrosis, and Usher syndrome131; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson.72

NICU?
- LBW (<1500g)
- Birth Asphyxia (1min Apgar <4, 2min Apgar <6)
- Mechanical ventilation for 5 days or more
- Unskilled birth attendant*
- Maternal hypertension*
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5. HIV/AIDS related opportunistic infections?
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8. Neurodegenerative disorders,§ such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome.131
9. Culture-positive postnatal infections associated with sensorineural hearing loss,§ including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis,130,131,141
10. Head trauma, especially basal skull/temporal bone fracture§ that requires hospitalization,127–129
11. Chemotherapy.§132

* Undernourishment?
RISK PROFILE

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Malaria
Measles
HIV/AIDS
RISK PROFILE

Meningitis deaths
Meningitis

• Most common cause

• Incidence ~10 times higher in developing world

• 350 000 – 560 000 annual child deaths in Africa

• Majority survive; Of those 1 in 3 to 1 in 5 have HL

(Baraff et al. 1993; Goetghebuer et al, 2000; Molyneux, 2006)
RISK PROFILE

Rubella

• Worldwide CRS – **110,000** annual cases

• **70 – 90%** of CRS cases - hearing loss

• HL most common (**50%** only symptom)
RISK PROFILE

Undernourishment
**RISK PROFILE**

**Undernourishment**

- 80% of world’s undernourished children live in 20 countries.
- Recent study first to link undernourishment in infants to HL (Olusanya, 2010).
- Infants significantly (1.7%) more likely to have HL and of a severe-to-profound degree.
- Mechanism? May be due to intra-uterine growth retardation, maternal problems (including mothers nutritional status) or insults arising from infectious disease at or soon after birth (Olusanya, 2010).
RISK PROFILE

Proportion of Measles deaths
RISK PROFILE

Measles

• Vaccine 1968 - But still *rife* in developing countries

• **345 000** deaths in 2007 (875 000 in 2001)

• **25 – 30 million** children infected annually

• Significant % at risk of SNHL (specific to these regions)

(UNICEF, 2001; Olusanya, 2006; UNICEF, 2008)
RISK PROFILE

HIV prevalence
RISK PROFILE

Malaria
Reducing risks important primary prevention strategy

BUT... an upper limit of 50% of cases will be prevented this way

Infant Hearing Screening – Important secondary prevention
STATUS OF EARLY IDENTIFICATION

Distribution of Infants with Hearing Loss

- Developing world: 90%
- Developed world: 10%
EARLY IDENTIFICATION?

- CA, 7 year 10 month old girl
- 1st diagnosis
- Profound bilateral sensorineural hearing loss
EARLY IDENTIFICATION?

- SM- 4 year 10 months old
- 1st Diagnosis with HL
- AN – no behavioral response to sound at 95 dB
- Parental suspicion? 3 years
- Thought child was “rude”
EARLY IDENTIFICATION?

- NZ, 6 years, 4 months of age
- First diagnosis
- Severe- bilateral SNHL
- No spoken language
**EARLY IDENTIFICATION?**

*Nigeria  (n=363)  (Olusanya et al. 2005)*

- 12% suspected in 6 months; 4% after 5 years
- Age of suspicion **12–24m**
- **18** month delay suspicion to confirmation
- 80% no hearing aids provided
- Only **6%** enrolled in school for deaf by **6 years**
EARLY IDENTIFICATION?

Kenya (n=122) (Omondi et al. 2007)

- First detection 5.5 years (mean age)
- 57% detected after 2 years
- 27% visited healthcare provider for assessment
- Only 9% received counsel on HL
- None received a hearing aid
EARLY IDENTIFICATION?

South Africa  *(Van der Spuy & Pottas, 2008; Venter & Viljoen, 2008)*

- Urban samples

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<tr>
<th></th>
<th>Western Cape</th>
<th>Gauteng</th>
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<tbody>
<tr>
<td>Ave age of diagnosis</td>
<td>23 months</td>
<td>31 months</td>
</tr>
<tr>
<td>Ave age of initial HA fitting</td>
<td>28 months</td>
<td>39 months</td>
</tr>
<tr>
<td>Ave age of enrollment into EI</td>
<td>31 months</td>
<td>43 months</td>
</tr>
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</table>
STATUS OF EARLY IDENTIFICATION

• >90% of babies born with HL - no prospect of EI

• Detection primarily passive:
  – Complications of OM
  – Speech & language delays
  – Unusual behavior

• Exacerbate impact of HL - consigns to seclusion, limited access & quality of life
WAY FORWARD?

“Although the world is full of suffering, it is also full of the overcoming of it”

Helen Keller
WAY FORWARD?

CHALLENGES

• Shortage of Hearing Healthcare Professionals
• Limited Audiological/Otological Health Infrastructure
• Awareness & Perceptions – Public and Professional
• Priority on Global and National Health Agendas
• Costs within restricted resource environment
• Contextual challenges (*birthing patterns, cultural & environmental challenges*)

\[1 : 20000 \text{ VS } 1 : 1000000\]
WAY FORWARD?

CONTEXTUAL SOLUTIONS

• **Contextually relevant** programs for developing countries
• **Immunization** clinics*:
  – *effective for babies born outside hospitals*
  – *valuable platform for community-based UNHS*
  – *long-term performance comparable to hospital-based UNHS*
  – *risk factors can be addressed within primary healthcare settings*
• **EHDI must be integrated** in Maternal & Child Health initiatives - in line with **WHO, UNICEF, World Bank priorities**

*Swanepoel et al. 2007; Olusanya et al. 2009*
WAY FORWARD?

COST EFFECTIVE SOLUTIONS

• Cost effectiveness of programs for developing countries
• Recent study from Nigeria*
• UNHS cost per child identified (PCEHL)
  – Hospital-based: $2,765
  – Community-based: $602
• UNHS more cost-effective than TNHS
• Initial evidence +

*Olusanya et al. 2009
WAY FORWARD?

PRIORITIES

• Priority - **Global alliance** of professional groups and NGO/NPO’s

• Reduce **costs** by global **partnerships** (private/public) through **economies of scale** (*Equipment, HA’s, disposables, batteries*)

• **Pilot programmes** at various levels – different systems

• **Education** programmes for non-specialist personnel

• **Telemedicine, e-Health, m-Health** models – training, quality control, diagnosis and intervention
WAY FORWARD?

MORAL OBLIGATION

• Moral obligation to extend benefits of EHDI

• Narrowing avoidable disparities - important pressing imperative – Global attention to silent, invisible epidemic

• “Better hearing for persons of ALL nations is an achievable, important goal” - Morton & Nance, 2006

• Urgency for most vulnerable – infants and children with HL
A SOUND FOUNDATION - FOR ALL CHILDREN