Paediatric Keynote Address: Interventions to promote behavioural recovery following acquired brain injury: The role of the family

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Treatment for Acquired Brain Injury: The Role of the Family

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Funding Sources

- National Institute of Child Health and Human Development
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- National Institute of Mental Health
- Centers for Disease Control
Overview

- Review of child and family consequences of ABI
- Relationship between child and family adaptation over time
- Levels of family involvement: examples and evidence for each
  - Interventions to treat the family
  - Interventions with the parent as therapist
  - Interventions in which the parent scaffolds treatment
  - Minimal parent involvement
- Implications for working with families
Brain Injury is a Family Affair: A model of reciprocal influences over time
The Psychosocial Consequences of ABI: Changes in Behavior

- Executive function deficits and behavior changes can be the most persistent and profound problems following ABI.
- Can range from apathy and withdrawal to emotional volatility and explosive anger.
- Secondary attention deficit hyperactivity disorder is common.
Social Consequences of ABI

- Children with ABI have poorer social problem solving skills than healthy children.
- They also have impoverished social networks and fewer reciprocal friendships.
- Behavior problems and social skill deficits may contribute to social isolation and reduced participation.
The Effects of ABI on Families

- Increased burden and distress
  - Frequent medical appointments
  - Concerns regarding the child’s recovery
- Parental anxiety and depression
- Family conflict and dysfunction
  - Family roles shift
  - Financial and work challenges
  - Marital strain
Dads Are More Distressed Than Moms: Especially following Severe TBI and Orthopedic Injuries

Wade et al., *Neurorehabilitation*, 2010
Mother’s and Father’s Perceptions of Parenting Disagreements following Severe TBI

Why Family Adaptation is Important

- There is a reciprocal relationship between the family’s and the injured individual’s functioning.
- Individuals from well functioning families show greater recovery.
- Individuals with more severe injuries and greater changes in behavior have more stressed families and caregivers.
- Families can make a big difference in terms of the success or failure of behavioral treatments and school-based accommodations.
Involving Parents and Families in the Child’s Behavioral Treatment: Does it make a difference?

- Braga, DaPaz, & Ylvisaker (2005) demonstrated that rehabilitation intervention delivered by the family was more effective in improving outcomes long-term than rehabilitation intervention delivered by hospital-based clinicians.
- Parents can be particularly effective interventionists because they are with the child on a daily basis.
Models of Family Involvement in Outpatient Rehabilitation following ABI

- Treatments targeting the family (example–family problem solving)
- Treatments in which the parent/family serves as therapist (i.e., Braga et al., 2005; parent-skills training)
- Treatments in which parents scaffold or support treatment (e.g., attention training)
- Families must be involved at some level because they need to consent, bring the child to treatment etc.
Problem Solving Therapy as An Intervention for ABI

- Facilitates parent/family coping in response to injury and other stresses in their lives.
- Provides the injured individual with an executive function heuristic for addressing post-injury challenges.
- Flexible to accommodate the different kinds of issues facing survivors and their families.
Problem solving, self-regulation and communication skills are helpful for youth with TBI as well as their family members (parents and siblings).

Sometimes, problems with other family members contribute to family burden and can be addressed through family problem solving.

Better caregiver coping/problem solving will support the child’s recovery.
Family Problem Solving: Model of Intervention Effects

- Family Treatment
  - Parent/Child X
  - Parent/Family Functioning
  - Child Functioning
Online Family Problem Solving

- 7–10 core sessions and up to 4 supplemental sessions
- Initial face to face, in person meeting between the therapist and the family
- All subsequent meetings are conducted using videoconferencing
- Each session has 2 components:
  - a self-guided web module
  - a synchronous session with the therapist
- Problem-solving is introduced in session 3 and is a central feature of subsequent sessions with the therapist.
The Evolution of Family Problem Solving Interventions

- Study 1: Face-to-Face Family Problem Solving (FPS)
- Study 2: Online Family Problem Solving (OFPS)
- Study 3: OFPS versus Multi-family problem solving and support
- **Study 4: Counselor-Assisted Problem Solving (CAPS)**
- **Study 5: Teen Online Problem Solving (TOPS)**
Iterative Approach to Intervention Development

- Identify the central problems based on the literature and stakeholder feedback.
- Develop an intervention built upon evidence-based strategies to address those problems.
- Pilot intervention.
- Refine content and approach based on empirical evidence (what worked/what didn’t) and parent and teen feedback.
- Conduct subgroup analyses to determine who is most likely to benefit.
Core Intervention Modules

- Getting Started and Setting Goals
- Staying Positive and Handling Stress
- Solving Problems
- Getting Organized
- Staying in Control (Self-Regulation)
- Controlling Your Anger
- Verbal and Nonverbal Communication
- Social Behavior and Problem Solving
- Taking Care of You (Previously crisis management)
  - Supplemental Sessions
- Moving Forward/Planning for the Future
Module Structure

- Didactic information about common problems facing youth with ABI.
- Videos of adolescents with ABI talking about how they’ve been affected.
- Didactic information about cognitive behavioral skills (e.g., cognitive reframing).
- Exercises to help families practice and consolidate their skills.
- Appeals to different approaches to learning—visual, auditory, experiential.
Recovery from brain injury is different for everyone. For teens with mild injuries, they may seem like themselves again after a few weeks or months. For teens with more severe injuries, recovery may take longer.

Below are links to videos with Michael (click here for more on Michael), Jon (click here for more on Jon), Lisa (click here for more on Lisa), Devin (click here for more on Devin), and Carter talking about their experiences with brain injury and their individual paths to recovery.

- Michael and Jon's video
- Lisa's video
- Devin's video
- Carter's video
Staying Positive

Negative to Positive

The following series of questions present a negative approach to problem solving. Take turns rewriting each sentence so that it presents a positive approach to problem solving. See if you can come up with more than one positive self statement for each negative.
Rewrite the following Negative Self Statement as a Positive Self Statement

It's the end of the world when things don't go right.
Impulsive responding/lack of inhibition is common following ABI.
It can create problems academically, socially, and vocationally.
A prerequisite to problem solving is inhibiting the “usual” response and thinking about alternatives.
Key Heuristics: Steps of Problem Solving (ABCDE)

- **Aim**– Identify goal
- **Brainstorm** possible options and their +/−
- **Choose** the option with > + and < − consequences
- **Do it**– develop detailed implementation plan
- **Evaluate**– did it work?
Key Heuristics: Self-Monitoring (SMART)

- **Stop** and think
- **Monitor**—am I doing what I planned to do
- **Appraise**—how are others reacting?
- **Reflect**—Is it likely to turn out the way I want
- **Try** something new (problem solve using ABCDE)
Key Heuristics: Anger Management (STARRS)

- Stop
- Think
- Accept
- Relax
- Reframe
- Solve
Supplemental Sessions: Up to 4 based on needs

- Taking Care of Yourself (for parents)
- Guilt/Grief
- Marital Communication
- Sibling Issues
- Working with the Schools
- After High School
- Pain
- Sleep
- Coping with Seizures
Counselor Assisted Problem Solving (CAPS) Study Design

- Randomized Controlled Trial
  - evaluator was naïve to condition
- Participants in the control group received access to internet resources regarding TBI (Internet Resource Comparison; IRC)
- Everyone received computers and high speed internet access
- Those in the CAPS group received access to the CAPS web-sessions and videoconferences.
- Evaluators were naïve to group assignment (single blind)
- Randomization carried out by stratifying by both gender and race to ensure these factors were balanced across the groups.
Time Line of Intervention

- Injury
- Baseline Assessment
- CAPS or IRC Intervention
- 6 Month Assessment
- 12 Month Assessment
- 18 Month Assessment

Months
Eligibility Criteria

- Multicenter cross-section study
  - 3 tertiary pediatric hospitals, 2 tertiary general medical centers

- Inclusion Criteria
  - Ages 12–17 years at injury
  - 1–7 months post injury at enrollment
  - Overnight hospitalization for complicated mild to severe TBI
Participant Characteristics
(IRC = 67; CAPS = 65)

- Groups well matched on all characteristics at baseline
- Average age at injury 14.5 years
- Average of 3.6 months post injury
- 20% nonwhite
- Mean GCS 10.05
  - 40% had severe TBI
Child and Adolescent Functional Assessment Scale (CAFAS)
- Clinical rating derived from parent interview

Child Behavior Checklist (CBCL)
- Internalizing, Externalizing
- Subscales on attention and aggression
- DSM scales on ADHD and Conduct Disorder

Behavior Rating Inventory of Executive Function (BRIEF)
- “Real World”/Functional Measure of executive functioning
- Global Executive Composite (GEC)
  - Behavioral Regulation Index (BRI)
  - Metacognition Index (MI)
Caregiver and Family Outcome Measures

- Center for Epidemiology Scale for Depression
- Symptom Checklist –90 revised
- Caregiving Self-Efficacy Scale
- Family Assessment Device (family functioning)
- Parent–Teen Conflict Questionnaire
- Iowa Family Interaction Rating System (Parent–teen interactions)
High school-age children in CAPS were rated as having lower levels of:
- Executive function behaviors
- Externalizing problems
- Aggressive behaviors
- Attention problems
- ADHD
- Conduct Disorder

No group differences among middle school-aged participants
Maintenance of Treatment Effects

- Group differences in externalizing symptoms were not maintained over time.
- Treatment group differences in overall functioning did not emerge until 12 months following treatment.
- For older adolescents, CAPS participants had significantly lower internalizing symptoms, anxiety/depression, and executive dysfunction than IRC participants at the 12-month follow-up.
Examined differences in sessions completed and nonadherence, involvement of both parents, and satisfaction with treatment.

Contrary to expectations, younger participants spent more hours on the website (11.58 versus 7.37) and rated the skills training as more valuable.

Anger management was rated as significantly more helpful by younger participants (very helpful versus somewhat helpful).
Improvements in Caregiver Outcomes

- Trend for greater reductions in depression in the CAPS group at follow-up.
- Improvements in caregiver efficacy immediately following treatment were moderated by prior computer use, with less experienced users reporting greater increases in self-efficacy.
Long-term Caregiver Outcomes: Lower Income Families Report > Reductions in Psychological Distress
Improvements in Family Outcomes

- No changes in observer ratings of parent-teen interactions or global family functioning
- High school age children and their parents receiving family problem solving treatment reported fewer conflicts over time
Family Conflicts Over Time—Greater Improvements in CAPS HS Group
Summary: Who Benefits

- Older adolescents
- Those at greater risk due to economic disadvantage/less education or lack of familiarity with computers
- Families with more resources may need less intensive treatment
Improvements in older participants

Improvements in parent-teen conflict in older teens

Family functioning is associated with child behavior

Family Problem Solving: Actual Intervention Effects

Family Treatment

Child Functioning

Parent-Child X

Parent/Family Functioning

Reductions in caregiver depression
Conducted two sets of analyses to understand the role of family participation in the treatment.

First examined how treatment effects differed in single versus two-parent families in the cohort as a whole.

Second examined differences in treatment outcomes within the CAPS group for: single parents, two-parent families with only one parent participating, and two-parent families with both participating.
Youth in CAPS with Married Parents Have the Greatest Improvements in Behavior
Within the CAPS Group, Youth from 2–Parent Families Showed Improved Functioning Regardless of Whether One or Both Participated
Improvements in Executive Function in CAPS Were Limited to Youth from 2–Parent Families in Which Only One Parent Participated.
Findings for Maternal Depression Suggest that Father’s Involvement is Advantageous
Single parents have higher levels of burden and life stress.

Their adherence (ability to complete sessions and implement strategies) may be less than in two-parent families.

Within two-parent families, participation of both parents may take the focus away from the adolescent’s issues with executive functioning and place it more on family communication, roles, and responsibilities.

Youth with ABI learn the executive function heuristic better if it’s just them with a single parent scaffolding their learning and implementation.
The Advantages When Both Parents Participate

- Better communication and collaboration between the parents.
- Ultimately the father’s participation contributes to less maternal depression.
- Family’s with better initial functioning are more likely to have both parents participate.
Key Question

- What can we do to support better outcomes in single parent families?
  - Is intervention participation itself another drain on their finite resources?
  - Would they respond better to an intervention targeting their depression and burden first?
Comparative Effectiveness of Problem Solving with the Whole Family versus the Teen Alone

- Ongoing study comparing the efficacy of 10 sessions of online family problem solving treatment to 10 sessions of problem solving with the teen alone.

- Participants were randomly assigned to 1 of 3 groups: family treatment, teen only treatment, or an internet resource comparison group.

- In the teen-only version, the therapist meet with the teen and family together for the first 2 sessions and the final session. All other sessions were 1 on 1 with the adolescents.
Eligibility Criteria

- Current age 11–18.
- Sustained a complicated mild to severe TBI in the previous 18 months.
- Must live in an area where high speed internet service was available. (This was paid for by the study.)
- Teen must be sufficiently recovered to participate independently in the sessions.
Enrollment and Follow-up To Date

- Total of 153 adolescents ages 11–18 enrolled.
- 101 have completed 6-month follow-up assessments.
- 15 are still enrolled in treatment.
Adolescent Perceptions of Improvement

Plan for future
Understand Injury
Strategies for...
Get Along with...
Better in School
Less Stressed
Recommend

Family
Teen Alone
Adolescent Perceptions of Helpfulness of Content

Overall  | Brain Injury  | Problem Solving  | Communication  | Anger  | Skype sessions
---|---|---|---|---|---
Family  | Teen Alone

[Bar chart showing comparisons between Family and Teen Alone perceptions for various topics including Overall, Brain Injury, Problem Solving, Communication, Anger, and Skype sessions.]
Take Home Messages from Teen Online Problem Solving to Date

- Teens find it easy to use and helpful
- Nearly all teens in both groups (family or teen alone) are reporting improvements in behavior and reductions in stress.
- Teens in the family intervention were more likely to report improved relationships with their family.
Preliminary Evidence for Efficacy: Improvements in Self Management

- TOPS Family
- Teen Only
- IRC

Comparison between Pre-Tx and Post-Tx
The Pros and Cons of Family Involvement

- Family members have insights into challenges that the teen faces that he/she might not acknowledge.
- The family can better understand the teen’s challenges and support his or her plans if they’re involved.
- Some parents are uninvolved or have extremely negative interactions with the adolescent such that their participation undermines change.
- Younger adolescents may need parental involvement to support and scaffold their problem solving.
Family Involvement in Interventions with Younger Children

- Parent skills training has shown promise as an approach for reducing behavior problems in younger children with ABI.
- Parents can be trained to be responsive and consistent and to shape positive behaviors (parents as therapists).
- Consistent with the idea of using everyday people (parents, teachers) to promote behavior change.
- Also consistent with the literature documenting associations between maladaptive parenting and poor behavioral outcomes (Micklewight, 2012; Yeates et al., 2010).
RCT by Brown et al. (2014) of Stepping Stones Triple P together with Acceptance and Commitment Therapy.

59 participants with ABI were randomly assigned to combined therapy or treatment as usual.

Group treatment was delivered in person over a period of 10–weeks.

Improvements documented in number and intensity of behavior problems and child emotional symptoms.

Parents reported less parental laxness.

- 9 sessions with information about parenting provided in informational booklets.
- Delivered in phone or face to face.
- Evidence for feasibility, satisfaction, and preliminary efficacy.

I-INTERACT: Our Approach for Younger Children with ABI

- *Online* intervention to improve parent-child interactions following TBI
- Based on parent-child interaction therapy (PCIT)
- Parents learn to follow their child’s lead and to provide consistent direction and follow through.
- Unlike other approaches, PCIT and I-INTERACT include live coaching of the parent’s interactions with the child.
Two Trials of I–INTERACT to Date

RCT comparing online positive parenting skills training to access to internet resources.
- 40 families of young children ages 3–9 with a history of ABI.
- Outcomes assessed pre-, mid-, and post-treatment (Antonini et al., 2014; Mast et al., 2014; Raj et al., 2014).

Ongoing RCT comparing online positive parenting skills training with stress management and brain injury education to parent skills alone or access to internet resources.
- 107 enrolled to date, 70 completed final follow-up.
Goal of direct attention training is to improve the underlying attention deficit by targeting specific attention skills (Butler et al, 2008; Sohlberg et al., 2003).

Attentional abilities can be improved by providing structure opportunities for exercising a particular aspect of attention (i.e., selective attention, sustained attention, inhibition, working memory, etc.).
Improvements in Parent–Reported Executive Function on the BRIEF

GEC | MI | BRI
---|---|---
Pre | Post

- GEC: Pre 65, Post 60
- MI: Pre 70, Post 65
- BRI: Pre 55, Post 50
There is a continuum of family involvement in treatments to improve behavior following ABI ranging from family therapy to parent-supported treatments.

Regardless of the nature of the treatment, family engagement and scaffolding promotes adherence and treatment efficacy.
Future Directions

- Integrating different approaches to treatment to facilitate both family and child adaptation.
  - Example van’t Hooft and Lindahl Norberg (2010)
- Identification of who is most likely to benefit from different approaches to treatment and differing levels of family involvement.
- Developing evidence-based guidelines regarding timing and intensity of treatments.
- Timing of treatments to ultimately promote neuroplasticity.
Thank You!
Come and Visit!