

Loss to Follow-Up: Providing Information to Keep Children from Slipping Through the Cracks

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Introduction

According to the World Health Organization (WHO), approximately 7.5 million children in the world have a disabling hearing loss. In the absence of timely intervention, these children may experience lifelong difficulties in speech and language, and potential complications in educational and vocational achievements. The implementation of Universal Newborn Hearing Screening has enabled early identification of infants with congenital hearing loss. However, follow-up of infants who have failed the initial screening; or those who may have passed, but have a risk factor for developing delayed-onset hearing loss, is critical for timely intervention. The Joint Committee on Infant Hearing (JCIH) recommends a follow-up rate of more than 95% of infants, but a 70% benchmark has been reported as more feasible. Therefore, a major challenge reported by healthcare providers is the high loss to follow-up rate. A systematic review by Ravi et al. (2016) identified educational disparity and lack of adequate knowledge among parents were associated with loss to follow-up. Cunningham et al. (2018) also found that low-income, rural, and minority infants are at a higher risk for loss to follow-up. This project seeks to determine if providing parents with more accessible information during appointments can help to increase follow-up rates.

Methods

Participants: 22 parents/guardians of children with follow-up appointments at Denver Health due to failed newborn hearing screenings.

Procedures: Upon arrival to the Denver Health Audiology clinic for follow-up newborn hearing screening appointments, parents were asked if they would be willing to complete a questionnaire prior to the appointment that asks five questions involving knowledge of hearing loss, speech and language development, and if they understand the reason for the follow-up visit. After testing was completed for the baby, results of the hearing screening were reviewed with the parents, as well as the need for any further testing or follow-up. Parents were given an educational handout that included the results of the test, information on the purpose of the hearing screening and follow-up, and speech and language milestones. The parents were then asked to review the handout and fill out the "after visit" questionnaire. This questionnaire included the same five questions and two additional questions asking if the handout was helpful and easy to understand. Both the questionnaire and information sheet were available in English and Spanish. Results of the questionnaires were compared before the visit and after the visit to determine if educational information was retained during the appointment.

Newborn Hearing Screening Parent Questionnaire (After Visit)

Instructions:

For the following questions please circle your answers.

- Does your baby have a higher risk of having a hearing loss?
 - Yes/No/I don't know
- What are some ways to know if your baby is hearing? (You can pick more than one):
 - Baby jumps or reacts to loud sounds
 - Baby turns their head or eyes to find you when you say their name
 - Baby turns their head or eyes to find the location of a sound
 - Baby calms down when they hear a familiar voice
- What are some ways to help your baby learn how to communicate? (You can pick more than one):
 - Responding to the sounds that your baby makes
 - Talking to your baby about things that you're doing
 - Singing songs and nursery rhymes
 - Reading to your baby while they look at the pictures in a book
- My baby should say their first word by:
 - 6 months
 - 1st birthday
 - Age 1 ½
 - Age 2
- I understand why this visit is important
 - Yes/No
- I understand why this visit was scheduled
 - Yes/No
- Was the information sheet helpful?
 - Yes/No
- Was the information sheet easy to understand?
 - Yes/No

Thank you for bringing your baby in today! Don't hesitate to contact us with any questions.

Figure 1: Questionnaire

A hearing screening using Automated ABR or OAE was completed on your baby.

Right Ear:

- Passed
- Passed, but follow-up is needed
- Did not pass and further testing is required
- Testing could not be completed and further testing is required

Left Ear:

- Passed
- Passed, but follow-up is needed
- Did not pass and further testing is required
- Testing could not be completed and further testing is required

An appointment has been scheduled for you: _____ (Date/Time)

Denver Health Audiology Clinic
777 Bannock Street-Pavilion E 2nd Floor
Denver, CO 80204

OR

Please call 303-602-6137 to schedule and appointment.

Please take this with you to your baby's doctor and audiology appointments.

Why should my babies hearing be screened?

One out of every 500 babies has a significant hearing loss at birth. More than half of babies born with hearing problems are otherwise healthy and have no family history of hearing loss. Therefore, to be sure we identify every baby with hearing loss, hospitals in Colorado are required to provide a hearing screen.

It is unlikely that your baby will have a hearing loss. However, it is important for you to be sure that your baby has normal hearing. The first year of life is critical to the development of normal language and speech.

What if my baby does not pass the test?

There are many reasons why your baby may not 'pass' the first hearing test and require a second evaluation; your baby may have been too active or wide awake.

If my baby passes the screening, do I need to have the hearing checked again?

The hearing screening test can usually confirm that your baby has normal hearing at the time of the procedure. However, hearing loss can develop later, as your child grows, for a variety of reasons. If you have a family history of hearing loss, your baby should be tested every year. Ear infections that occur as your child grows can also cause hearing loss. If you ever have concerns about your child's hearing, speech, or language, be sure to discuss this with your audiologist and/or physician.

Speech, Language, and Hearing Skills to watch for based on age:

Around 2 months of age

- Startles to loud sounds
- Quiets to familiar voices
- Makes vowel sounds "oo" and "ahh"

Around 4 months of age

- Looks for sounds with eyes
- Starts babbling
- Uses variety of voice sounds, such as squeals, whimpers chuckles

Around 6 months of age

- Turns head towards sounds
- Begins to imitate speech sounds
- Babbles ("ba-ba", "ma-ma", "ga-ga")

Around 9 months of age

- Imitates speech sounds of others
- Understands "no-no" or "bye-bye"
- Gives toy when asked for
- Turns head toward soft sounds

Around 12 months of age

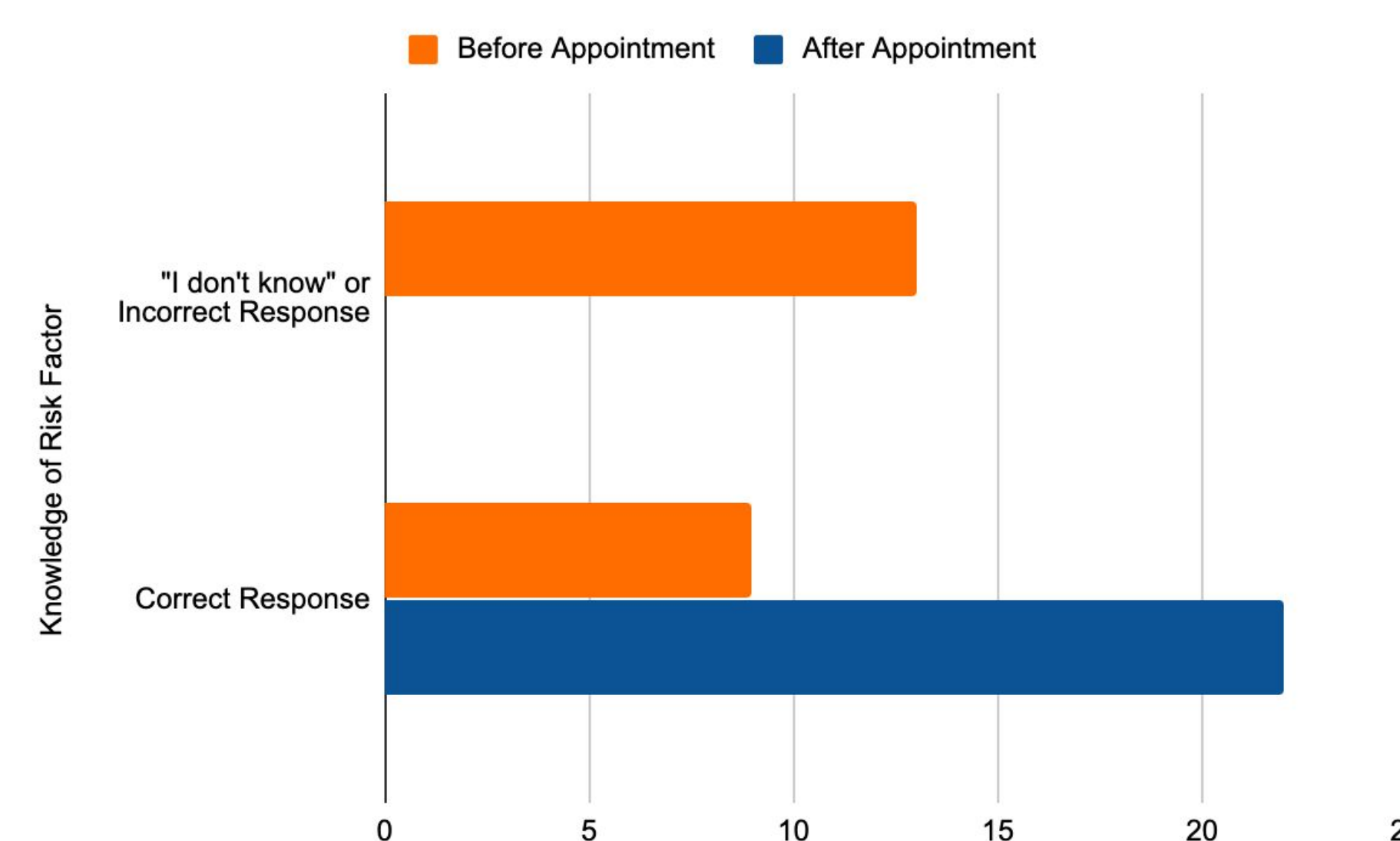
- Correctly uses "ma-ma" or "da-da"
- Responds to singing or music
- Locates sounds on all levels

Figure 2: Educational handout

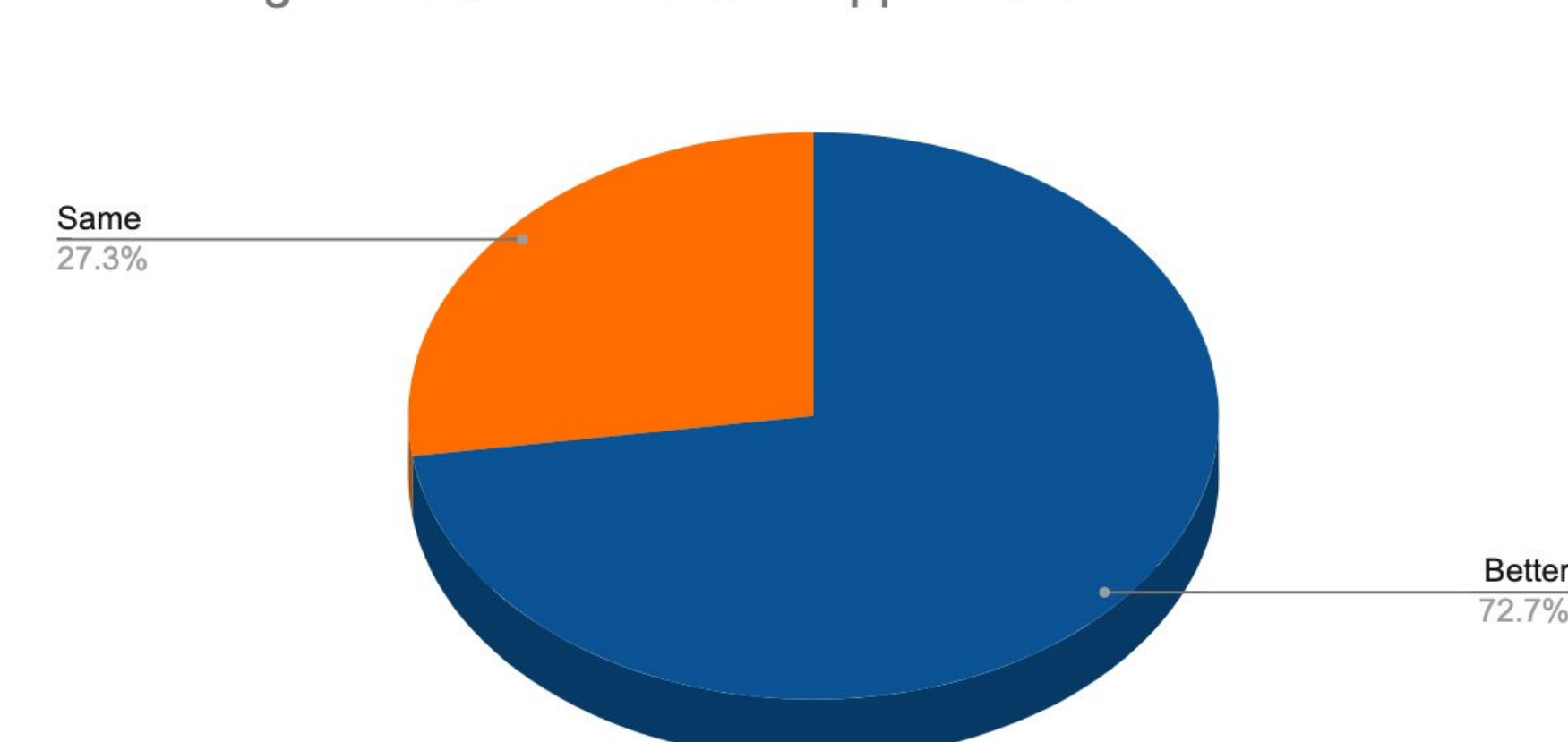
Results

The before and after visit questionnaire responses were compared in three areas, and the after visit questionnaire was used to determine how many parents found the information sheet helpful and easy to understand.

- The first comparison was between the parents' knowledge of their baby having a risk factor for hearing loss prior to the appointment and after the appointment. Thirteen parents responded "I don't know" or responded incorrectly prior to the appointment, and all thirteen parents answered correctly after the appointment. Nine parents answered correctly both prior to and after the appointment. No parents answered incorrectly following the appointment.
- The second comparison combined questions 2-4 on the questionnaire as knowledge of speech and language milestones prior to and after the appointment. Sixteen, or 73%, of parents improved knowledge of milestones after the appointment and being given the informational sheet, six or 27%, of parents had no change in knowledge, and no parents did worse on the milestone questions following the appointment.
- Only one parent responded that they did not understand why the appointment was important prior to the appointment. They responded "yes" to this question following the appointment.
- All 22 parents responded "yes" to the information sheet being helpful and easy to understand.



Knowledge of Milestones: After Appointment



Discussion

Preliminary findings suggest that written information and educational materials given out during appointments increases knowledge and understanding of results and importance of appointments. Results may have been affected by the fact that the parents who came to the appointments, came because they knew it was important. Those that no-show for the appointments may do so because they do not understand the importance of the appointment or why it was scheduled. This is a possible reason for only one parent responding that they did not understand the importance of the appointment prior. It should be noted that this project only encompassed a narrow scope of patients and goals of future directions are to expand educational materials to the nursery to reduce no-show rates for follow-up appointments.

Future Directions

- Modify the the questionnaire sheet to better encompass parents' understanding of results of their baby's initial newborn hearing screening.
- Implement the information sheet into the nursery at the initial newborn hearing screening.
- Translate the information sheet and questionnaire into more languages to make information accessible to more families.

References

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Acknowledgments

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