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Pediatric Traumatic Brain Injury: Families and Healthcare Team Interaction Trajectories During Acute Hospitalization

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Introduction

Traumatic brain injury (TBI) in a child can have life-long consequences. The sequelae following a pediatric TBI may manifest as physical and cognitive conditions that reduce neurologic function and alter executive functioning (Yeates & Taylor, 1997). A TBI can also augment behavior by interfering with attentiveness, socialization, and adaptive post-injury function (Anderson et al., 2006; Ewing-Cobbs, Prasad, Landry, Kramer, & DeLeon, 2004; Schwartz et al., 2003; Stancin et al., 2002). Unfortunately, the impacts of a TBI are not limited to just the child. Families can be greatly affected by their child's TBI and the family environment post injury can play a role in a child's functional outcome (Taylor et al., 2001). Experts hypothesize that children are more vulnerable to his or her family's responses to neurocognitive and functional outcomes post-injury; that families who create a stable environment for their children help facilitate recovery; and lastly that the child and his or her family are equally susceptible to the influence of the other post injury (Taylor et al., 1999). However, it has yet to be concluded that a healthcare team's interactions with the patient and family can alter the nature and direction of a child's outcome.

There is increasing evidence that TBI can generate a large burden on caregivers. Research has described caregiver burden was associated with family stress, psychological and emotional sequelae in addition to unmet requests for follow-up health care and/or social service supports (Aitken, Mele, & Barrett, 2004; Hawley, Ward, Magnay, & Long, 2003; Rivara et al., 1992; Wade et al., 2006; Wade, Taylor, Drotar, Stancin, & Yeates, 1996, 1998; Wade et al., 2002). A study conducted by Aitkens and her team found that communication (or a lack thereof) with caregivers was reported as the most challenging unaddressed need during hospitalization (2004). Their study reported that caregivers struggled to understand the child's diagnosis as it pertained to making therapeutic decisions during the acute care phase of recovery (Aitken

et al., 2004). Bond, Draeger, Mandleco, and Donnelly (2003) found in their study that a primary need for families of patients with severe brain injuries was information about the patients' condition and what to expect in the present and the future. Being in a family that is overwhelmed by caring for a severely injured child is often predictive of negative recovery outcomes for the child (Anderson et al., 2006; Schwartz et al., 2003; Taylor et al., 1999; Taylor et al., 2001).

We wanted to understand common or unique trends in family-healthcare team interactions during hospitalization for pediatric TBI. Therefore, a life course trajectory (LCT) approach was used to capture those interactions. We also wanted to determine if a relationship existed among family-healthcare team interactions and injury severity. If a relationship existed, we sought to identify common phases as described in the adult TBI literature (Bond et al., 2003).

Life Course Trajectory (LCT) Theoretical Approach

Maltz and Mullany (2000) described a life course trajectory (LCT) as a graphic or text-based visualization of an individual, or a group's, experience, interaction, or pathway. These graphic and text-based representations have been used to describe the course of a patient's illness, the death rate of a population, and the complications associated with a certain illness (Goldman, 1992; Maltz & Mullany, 2000; Post, Roy-Byrne, & Uhde, 1988). By illustrating these events over time, the stories become increasingly clear. In one example, LCT was used to analyze experiences of premature infants' mothers. The mothers reported experiencing difficulties with making care decisions because they lacked the social and biological ties to their acutely-ill, premature infants (Black, Holditch-Davis, & Miles, 2009). However, no studies have been conducted to represent the LCT of families dealing with their acutely ill child or the healthcare team. This gap in knowledge was the motivation behind this study.

Study Aims

The primary aim of this study was to better understand the timeline of family-healthcare team interactions during their child's

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hospitalization, and if interaction time points varied based on injury severity. The secondary aim of the study was to identify common phases associated with the quality of interactions at different points in a child's hospital stay by visualizing the *life course trajectory* of the first 8 days of an acute hospitalization following a TBI. By finding a common trend among patients of varying severity groups, we could illustrate how families' needs at certain times during their child's hospitalization change, and how the healthcare team could potentially address those changes effectively and in a timely manner. This novel approach could guide the development of best care practices that facilitate easing of the caregiver's burden.

Methods and Measures

Participants and Setting

This prospective observational study included 35 children who were admitted to a large urban medical center for a TBI from December 2012 through August 2014. Study enrolment was initiated after internal review board approval. Those eligible for study enrolment included children ages 5 days to 15 years of age who were previously healthy, had sustained a TBI, and required admission to the hospital for care. Families were consented in English or Spanish, and children greater than 12 years of age who were neuro-cognitively intact upon enrollment were provided the opportunity to assent.

Measures

Data was obtained from the patient's electronic health record (EHR), and included demographic information such as gender, age, race/ethnicity, injury severity based on admission and daily assessment of the Glasgow Coma Scale (GCS), mechanism of injury and length of stay (LOS). Additional data were extracted from the admission, discharge, and daily progress notes written by members of the healthcare team, such as nursing, medicine, child protective services, physical therapy, nutrition, and speech pathology.

Data Collection Procedure

Two members of the study team examined the patient care notes for family interactions with the healthcare team, which included communication, skills development, and therapy recommendations for ongoing or preventative care. The study's principle investigator addressed all questions pertaining to data retrieval as well as conducted random chart review for accuracy. To portray the daily family-healthcare team interactions, a LCT approach was used (Maltz & Mullany, 2000). Text-based descriptors of each interaction were retrieved from the patients' EHR notes and organized in an excel worksheet and categorized by day, type of interaction, and family and team members involved. From this data, a graphic visualization was developed of the interactions. This method reflected daily family-healthcare team interactions while the child was hospitalized.

The GCS is the most commonly used standardized measure of primary injury in the pre-hospital and acute care phases for grading TBI severity (Teasdale & Jennett, 1974). This clinical tool is a 15-point scale assessing three dimensions: eye opening, best verbal response, and best motor response. A score of 13 to 15 indicates a mild brain injury, 10 to 12 a moderate brain injury, and 3 to 8 a severe brain injury. The reliability of the GCS has been reviewed on 52 studies with seven deemed high-quality studies whose intra-class correlation coefficients indicated the GCS to be reliable and valid measure of neurocognitive state (Reith, Van den Brande, Synnot, Gruen, & Maas, 2016).

Analysis

The collected data were analyzed in three ways. First, demographic and injury related data were evaluated. Demographic data was used to describe the population of the study. Frequencies, measures of central tendencies (mean), and measures of variability (standard deviation [SD]) were used to describe the sample in the analysis. Analyses were conducted using SPSS version 19.0 (IBM Corp., 2010).

Second, each documented family-healthcare team *interaction* was coded as an *event*; individual events were tallied for each day, and then represented graphically using MATLAB® software to display the frequency of events over time. Therefore, individual graphs depicted the patient and families' daily interactions with the healthcare team. A mean number of events for each injury severity group were calculated based on the daily number of family events. Each injury severity group was displayed on a line graph to represent the mean trajectory of events during that patient's acute hospitalization time period.

Finally, the characteristics of interactions were documented for each patient. In collaboration with experts from the university's Data and Visualization Services, the study team was able to visually interpret three interaction phases found across all families based upon common characteristics. Data visualization can describe relationships between quantitative values and data that are not quantitative in nature (such as text-based). It allows important stories that live in data to be discovered and understood. The visual interpretations allowed us to extrapolate that the occurrence of each phase varied based upon the injury severity.

Results

Demographics and Characteristics

The sample consisted of 35 pediatric patients, 62.9% ($n = 22$) of whom were male. The mean age of patients was 64.86 months (SD = 63.72 months; range 2–185 months). The patients were primarily Caucasian/White (57.1%) and were admitted for a mild TBI (68.6%). The most common mechanism of brain injury resulted from a fall (42.9%). The mean length of stay (LOS) in the hospital was 9 days (SD = 6.9 days), with a mean initial GCS of 12 (SD = 4.39; range 3–15). Detailed study demographic characteristics are displayed in Table 1.

Table 1
Patient characteristics ($N = 35$).

Characteristics	Results	
Admission location, n (%)	Pediatric ICU	27 (77.1)
	Non-ICU	8 (22.9)
Gender, n (%)	Male	22 (62.9)
	Female	13 (37.1)
Age in year, mean (SD)		5.2 (5.1)
Race, n (%)	African American	12 (34.3)
	Caucasian	20 (57.1)
	Hispanic/Latino	3 (8.6)
ED GCS Severity, n (%)	Mild	24 (68.6)
	Moderate	3 (8.6)
	Severe	8 (22.9)
Mechanism n (%)	Non accidental- abuse	13 (37.1)
	Fall	15 (42.9)
	Motor vehicle collision	1 (2.9)
	Other	6 (17.1)
CT findings, n (%) ^a	Epidural hematoma	9 (14.1)
	Subdural hematoma	17 (26.6)
	Intraparenchymal hematoma	8 (12.5)
	Intraventricular hemorrhage	2 (3.1)
	Subarachnoid hemorrhage	8 (12.5)
	Skull fracture	18 (28.1)
	Diffuse cerebral edema	2 (3.1)
LOS in days, mean (SD)		9.0 (15.9)

CT: Computed Tomography, ED: Emergency Department, GCS: Glasgow Coma Scale, LOS: length of stay.

^a Most participants had more than one finding on CT scan.

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