Evaluating Treatment Efficacy for Language Facilitation in Autism

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What are the treatment issues re: autism?

- Language characteristics are highly heterogeneous
  - Some are able to acquire language forms with little more than a delay
  - Some never acquire language
  - In-between may see:
    - Echolalia
    - Longer delay in acquisition
    - Use of scripted phrases

What are the treatment issues re: autism?

- It is difficult to assess treatments because of:
  - Lack of control of:
    - Number of interventions the child is receiving
    - Individual differences in the population
    - Comorbidity of other disorders/medical conditions
    - Level of family support
    - Variability in administration
    - Measurement of success
      - generalization

Overview of current treatments

- Auditory integration
- Gluten free/ casein free diet
- Sensory Integration
- Facilitative Communication
- ABA/DTT early behavioral interventions
- PECS
- Floortime
- Hanen Program
- TEACCH
- Pivotal Response Training

Overview of current treatments

- Behavior-based treatments
  - Examples
    - ABA/DTT early behavioral interventions
    - PECS
  - Major tenets
    - Children with autism cannot learn in a "typical" environment
      - Need more structure
      - Need explicit teaching
    - Behavioral techniques can be used to shape coping, play skills and social interaction
  - Treatment is drill-based and intensive

Overview of current treatments

- Naturalistic treatments
  - Examples
    - Floortime (Greenspan)
    - Hanen Program (parent training) (Sussman, 1999)
  - Major tenets
    - Treatment should be based on typical development
      - Plays to child's strengths instead of focusing on deficits
      - Follows the child's lead in choosing activities
    - Naturalistic techniques can be used to address developmental delays in sensory modulation, motor planning and sequencing, and perceptual processing
  - Treatment is play-based

Overview of current treatments

- Middle-ground treatments
  - Examples
    - TEACCH
    - Pivotal Response Training
  - Major tenets
    - Treatment should be based on each individual's needs, interests and skills
      - Uses visual schedules
      - Activities are clinician-directed
    - Designed to help individuals with autism to function and live as independently as possible
  - Basis of treatment combines discrete trials and more naturalistic activities (e.g. play or work)

Does only one method have a scientific research base?

- To answer, obviously need to define "science" and "research"
  - *Science* (from on-line OED): "A branch of study which is concerned either with a connected body of demonstrated truths or with observed facts systematically classified and more or less colligated by being brought under general laws, and which includes trustworthy methods for the discovery of new truth within its own domain."
    - *Colligate:* "To connect together (isolated facts) by a general notion or hypothesis."
  - *Research: "*Investigation, inquiry into things.*"*

Key aspects of these definitions

- For science:
  - Importance of theory
  - Trustworthy methods
    - for domain of study
  - Systematicity
    - See: *Some Notes on the Nature of Science*
      - http://www.quackwatch.org/01QuackeryRelatedTopics/science.html (Schwartz & Barrett, 2001)

For research:

- Inquiry itself is research
  - Becomes scientific by the nature of the research carried out

Validity in intervention research

- Selecting appropriate population to study
  - Criteria used to select participants?
  - Ability levels?
  - What control groups were used?
- Controlling for alternative explanations: internal validity
  - Normal development & change
  - Something else introduced at same time
    - Diet, drugs, medical changes, school placement
  - Placebo effect
    - Belief of participant that treatment is helpful results in change
  - Hawthorne effect
    - Tendency of participants to improve behavior when they are being studied
    - Possible corollary: people may interact differently with children known to be undergoing treatment believed to be effective

Error sources undermining validity

- Measurement error
  - Inaccurate (reliability of measurement)
    - Raters blind to treatment condition?
    - Inter-rater, intra-rater agreement measured?
    - Validity of sample of behavior?
      - Natural variability in some behaviors
  - Inappropriate measurement tools (construct, content validity)
    - Tools must accurately measure outcomes
      - IQ?
      - Formal language tests?
      - Language or behavioral sampling?
      - School placement?
      - Caregiver ratings?
    - Many not fine-grained enough to measure subtle change
    - If use pre- and post-testing
      - Are changes within Standard Error of Measure of test?

Evaluating Research Designs

- Group designs
  - Double-blind, placebo-controlled study, random assignment to treatment conditions
    - E.g., Bettison (1996)
  - Placebo-controlled
    - May use alternating treatments
      - Random assignment to treatment conditions?
        - "convenience" samples
  - Treatment, no treatment
    - Delayed treatment

Issues with group designs

- Heterogeneity of population
  - Was group appropriately homogeneous?
    - If *too* homogeneous, may also be a problem
      - Can only generalize results to subset of population with ASD
  - Individual differences in response not always clear
    - Statistical tests on group means
      - Some researchers mention individual differences informally
    - For ideal treatment effectiveness, should be able to predict whether group results apply to particular individual cases
      - Some kids may have improved when no statistically significant group changes found
      - Other kids may have showed no change, even if group means went up

An alternative to group designs

- Single case design
  - Experimental design using participant as his or her own control
    - Often confused with case studies
    - Establish experimental control by
      - Withdrawal design (simplest—ABA)
        - Establish baseline behavior rate--A
        - Introduce treatment--B
        - Withdraw treatment --A
      - Multiple baseline (hold one behavior in baseline while treating another)
    - Use of visual significance
    - Replication important (across at least 3 participants)
    - Other issues
      - Variable or increasing baseline?
      - Control for normal development?

More Aspects of Validity

- External
  - In intervention research, applicability of treatment to real world conditions
    - E.g., Can research protocol be replicated by families?
  - Well-controlled study may still lack external validity
- Other threats to validity
  - Scientific consensus re: theory behind treatment
    - Sometimes called “content validity”
      - 7 Warning Signs of Bogus Science
        - http://www.quackwatch.org/01QuackeryRelatedTopics/signs.html
  - Need for documenting effectiveness of components of intervention
    - Interventions needing

Other issues in evaluating scientific research

- Importance of *replication*
  - Problem: study with apparent validity that cannot be replicated
- Publication in *peer-reviewed* media
- Are claims made for treatment aligned with *current knowledge* of autism?
  - Miracle cures….?
    - Autism known to be developmental disability affecting many brain systems
      - Sudden cures or huge change in short time unlikely
      - Scientific literature supports gradual change
  - Are proposed etiologies out of line with current biomedical knowledge?
- Do proponents have a financial interest in their treatment methods?

Early Intensive Behavioral Intervention: Evaluating Research

- UCLA Young Autism Project: Lovaas (1989)
  - Participant selection
    - Young children with autism referred to clinic
    - Assigned to intensive or less intensive treatment based on therapist availability
  - Basic Theory
    - Children with autism need special learning environments
      - Teaching of basic skills in small stepwise increments
        - Imitation very important
      - Generalization to natural environments
      - Intensive, early intervention allows brain plasticity to overcome learning problems (Lovaas, 2000).

EIBI, cont.

- Treatment method
  - Behavioral methods
    - Including discrete trial teaching
    - Planned generalization
  - Highly trained and well-monitored consultants & trainers
  - Parent involvement
  - Intensive: 40 hours per week
- Outcome measures
  - IQ tests
  - School placement
    - Note: long term follow-up measures looked at wider range of measures

How well does it hold up?

- Many severe criticisms have been leveled at this study
  - Not all have held up over time
    - E.g., charge that assignment to treatment group non-random somewhat serious
      - But no autism intervention study meets this criterion
      - Lovaas has denied his participant selection was biased (Lovaas, 2000)

Strengths of study

- Theoretical basis has support in literature
- Degree of effects shown hard to explain away by normal variation in population
  - Almost half of 19 participants functioning in typical range of IQ at close of study
  - Two control groups, one receiving 10 hours per week of treatment, the other a community sample receiving typical (unspecified) treatments available in the community
    - Neither exhibited gains shown by experimental group
- Careful adherence to study protocol
- In general, as carefully done as any relatively large-scale treatment study
  - Few competitors in realm of autism treatment research

Weaknesses of study

- Number one weakness: failure to replicate
  - Lovaas currently heading multi-site replication study
- Current protocol differs from YAP protocol
  - Punishment no longer used
- External validity questionable
  - Difficult to replicate results in community
    - Lovaas himself criticizes poorly run interventions claiming to use his protocol (Lovaas, 2000)
    - Lack of trained personnel
    - Lack of necessary intensity
    - Lack of careful generalization phases

Weaknesses, cont.

- Small n problematic
- Failure to use control group receiving comparably intensive treatment
  - Which is key: intensity or behavioral training?
- Theory weakened by lack of discussion of how/when natural learning takes over from training
  - Impossible to train all grammatical structures, all vocabulary, all pragmatic competence to within normal limits
    - Natural learning a logical necessity
    - Not addressed in behavioral literature

Another problem with EIBI and YAP

- E stands for Early, Y for Young!
  - This protocol not validated for older children
  - Behavioral approaches such as applied behavioral analysis useful but…
    - Enrolling school age children in a version of the YAP is not hypothesized by its developers to result in outcomes similar to those achieved by the youngest children
- Some children did not improve
  - Ability to imitate speech appeared to foster best outcomes
    - Lovaas and colleagues looking at visual communication modalities as alternative for those unresponsive to verbal treatments

Intervention research for other approaches

- Many studies using single participant designs or small N group designs show specific techniques work
  - E.g., sign language
  - Social skills
  - Milieu therapy
- Some program evaluation (uncontrolled pre- / post-designs available for alternatives to Lovaas model
  - Denver model
  - Greenspan
  - LEAP
  - TEACCH

Resources for evaluating research in autism

- National Research Council (2000). *Educating children with autism*.
- Goldstein (2002).

Talking points for discussing treatment methods with parents

- Science based on many foundations
  - No one approach can claim to be the only "science-based" one
- *Every* study has flaws
  - Complex nature of treatment research makes it almost impossible to control for everything
- Does the work you've heard about apply to your child?

How do I discuss these issues with parents?

- Using a family-centered practice setting
  - Cooperative goal setting
    - Following best practice ideals & the law: families are key decision makers

Ideas for opening the dialogue -- Building Bridges with Families (Briggs, 1998)

- Achieve a shared meaning with the families about their child, the problem and possible solutions
  - "think as one"
- Seek solutions
  - Together identify solutions by:
    - Finding exceptions to the problem (when does the problem not occur)
    - Reframing -- find an alternate and more positive way to view a problem

Ideas for opening the dialogue -- Building Bridges with Families (Briggs, 1998)

- Seek solutions (cont)
  - Together identify solutions by:
    - Scaling -- determine the degree of importance each issue carries for the family
- Select strategies
  - Think about strategies that have already worked for the family
    - Ask family to notice a target behavior that the child demonstrates-- look for exceptions and possible solutions
      - Relate these exceptions/solutions to possible treatment methods
    - Ask family to alter one behavior with their child

Ideas for opening the dialogue -- Building Bridges with Families (Briggs, 1998)

- Plan for future contacts
  - Co-create the future relationship you expect to have with the family
  - Use the "miracle question" to determine what goals the parents have in mind
  - Empower the parents by presuming they have all the skills necessary to cause change in their child
  - At the same time give them information they may not have
    - I.e. refer them to reliable sources (ASA, Quackwatch, National Research Council, etc.)

Options for dialogue

- Evaluate the research/claims surrounding the suggested treatment (in conjunction with the family)
- Contextualize your treatment suggestions in relation to their goals
- Use their terms to explain what you hope to do
  - E.g., speech language therapy may be seen as part of generalization training, in ABA terms
- Refer them to resources that fit within their paradigm supporting your suggestions
  - E.g., two influential behavioral books have chapters by SLP's describing how to facilitate communicative development naturally
- Stay open-minded, accept final decision of family
  - May need to refer them elsewhere
  - In school legal cases, knowledge of treatment literature helpful--I.e., specialized intensive training for behav. Interv. required by research literature

Key Issues in Treatment Selection

1) Does the intervention use a developmental model?
2) Is the developmental model used appropriate for the unique challenges of children with autism?
3) Is the treatment rooted in a valid theory of language?
4) What is the context of the treatment?
   - e.g. Home-based? School-based? Clinic-based?
5) What is the intensity of the treatment?
   - Can this be achieved?
6) Who are the agents of the treatment? How will they be trained, monitored? Are trained personnel available?
7) Is there current research supporting the intervention?
   - is the research "good"?
   - is there also research against the treatment?
8) What are the claims of the treatment? Are the claims realistic? Can they be recreated in "real life?"
10) Does the treatment include plans for generalization?
11) For what ages, levels of functioning is the treatment targeted?
12) What is my role in the proposed treatment plan--how can my expertise and training best contribute?

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