



Panel 1. State of the Science in the U.S. and Brazil

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Supporting Parents in Inpatient Pediatric Medical Rehabilitation

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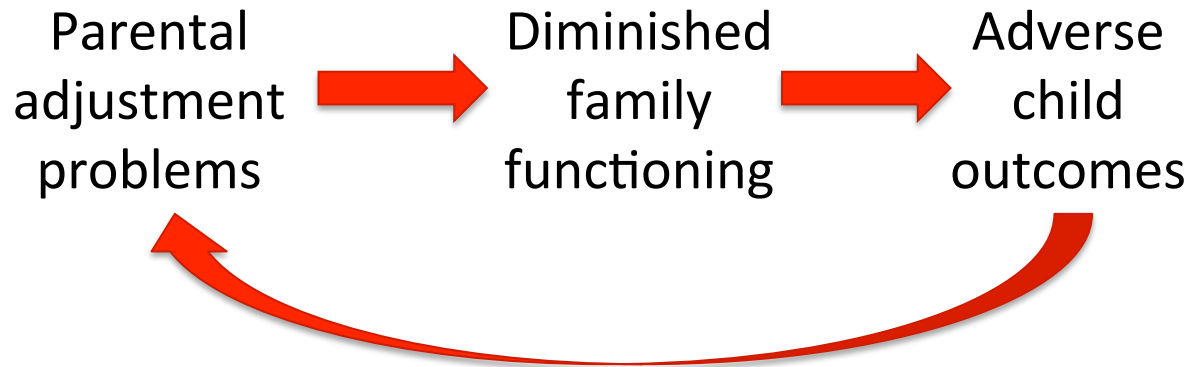
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Pediatric Rehabilitation and Parents

- A traumatic injury or major illness in a child has a profound impact on the entire family
- **Parents** are vulnerable to a range of psychosocial difficulties during child recovery, including:
 - High levels of stress
 - Anxiety and depression
 - Social isolation
 - Family strain and burden



OVER TIME:



Decreasing parents' stress and improving their mental health may have short and long-term benefits for children and their families.





*What can we do to meet
the needs of parents in the
context of their child's
inpatient rehabilitation?*



Building a Collaboration



Paul Springer, Judy Burnfield, and Natalie Williams



Alexis Verzal Children's Rehabilitation Hospital

- A 14-bed inpatient pediatric rehabilitation unit located within a larger rehabilitation hospital
- Most pediatric patients are in the early stages of recovery following a very severe injury or medical event (e.g., stroke)
- Average length of inpatient stay is 41 days



Initial Project Development

Meetings with research team, clinical staff, and families impacted by serious child injury or illness

Objectives:

- Understand Madonna's approach to working with the families of their patients, and the available resources
- Gain a better understanding of the experiences and needs of families at Madonna
- Share ideas and solicit feedback
- Build trust and good working relationships



Identification Shared Beliefs

Family Centered Care

- Family is the constant in a child's life
- Facilitation of the family/support system is critical
- Need to implement appropriate policies and programs that provide emotional and financial support to meet the needs of families
- The design of healthcare delivery systems should be flexible, accessible, and responsive to family/support system needs.



Alexis Verzal (2008)





“As soon as I started working on my emotions, Alexis seemed to begin to act more calmly when I was around and began to make more progress when I was with her during rehab sessions. **I feel that reducing parents’ stress during the time of rehabilitation is a primary key to a child’s successful recovery.**”

-Tiffany Verzal, mother of Alexis



Study Overview

- Randomized controlled trial (pilot study) investigating the effects of a two-week therapeutic massage intervention on parent well-being
- Outcomes measured pre- and post-intervention

Funding for this project is provided by the Massage Therapy Foundation of the American Association of Massage Therapy



Why therapeutic massage?

- A novel intervention to promote physical and psychological well-being in parents
- Documented symptomatic benefits include:
 - Reduced stress and decreased cortisol levels
 - Reduction in anxiety and depression
 - Improved sleep
- The optimal dose of massage to achieve these benefits is unknown



Project Specific Aims

- ① To determine the impact of dosage of the massage intervention on key aspects of parental psychological well-being
- ② To determine the impact of therapeutic massage on parent sleep and physiological stress reactivity
- ③ To assess feasibility and acceptability of the massage intervention



Participants and Recruitment

- Parents of 40 pediatric patients who have an anticipated hospitalization of at least 3 weeks
- Parents are referred to the study during the first week of their child's hospitalization by the Pediatric Program Manager
- Study research staff meet with parents on site for informed consent, enrollment, and study visits



Measurement of Primary Outcomes

Obtained Pre- and Post-Intervention

- Brief Symptom Inventory 18 (*parent-report*)
- Perceived Stress Scale (*parent-report*)
- Salivary stress biomarkers (*cortisol and alpha-amylase collected during a verbal stress task*)
- Sleep (*actigraphy, 72 hours*)



Intervention Group Assignment

Following enrollment, participants are randomized to either:

Group A: 3 massages per week for two weeks

Group B: 1 massage per week for two weeks

Massages are schedule to begin 72 hours after the first study visit and are delivered by Madonna's massage therapists.



Intervention Fidelity

- Massage therapists were trained to deliver massages following a specific protocol
- Checklists completed after each massage session are used to monitor protocol adherence and ensure consistency in intervention delivery
- Checklists reviewed by the PI



Project Status

- Currently enrolling participants
 - Initial feedback suggests that parents are interested in the study and receptive to the massage intervention
- Investment in project by hospital staff is key to participant recruitment



Future Directions

- Evaluation of the impact of parent-focused psychosocial interventions on children and family functioning
- Development and implementation of other psychosocial interventions that address the needs of children and their families in pediatric medical settings



Alexis and Her Family (2016)



“I truly believe that by helping the entire family heal, we will continue to see more positive outcomes with children recovering from severe injury and illness. This research should truly make a difference in the lives of future parents caring for children who have experienced a life-changing event.”

-Tiffany Verzal, mother of Alexis





Thank You