

Communication Needs of Twins with Angelman Syndrome: A Qualitative Approach

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Abstract. Families of children with low incidence, severe disabilities have unique needs, which may not be revealed through traditional assessment. Qualitative studies, using multiple data sources allow professionals a more realistic view from families' perspectives. Nine year old twins with Angelman syndrome and their families participated in this qualitative study. Information from previous ethnographic interviews of family members revealed three domains. These domains then framed additional data collection using results from a questionnaire, parent interview, and observations at home. Two overarching themes were identified: current differences between the twins and ways each encounters communication and learning. These data will be used to address goals and intervention. Results demonstrate how qualitative approaches allow identification of children's preferences and family's priorities.

1. Introduction

Families of children with severe disabilities have unique concerns and needs. A main concern is communication. Many of these children are nonverbal, but that does not mean that there is no communication. Families often recognize communication that even professionals do not. Qualitative studies allow a more realistic view of a family's perspective about the abilities and needs of their children.

Twin girls with Angelman Syndrome (AS), a low incidence genetic syndrome that causes severe disabilities [1], are being followed in a longitudinal study. A previous study conducted when the twins were in preschool [2] was based on family ethnographic interviews and observation. Most communication of both girls was at the perlocutionary stage (communication was perceived by the listener who then responded appropriately to the communication intention). There were a very limited number of communication intentions, which could be classified as illocutionary (intention is communicated through gestures) [3]. Results of this qualitative study revealed that the participants showed a desire to communicate that was often missed by communication partners who could have given voice to the girls' words [4].

In order to more appropriately meet the needs of the twins and their family and to determine the least restrictive communication system for the girls, this qualitative study was conducted using multiple data sources. Researchers were allowed to investigate current needs, communication in particular.

2. Experiment, Results, Discussion, and Significance

Method

Participants. Participants for this study were twin girls, ages 9;4, with AS and their mother. In addition, transcripts of ethnographic interviews of their maternal grandmother, their paternal grandparents, and their mother collected for the 2008 study were used for the preliminary stage review.

Preliminary Stage. The researchers first conducted a preliminary review of the transcripts of ethnographic interviews gathered for the 2008 study. Emerging domains [5] were identified. These domains were used to frame the data collection in the investigative stage.

Investigative Stage. Data were collected using three sources: a questionnaire completed by the twin's mother which focused on parent priorities regarding use of communication devices [6], an interview with the twin's mother conducted by the primary investigator to follow up on changes since the 2008 study, and observation of the twins

through video recordings made during three home visits within the same time period. Analysis of data focused on obtaining information regarding the previously emerging domains and revealed overlapping themes.

Reliability. The twin’s mother was asked by the primary investigator to verify the results of the questionnaire and interview, which she confirmed with two additions regarding current social differences. Reliability of the transcript coding was determined through independent comparisons of codes used by the first and second investigators. Consensus was used to validate these data. Triangulation, corroboration of evidence from at least three sources, was achieved using data from all three sources (questionnaire, interview, and observation) [7].

Results

Analysis of the ethnographic interview transcripts revealed three unique domains: (a) differences between the girls, (b) family needs, and (c) communication needs. Comparisons were made between the results of the 2008 study of the twins as preschoolers and the current study of the twins at 9;4 years. Review of the new data sources indicated two overarching themes: more divergent personalities and the ways each encountered communication & learning. Results of each theme are in Tables 1 and 2.

Table 1. Differences Between Girls

Angela	Breanna
2008 & 2011	
Laid back	Active
Snuggler	Explorer
Follower	Protector
Fine motor: how things work	Gross motor movement
Contact with people	Tight spaces & textures
2011	
Likes music & movies	Likes being outside
Picky eater	Better eater
Poor sleeper	Better sleeper
Angelic	Silly & ornery

Table 2. Communication & Learning

2008	2011
<i>Request</i>	
Stand beside, reach, or stare at	Lead to what they want*
Choose between several	Same
<i>Protest</i>	
Turn away	Shake head or fuss/vocalize
<i>Greet/Social Closeness</i>	
Hug	More natural attempts
<i>Joint Attention</i>	
Limited	More attempts and eye contact

*At school, learning Picture Exchange Communication

Discussion

The comparison of the twins’ communication and learning from 2008 to 2011 illustrated that the twins were exhibiting more conventional communication intentions (illocutionary), which is recognizable to a wider variety of communication partners (e.g., leading to a desired object and shaking head to indicate “no”). There were more clear attempts at joint attention, including appropriate and longer eye contact. At times, both girls responded more efficiently when allowed to make a choice between two items. The twins appear to be poised for a more conventional communication system. iPad applications might appeal to their emerging communication interests and joint attention ability, as well as provide a system that is motivating and which allows for choices. The iPad could also have the potential to reduce their frustrations when communicating. Results of this study might indicate that Angela is more ready for this device because of her interest in fine motor activities.

3. Conclusions

The qualitative approach to this study allowed the researchers to determine the family’s perspectives, as well as to address known parent priorities regarding augmentative and alternative communication (e.g., goals for their children, child’s preferences, sensitivity to family’s beliefs and cultural values [6]). Based on the findings of this study, the twins seem prepared to utilize a more conventional communication system, such as the iPad.

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