Facilitating Parent Participation in Intensive Therapies: the Parents as Partners Approach

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Session Objectives

Articulate the supports for and challenges of parent participation in home therapy programs
Define the essential elements of parent-therapist partnerships
Apply strategies for enhancing the parent-therapist partnership to their clinical practice
Discuss benefits and challenges to parent and/or family responsibility for implementing complex therapies outside therapy visits

Course Format

10 minutes: Introduction and Overview. Intensive therapies, key ingredients of intensive therapies, rationale for home programs,
15 minutes: Parents as Partners Approach. Description, examples, and discussion
15 minutes: Essential Elements for Successful Partnership. Shared goal setting, individualized recommendations, communication, chunking, integration into everyday activities
20 minutes: Strategies, Questions and Answers. Review of parents as partners training module, worksheets, and activities. Discussion of effective strategies, challenges to parent participation, and the importance of communication.
Intensive Therapies: CHAMP and Baby CHAMP

Children with Hemiparesis Arm & Hand Movement Project (CHAMP)

Multisite RCT funded by the National Institutes of Health comparing the efficacy of alternative therapies for young children with hemiparetic cerebral palsy

- Participating Sites:
  - University of Virginia
  - Virginia Tech Carilion Research Institute
  - Ohio State University

This study will be the first that will directly compare different amounts of therapy and different types of constraint to evaluate what is most effective in improving motor outcomes for young children.

Baby CHAMP

Three protocols all highly promising

Full-time constraint + 3 hrs/day X 5 days/week X 4 weeks in home
Part-time constraint + 3 hrs/day X 5 days/week X 4 weeks in home
No constraint (Bimanual) + 3 hrs/day X 5 days/week X 4 weeks in home

All 3 protocols include home programming for parent implementation

First RCT/ Comparative Effectiveness Infant Trial (multisite, adequately powered)
Ages 6 to 18 months when enrolled, treatment must be prior to 24 months
ACQUIRE therapy

ACQUIRE stands for:
- Acquisition of new motor skills through
- Continuous practice and shaping to produce
- Quality movement of the
- Upper extremity through
  Intensive therapy and
  Reinforcement in
  Everyday patterns and places.

Common Core Elements of pCIMT
(cf. Ramey, Coker-Bolt, & DeLuca)

• Structural Core Elements
  - Constraint of less impaired Upper Extremity (type, amount)
  - High Intensity (requires specification)
  - Treatment Plan with specified goals
  - Transition Plan building on progress
  - Trained provider/parent
  - Natural environment

• Functional Core Elements
  - Active Shaping & Successive Approximations
    (Higher goals)
  - Repetitive practice with feedback

• Good Pediatric Practice principles

Key Features of ACQUIRE

Therapist-Lead

1. Movement
   2. Reinforcement

Parent-Lead

1. Movement
   2. Reinforcement

Innovative Uses of Treatment Fidelity (page 1 of 2)

• As a way to train the individual clinicians or practitioners in delivery methods
• As a way to monitor clinical performance
  • Increased consistency
  • Increased quality
• As a way to plan and measure “planned deviations” in treatment model
  • Realize extra benefits, efficiencies, and/or ease without compromising expected benefits

Innovative Uses of Treatment Fidelity (page 2 of 2)

To determine whether the highest level of fidelity produces greater patient benefits; if not, to explore
• what the minimal or threshold levels of treatment fidelity are,
• whether some features of the original treatment model are not “active ingredients” critical to realizing measurable benefits, and
• whether some patient or setting characteristics make it particularly difficult to deliver the treatment with high fidelity
• To determine whether there is a need to develop more tailored models for these patients

Baby CHAMP Parents as Partners Orientation

Parents as Partners approach
Parents work closely with therapist(s) to learn to use some of the therapy methods with their child during everyday activities and in everyday environments.

❖ We are training the parents in the intervention but also to help us maximize the intervention
Parents As Partners

Parent training is designed to:
1. enhance parent knowledge
2. improve fidelity of intervention
3. facilitate communication between parent and therapist.

Parents as Partners:
Expectations of Therapists

Provide:
2 – 3 hours of in-home training prior to initiation of treatment
Individualized, daily recommendations for home-based activities using Parents as Partners Worksheets (PPW)
Daily communication/problem solving with parents about integrating activities into everyday life.

Parents as Partners:
Expectations of Parents

Provide:
45 minutes/day
7 days/week
Engage in shared goal setting
Document activities and times daily (PPW)
Communicate with therapist
Goal

**Child's Treatment**

**Therapist**

**Parents**

**Improved Outcomes:**
- Increased awareness of the involved side
- Increased use of the involved arm and hand
- Increased core stabilization
- Increased gross motor abilities
- Development of more functional behaviors

**Parents as Partners**

Training includes:
1. Personalized Workbook
2. Training Video
3. Participation in Treatment

**Movement-Reinforcement-Repetition-Refinement (MR²).**

At the heart of this intensive therapy is the MR² cycle. The four elements of this cycle are based on well-established principles of learning and development. The four elements are:

- Movement: You will encourage, prompt, stimulate, and guide movement using the therapy techniques you will learn today.
  
  Examples can include any movement intended or accidental
Reinforcement: You will provide immediate, positive, and varied responses to your child’s movement. This serves as a natural reward for your child’s effort and progress. It can include verbal praise, positive physical expression, concrete rewards, or rewards that are a part of completing the activity.

Examples of reinforcers and rewards:

Repetition: You will encourage practice, rehearsal and extended play involving a particular movement pattern or skill. It should feel integrated into the play and functional activities in which you engage with your child, not forced, mechanical, or invasive.

Examples of repetition are:

MR 3 Can be Completed with:

- **Routine activities.** Routine activities like bath time, mealtime, and dressing are wonderful opportunities for your child to practice his or her new skills with you.
- **Non-routine activities.** You may also choose to set aside some playtime with your child to introduce new toys or a new way to play with favorite toys.

Analysis

**Quantitative**
Calculated amount of time each day x # days
Calculated total time over the 4 week period

**Qualitative**
Two analysts with regular consensus meetings
Occupational Therapy Practice Framework used to develop for preliminary coding structure
Results

Each parent provided, on average, about 18 hours of therapy practice to 18 infants/toddlers, for a total of 326.5 hours of practice.

They averaged 44 minutes per day for days practiced and 41 minutes per day for the total 4 weeks.

Range: 30 – 60 minutes per day; 19 – 29 days practiced; 1-10 days missed; 12.5 hours – 28 hours over 4 weeks

Parents implemented the recommendations of therapists primarily in the context of play (books, puzzles, etc.), functional mobility, and mealtime activities.

Activity practice was typically organized into small blocks of time, from 5 – 15 minutes, during routine family activities.

On days families were unable to complete the full 45 minutes of practice, they typically identified:

- Tired or ‘ill’ child,
- Family scheduling conflict, or
- Parent work hours conflict

as the primary reason for not completing partnership.
Conclusions

45 minutes seems reasonable for families, however many families did not provide daily practice.

Practice was integrated in family routines, particularly mealtime and play time.