Parents as Caregivers of Injured Children

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Background

- 475,000 children (0-14 years old) in the US experience traumatic brain injuries each year.
- Preschoolers with even mild head injury have impairments that continue into their school age years, including lower reading ability & behavior disorders that interfere with school performance.
- Challenges for parents and families
- Few studies of parent & family functioning after a preschool child's head injury

Purpose

1. To investigate effects of a preschool child's head injury on:
   - Mothers' reactions to injury & hospitalization before hospital discharge
   - Mothers' mental health, mother-child relationship, & family functioning at 2 weeks and 3, 6, and 12 months post-hospital discharge
2. To identify mother, child, and family factors related to mothers' reactions and to post-discharge functioning of mothers, mother-child dyads, and families

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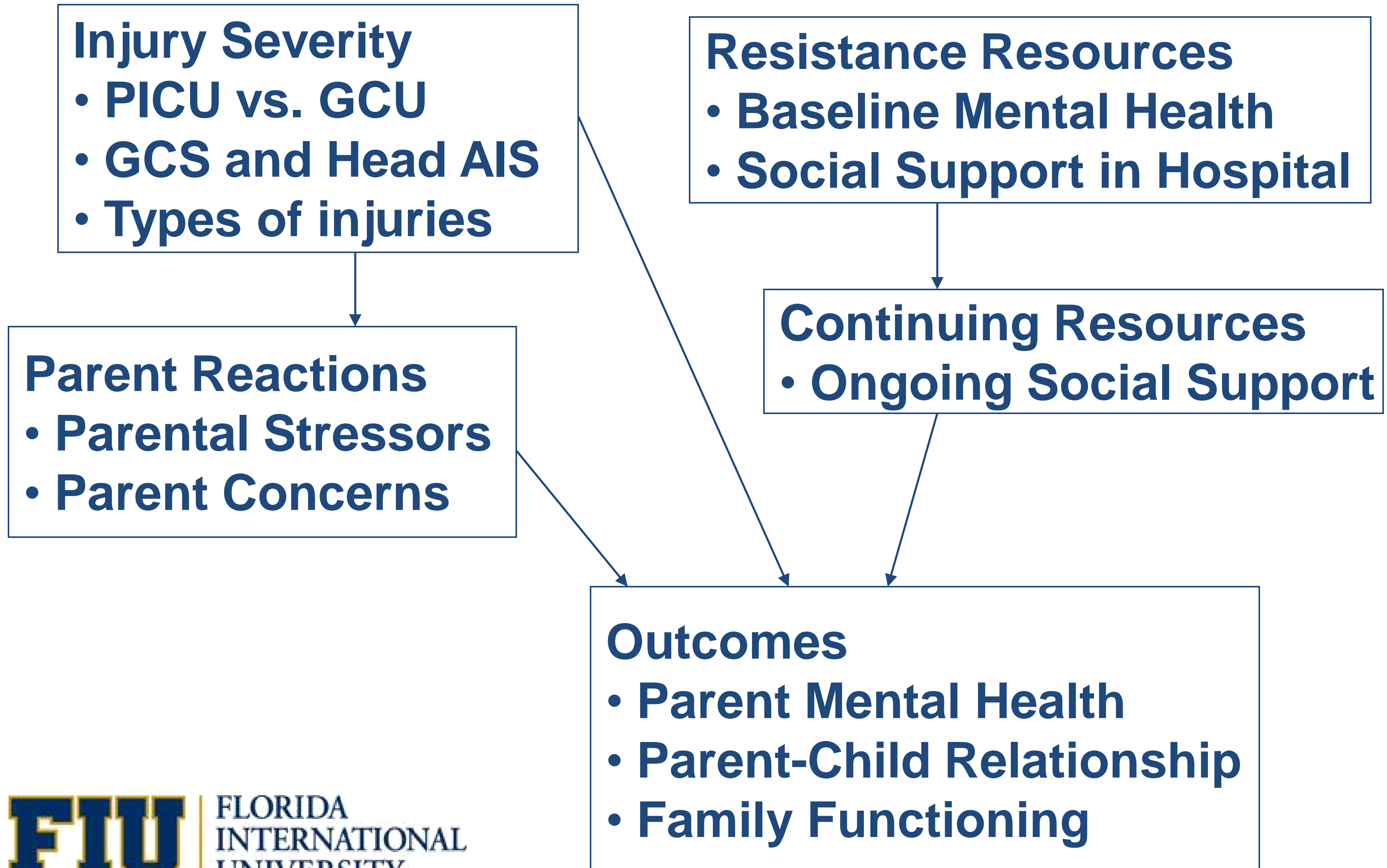
Conceptual Framework



Methods

Sample

- 183 mothers with a preschool child (3 - 6 y.o.) hospitalized with a head injury
- Recruited from PICUs and general care units (GCUs) in 7 hospitals in the Cleveland and Miami metropolitan areas

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Inclusion Criteria

- Event where head injury possible
- At least 1 physical symptom of head trauma
- X-ray, CT, or MRI suggesting head injury
- Living with parent before injury
- No previous hospitalization

Exclusion Criteria

- Severe cognitive deficits prior to injury
- Considered brain dead after injury
- Parent hospitalized or died in injury event

Description of Mothers

- Mean age 31.3 years (SD = 7.16)
- 56% White, 30% Black, 13% Hispanic, 1% Asian
- 84% completed high school; 56% with some post-secondary education
- 83% partnered, 55% employed
- Annual family income
  - Under $20K (29%)
  - $20-50K (36%)
  - $50K & over (35%)

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Description of Children

Age (months)		59.8 (14.78)
Sex	Male	104 (57%)
Birth order	First born	71 (39%)
Injury event	Fall	89 (45%)
	Motor vehicle	57 (31%)
Admission Unit	Pediatric ICU	91 (50%)

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Procedure

- Recruited 24 - 48 hrs after admission
- Informed consent
- Data were collected at:
  - 24 - 48 hours after admission (T1) in hospital
  - 2 weeks and 3, 6, 12 months post-discharge (T2, T3, T4, T5) in family's home
- Child's hospital chart reviewed by RNs after child's discharge

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Injury Severity Measures

- Perceived severity of injuries (mother)
- Objective injury severity
  - Initial admission unit (PICU or GCU)
  - Glasgow Coma Scale (lowest)
  - Anatomical Head Injury Severity
  - Types of Injuries

Measures: Parent Reaction & Resistance Resources

- Parent Reaction
  - Parental Stressors Scale: PICU (T1)
  - Parental Concerns Scale (T1)
- Resistance Resources
  - Baseline Psychological Distress & Wellbeing (T1)
  - Multidimensional Scale of Perceived Social Support (T1 – T5)

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Measures: Parent & Family Outcomes (T2 – T5)

- Mental Health Inventory
  - Psychological Distress & Wellbeing
- Parenting Stress Index
  - Parent distress, Dysfunctional parent-child relationship, Difficult child
- FACES II
  - Family Cohesion, Family Adaptability

What did we find??

Mothers' Top Concerns at 24 - 48 Hours after Admission

- Child's Experience
  - Child's pain
  - Child's understanding of what's happening
  - Child's memories about the hospital

- Parenting Role
  - What can I do now for my child?
  - What could I have done to prevent it?

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Mothers' Top Stressors at 24 - 48 Hours after Admission

- Child behavior and emotions
  - Child acting or looking as if in pain
  - Rebellious or uncooperative behavior
  - Child's fright, crying or whining

- Procedures done to child
  - Putting needles in child
  - Injections/shots

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Mothers' Reactions in Hospital

Greater stress & concern in hospital when:

- Greater perceived severity of the child's injuries
- Greater psychological distress in hospital
- Lower social support in hospital

Youngblut, J.M., Brooten, D., & Kuluz, J. (2005). Parent reactions at 24-48 hrs after a preschool child's head injury. *Pediatric Critical Care Medicine, 6,* 550-556. PMC 2614927.

Implications – Mothers' Reactions

Focus assessment & interventions on:

- Mother's perception of the child's injury and experience in hospital
- Changes in parental role in hospital
- Mother's mental health before & during hospital stay

Mother, Mother-Child Relationship, and Family Functioning Outcomes

- Findings at 2 weeks & 3 months post-hospital discharge
  - Youngblut, J.M., & Brooten, D. (2006). Pediatric head trauma: Parent, parent-child and family functioning 2 weeks after hospital discharge. *Journal of Pediatric Psychology, 31,* 608-618. PMC 2424404.
  - Youngblut, J.M., & Brooten, D. (2008). Mother's mental health, mother-child relationship, and family functioning 3 months after a preschooler's head injury. *Journal of Head Trauma Rehabilitation, 23*, 92-102. PMC 2442865.
- Preliminary findings at 6 & 12 months

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Differences by Injury Severity

- At 2 weeks post-discharge:
  - TBI with organ damage → Lower wellbeing; greater distress in parenting & mother-child dysfunction
  - GCS Mild group compared to Severe Group
    - Higher psychological wellbeing
    - Lower psychological distress
- At 3 & 6 months, No differences

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Differences by Injury Severity

At 12 months, GCS Moderate group compared to Mild group had:

- Greater dysfunction in mother-child relationship,
- Greater perceptions of the child as difficult,
- Lower psychological wellbeing,
- Less support from family and significant other

Influence of Mothers' Baseline Mental Health

- Mothers' Reactions in hospital
- Mental Health @ 2 weeks & 3, 6, 12 months
- Family Cohesion @ 2 weeks and 6 months
- Distress in Parenting @ 6 and 12 months
- Difficult Child @ 6 and 12 months

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Influence of Mothers' Concerns & Stress in Hospital

- Family Adaptability @ 2 weeks
- Mental Health @ 2 weeks, 6 and 12 months
- Distress in Parenting @ 12 months
- Difficult Child @ 12 months
- Family Cohesion @ 12 months

Influence of Mothers' Concurrent Social Support

- Mental Health @ 2 weeks, 6 months
- Family Cohesion @ 2 weeks, 6 & 12 months
- Distress in Parenting @ 2 weeks, 12 months
- Family Adaptability @ 3, 6, & 12 months
- Dysfunctional Mother-Child Relationship @ 12 months
- Difficult Child @ 12 months

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Influence of Injury Severity

- Perceived injury severity
  - Distress in Parenting @ 2 weeks
  - Mental Health @ 12 months
- Objective injury severity
  - Mental Health @ 3 & 6 months
- Length of Hospital Stay
  - Mental Health at 6 and 12 months
  - Difficult Child at 12 months

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Influences of Mother & Family Characteristics

- Mothers' education
  - Dysfunctional Mother-Child Relationship @ 12 months
  - Family Cohesion & Adaptability @ 12 months
- Number of children
  - Family Adaptability @ 2 weeks
  - Mental Health @ 3 months
- Being partnered
  - Family Cohesion @ 2 weeks & 3 months

Potential Short Term Risk Factors

- ***Greater objective injury severity, Severe GCS scores***
  - Represent the mother's additional caregiving responsibilities when injured child goes home (assistive devices, traction, casts, new medications or treatments, coordination of rehab services, visits to health care provider, schooling needs)
- ***More children, single mother***
  - Represent pre-existing demands on the mother that must be integrated with the injured child's needs
  - Perhaps less flexibility in time to accommodate new demands

Potential Long Term Risk Factors

- ***Moderate GCS score, longer hospital stay***
  - Changes in child may not be physically visible
  - Others see child behavior problems without knowledge of the head injury
  - Greater caregiver stress in dealing with child's more difficult behavior, eg, hyperactive, impulsive, inattentive, memory deficits, information processing difficulties, loss of function/skill previously mastered
- ***Less maternal education***
  - Perhaps indicates less cognitive talents, knowledge of potentially helpful services, creative problem solving

Potential Short & Long Term Risk Factors

- ***Mother's perception of child risk:***
    - Greater perceived injury severity
    - More concerns and stressors in hospital
  - – More perceived need for vigilant surveillance to protect child, e.g. smother mother, helicopter mom, Green & Solnit's vulnerable child
- ***Fewer resistance resources***
    - Poorer baseline mental health
    - Less social support in hospital and post-discharge
  - – Limited resources to support and sustain mother through stressful or difficult times

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Pre-discharge Clinical Implications

- Focus in-hospital assessment and interventions on mother's mental health and her perceptions of the child's injuries and hospital stay.
- Help mothers identify:
  - Sources of post-discharge support
  - Strategies for renewing contact with and maintaining existing sources &/or accessing new sources.
- Anticipatory guidance about caregiving challenges in first 3 months. Identify strategies to meet challenges.
- Daily availability of advanced practice nurse (APN) by phone to help mother with problem solving.

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Clinical Implications for Follow-up

- Monitor effectiveness of sources of support.
- Assess and support mother's mental health.
- Assess mother's perceptions of child's injuries and hospital stay and reflections on time since discharge.
  - Influence of injury and hospital stay fades through 6 months, but reappears at 12 months - the anniversary of the injury event
- More frequent surveillance of families at risk.

Future Research

- With this dataset:
  - Relationship of child's abilities and deficits with mother, mother-child, and family functioning
  - Changes in outcomes over time
  - Identify factors related to pattern of change
- Research with fathers
  - Perceptions, outcomes, & risk factors may be different due to fathers' parent & family roles
  - Identify effective incentives to recruit & retain fathers

Thank You!!

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