Research in Communication in Rett Syndrome: Where We Are, Where We Want to Be

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Review of recent research in communication treatment for girls with Rett Syndrome

  ▫ Reviewed nine experimental studies of communication intervention
  ▫ Positive outcomes reported for all 84% of participants (26 of 31 girls with RTT)
  ▫ Results interpreted with caution as evidence is weak
Characteristics of the studies

- Girls between 2.7 – 17 years of age
- Home and classroom environments
- Communication modes targeted:
  - Speech or vocalization
  - Gesture
  - Graphic symbols &/or printed words
  - Electronic or computer based systems
- Functions targeted:
  - Requesting (food, drinks, toys, songs)
  - Imitation of speech
  - Naming objects or commenting
  - Receptive language (following commands, answering questions)
Outcomes

- Some positive gains in communication reported for most girls
- Evidence is weak because of lack of follow up, lack of clear reporting of data
- Only one study reported certain evidence – three girls were trained to touch a picture on a computer screen to request favored objects
What does this mean?

• We know it’s very challenging to study communication in a very controlled way in children with severe disabilities
• You often need to “know them well” in order to determine what they understand and can communicate
Recent findings

- Girls with RTT are reported to communicate by their parents, teachers and therapists
- They use eye gaze most frequently, followed by picture/symbol boards and body movement
- Clinicians should evaluate all modalities (gaze, gestures, vocalizations, pictures/symbol use)
- Not all modalities work at all times
- Consider:
  - influence of apraxia, delayed response time, inconsistency, level of awareness
    - (Bartolotta et al., 2011)
Recent findings

• Communication coaching
  ▫ Study of four girls with RTT and their feeders at mealtime in schools
  ▫ Videotaped meals to explore use of communication
  ▫ Identified “teachable moments”
  ▫ Provided training of communication strategies to the feeders

  • (Bartolotta & Remshifski, under review)
Communication Strategies

• Offer choices of food or drink
• Increase wait time before asking again or feeding
• Offer opportunities to use AAC devices if the girl is able – provide these consistently
• If you think she might be communicating, assume that she is – “assumed competence”
• Data suggests both girls and their feeders change their communication as a result of coaching
  ▫ Girls make more requests and provide more responses
  ▫ Feeders make more requests and provide more responses
  ▫ Behavior of others in the classroom changes – begin to offer more opportunities for communication in other contexts (e.g. circle, work time, etc.)
Example of coaching

- Girl with RTT, age 10
- Classroom aide as feeder
- Time 1 – pre-coaching – typical meal
- Time 4 – six weeks post-coaching
Example of coaching

• Strategies
  ▫ Increase delay time (by 5 seconds) between presentation of each bite or drink.
  ▫ Allow time for identification of a motor behavior that is potentially communicative, such as:
    • Eye gaze
    • Open mouth
    • Vocalization
    • Body movements
• Maintain direct eye contact post-spoonful
Future directions

• Need for evidence to guide clinical practice

• More studies planned with partners – parents, teachers, therapists – with tighter controls
References