Family Perceptions & Experiences with the Early Hearing Detection and Intervention System in Rural Communities

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Disclosures

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• No off-label use of drugs or devices

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Infant Hearing Loss is a National Priority

• United States Preventive Services Task Force:
  – Significant effect of congenital hearing loss on communication skills, psychosocial development, and educational progress

• Early identification of hearing loss leads to utilization of early intervention services.

• Screening diagnostic testing by 1 month of age

• Diagnosis ➔ 3 months, Treatment ➔ 6 months

Appalachia – Still a Great Frontier…

- Large rural region of health disparity
- 8% of total US population
- Rural Appalachian children are delayed in:
  - Diagnosis (7-9 months)
  - Amplification (1.7 yrs)
  - Cochlear implantation (3.5-4.5 yrs)

Bush et al 2013, Bush 2014 et al
What Factors Play a Role in This?

The purpose of this study is to assess parental knowledge and attitudes regarding barriers in the diagnostic and therapeutic process following abnormal newborn hearing screening testing.
Assessment of Parental Knowledge

- Questionnaire pilot study of KY parents of children failing infant screening 2009-2011
- 460 participants from throughout the state (117 rural Appalachian region)
- Assessed parental demographics, experiences and barriers with NHS program, and attitudes toward infant hearing loss.
- Comparison between Appalachian and non-Appalachian parental responses
Economic and Educational Concerns

- Medicaid: p < 0.001
- Less than 12 years of education: p = 0.02

Bar graph showing differences in Medicaid and education levels between Appalachian and Non-Appalachian groups.
Lack of Hearing Health Knowledge

- Unaware of NHS Results: p=0.9
- Ignorance of NHS at Discharge: p=0.03
Unaware of Cochlear Implants

![Bar chart showing CI Ignorance with p=0.01]

- Rural
- Metro
Need for Greater Access

- Need for Closer Center: p=0.17
- Need for Telemedicine: p=0.001

Appalachian
Non-Appalachian
Limitations

1. Inherent bias and weakness of a questionnaire study
2. Poor representation of those of low literacy
3. Lack of generalizability of the results to other regions
To address these limitations...

We conducted a 2nd study to further elucidate the barriers rural Appalachian families face in receiving hearing health care for their children.
## Methods

<table>
<thead>
<tr>
<th><strong>What</strong></th>
<th>Semi-structured Telephone Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who</strong></td>
<td>Families of children failing Newborn Hearing Screen</td>
</tr>
<tr>
<td><strong>Assessed</strong></td>
<td>Parental knowledge, attitudes, and experiences as they progressed through the processes of follow-up, diagnosis and treatment</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>Qualitative Data Analysis</td>
</tr>
</tbody>
</table>
Our Sample

- 40 subjects interviewed

  - **The Interviewees:**
    - Relationship to patient
      - 30 Mothers
      - 2 Fathers
      - 8 Grandmothers
    - Ages: 20-60 yo

  - **The Children:**
    - Hearing Status
      - 29 passed
      - 2 in process
      - 9 diagnosed
### Demographics

<table>
<thead>
<tr>
<th>County</th>
<th>Participants</th>
<th>Beale Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathitt</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Clay</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Floyd</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Harlan</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Knott</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Knox</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Laurel</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Leslie</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Letcher</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Magoffin</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Martin</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Perry</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Pike</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Pulaski</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Rowan</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Whitley</td>
<td>1</td>
<td>7</td>
</tr>
</tbody>
</table>

**Urban population:**
- **5** Urban population: 20,000 or more, not adjacent to a metro area
- **6** Urban population: 2,500 to 19,999, adjacent to a metro area
- **7** Urban population: 2,500 to 19,999, not adjacent to a metro area
- **8** Completely rural or < 2,500 urban population, adjacent to a metro area
- **9** Completely rural or <2,500 urban population, not adjacent to a metro area

**Insurance:**
- 28 Medicaid
- 8 Private
- 3 Both
- 1 None

**Education of Caregiver:**
- 8 <12 yrs
- 9 High School Grad
- 15 Some college
- 4 Degree
Results

• Shared barriers across interviews:
  » Distance
  » Financial Stress
  » Misinformation
• 25 participants
“It was just kind of out of the way … we had to drive an hour and so she would sleep the whole way…then she wakes up and they can’t do the test.”

“It was better than going to Lexington. I mean Lexington takes like 4 hours and Hazard just takes about 2 … they wanted me to come down there for a bunch of stuff and it was too much.”

“If we have to go to Lexington, then my dad takes the day off work and takes us… you know it’s a big trip, so he’ll go with us.”
“At the time we didn’t have you know like a dependable vehicle and stuff.”

“The first one or two that we didn’t [go] to; we had to reschedule because of our car broke down. The brakes just was bad on the car and we was afraid to put the babies in it.”
Financial Barriers

- 6 Lack of funds
- 7 Insurance Issues
- 11 Home/work responsibilities
Financial Barriers

“Whenever you’re a single parent; you know you ain’t always got the cash to work on stuff right away.”

“Sometimes it’s hard to get the money to get down there, but you know like I said, she’s working now and the father left them all so I’m helping her.”
“The audiologist, had tried to get in contact with them but they would never answer and she would keep leaving messages, and then finally, after like 2 weeks and she’d already ordered them… they still hadn’t approved it yet. That’s why it took so long.”

“Well I’ll tell you what I had to do; I had to have it changed because … the doctors up here … they wouldn’t take that no more; I had to change it to Wellcare.”

“If I’d had to take [her] to Lexington, you know maybe stay all night or something like that, I’d … had to have somebody watch the baby because my husband worked in the coal mine so he couldn’t watch her and go work.”
Misinformation

- 7 participants misinformed
- 7 participants had trouble with pediatrician
“So I thought you know … they’re all going to have all the same programs; well they didn’t. So it took us forever to get the number … it was just a big mess.”

“She went every 2 months, she never passed it which I didn’t realize until the, until you know she was like going on 2 [years old].”
“His pediatrician … never told me about First Steps. He’s only about 2 or 3 months behind … if she would’ve told me when he was born that I could’ve put him in … therapy, then he’d have been in it for an extra 4 months.”

“A lot of people don’t take it that seriously. For example, … I can go to Lexington and get my questions answered and be in and out, whereas I can sit in a waiting room for 2 hours in Somerset and still not get nothing from it.

“Every time that I had a concern, she just played it off like I was a paranoid new parent.”
Limitations of the Study

1. Inherent bias and weakness of an interview study

2. Poor representation of those families unable to be reached by telephone

3. Lack of generalizability of the results to other regions
Conclusions

1. Lack of education and knowledge of infant hearing healthcare are significant concerns in Appalachian parents
2. Distance to advanced hearing healthcare complicates the process
3. Personalized education and telehealth may provide important links to this disparity
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Thank You!

Questions?

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