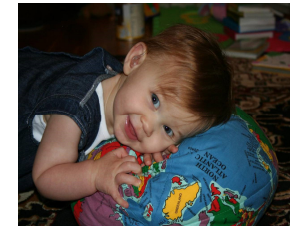




Assessing Family Satisfaction and Outcomes from an Interdisciplinary Clinic for Children Diagnosed with Hearing Loss

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Abstract

Arkansas Children's Hospital (ACH) offers an interdisciplinary multi-specialty clinic for children of newly identified children with hearing loss and their families. The day-long clinic consists of appointments with Genetics, Audiology, Speech Pathology, Otolaryngology, Psychology, a representative from Arkansas Hands & Voices and a representative from Part C/Early Intervention Services. The team strives to assist families in the acquisition of knowledge and resources that will be needed for the journey ahead. This poster reports findings from a Quality Improvement survey conducted to determine family satisfaction following a visit to the ACH interdisciplinary clinic. The survey, which was conducted via telephone by two Au.D. graduate interns, consisted of five statements rated using a Likert scale and two open ended questions. The statements were developed to match the goals of the clinic including increasing parental understanding of the child's specific hearing loss and providing information about etiology, community resources and communication development, as well as facilitating connections to other families. The two open ended questions allowed the parent to comment on how information learned at the clinic visit impacted decision-making about the child, as well as an opportunity to offer suggestions on ways to improve the clinic for families in the future. Findings will be reported, as well as ideas about "next steps" to improve this clinical experience by further embedding a family-centered philosophy and practices under the diagnostic/medical umbrella.

References

Eleweke, J., Gilbert, S., Bays, D., & Austin, E. (2008). Information about Support Services for Families of Young Children with Hearing Loss: Review of Some Useful Outcomes and Challenges. *Deafness and Education International*, 10(4), 190-212.

Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I., & Coyle, I. (2008). Parents' Needs Following Identification of Childhood Hearing Loss. *American Journal of Audiology*, 17, 38-49.

Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4(2), 138-163.

Jamieson, J., Zaidman-Zait, A., & Poon, B. (2011). Family Support Needs as Perceived by Parents of Preadolescents and Adolescents Who are Deaf or Hard of Hearing. *Deafness and Education International*, 13(3), 110-130.

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Background

The opportunity to embed parent education as an integral part of the diagnostic process for families of a children newly identified as Deaf/Hard of Hearing is both challenging and complex. Approximately 95% of children are born to parents with typical hearing, who have no previous experience or knowledge about hearing loss (Holt, Hatto, and Cole, 1994). Following this diagnosis, parents may experience a range of emotions, as well as an ongoing need for information. They are faced with decisions for which they may feel unprepared or did not anticipate. Determining what parents need and when they need certain information can be an imposing responsibility for professionals working with these children and families. According to Eleweke, Gilbert, Bays and Austin (2008), parents want specifics regarding their child's hearing loss, information about services/intervention, community resources and guidelines for appropriate expectations. Family support is vital to parents of children with hearing loss and should focus on the development of parenting skills, emotional support, information about financial resources and assistance, options relative to educational services and access to support for children with additional special efforts according to Jamieson, Zaidman-Zait, and Poon (2011). In addition to meeting parent needs, research shows that aligning services provided with parental expectations and desires may positively impact early intervention outcomes (Fitzpatrick, Angus, Durieux-Smith, Graham, and Coyle, 2008). Opportunities to increase parent knowledge and skills synchronously during the early diagnostic and decision-making process hold promise for enhanced parent and child outcomes and warrant ongoing investigation.

Method

Participants

Thirty-seven out of fifty-five families that participated in an interdisciplinary, multi-specialty clinic for children newly diagnosed as Deaf/hard of Hearing completed the quality improvement survey. Eighteen families were not included for multiple reasons, including disconnected phone number, inability to reach after multiple attempts, deceased parent or child, or no interpreters available for Spanish-speaking families.

Procedure

The participants were contacted via telephone by two graduate students using a scripted guide and worksheet which was completed during the call. Parents or guardians were asked to rate their answers on five questions, and then asked two open-ended questions. A sample of the Family Survey is shown in Figure 1.

| Date of call: | Date of HI Clinic Visit: | MR#: |
|---|--------------------------|------|
| <p>This is (your name) with the Audiology Clinic at Arkansas Children's Hospital. I was following up on your visit to the Multidisciplinary Clinic you attended on (insert date) when your child was seen by a group of specialists from Audiology, Genetics, Speech, ENT and others. I would like to ask you a few questions about that appointment if you don't mind. It will take around 5 minutes and we will use the information to improve the clinic for others. I don't record your name, so it is confidential.</p> <p>On a scale of 1-5 with 1 meaning strongly agree, 2 meaning agree, 3 meaning neutral/neither agree nor disagree, 4 meaning disagree and 5 meaning strongly disagree, how would you rate the following statements after coming to the Multidisciplinary Clinic.</p> <p>Statements:</p> <p>I have a better understanding of my child's hearing loss. I know how to connect with other parents who have children that are Deaf or Hard of Hearing. I understand what I can do to help my child communicate better. I know more about what may or may not have caused my child to have hearing loss. I know about other people, therapies, and agencies in our state that are available to help our family.</p> <p>Questions:</p> <p>1. How did information that you learned from your HI Clinic visit impact decision your family has made about your child?</p> <p>2. What would have improved your experience in HI Clinic?</p> | | |

Fig. 1: Sample Family Survey Worksheet

Results

The survey was undertaken to determine if the goals of the clinic were met—increasing parental understanding of the child's specific hearing loss and providing information about etiology, community resources and communication development, as well as facilitating connections to other families. Results generally indicated a high measure of success in meeting the clinic goals. Figure 2 represents the frequency of rating, range and mean for the five statements on the survey. Responses to open-ended questions were grouped according to similar theme and intent. The most frequently occurring responses for Question 1 (How did information that you learned from your HI Clinic visit impact decisions your family has made about your child?) indicated that parents felt they understood their options better and had a better understanding of their child's hearing loss, as well as how to help their child following clinic attendance. Table 1).

Sample parent response for Question 1:

How did information that you learned from your HI Clinic visit impact decision your family has made about your child?

"It has helped me learn more so that I could better explain it to other people."

"I felt like I had a voice, not just a doctor saying 'do this or do that.'"

"It was a positive experience to have all the pieces of the puzzle at one time."

"We were more aware of what to do at home to help him."

Table 1: Parent responses from Question 1

For Question 2 (What would have improved your experience in HI Clinic?), recommendations centered on length of the day, delays in getting test results after the clinic and limited time for counseling (Table 2).

Sample parent response for Question 2:

What would have improved your experience in HI Clinic?

"We wish it could have been faster, it was very long."

"We would have liked to have gotten genetic results and feedback sooner."

"We felt very rushed."

"We would have liked more counseling and information about why our child has hearing loss and more detail about our options."

Table 2: Parent responses from Question 2

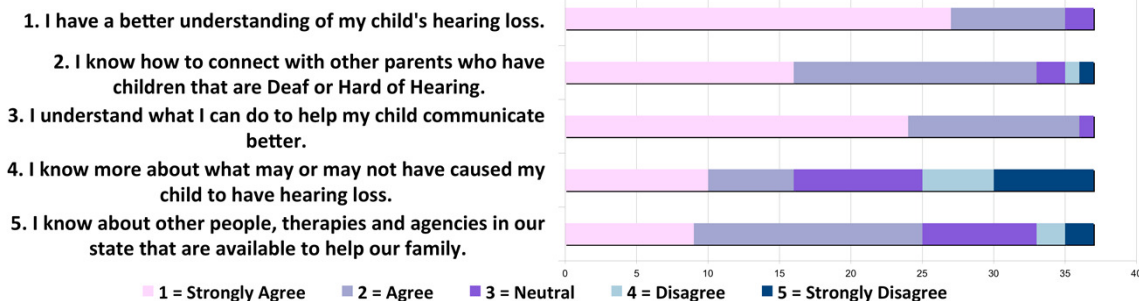


Fig. 2: Parent Responses to Statements 1 through 5