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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;

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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 et al. (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, Draeger & Donnelly, 2003).

Life Course Trajectory (LCT) Theoretical Approach

Maltz & 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 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 et al., 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 et al., 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.

Life Course Trajectories of Pediatric TBI

The visual representations of the LCT graphs allowed us to identify trends based on injury severity. The injury severity groups (mild, moderate and severe TBI) each had unique graphic presentations, and when juxtaposing the graphs with that of injury severity, the study team concluded that the phases occurred during different time periods based on severity group.

For families of children with mild TBI, a large number of events were observed in the first two days (see Figure 1). Since the mild TBI patients' hospital stays were brief, the family-healthcare team interactions were frequent and occurred in a shorter time period. The graph therefore illustrated three phases in rapid succession, indicating multiple interactions that addressed direct patient care and future care planning stacked upon each other.

Figure 2 represents the trajectory of events for children with moderate TBI. The events demonstrated a clustering of early interactions with families and the healthcare team focused on direct care and awaiting diagnostic tests or the patients' response to the brain injury. Because moderate TBI patients may quickly improve or worsen, there is more hesitancy in

prognostication, so there is steady interaction with the healthcare team, as the patient's status is evaluated. The first and second phases occur simultaneously in the first 72 hours. Within the first 72 hours, families have multiple interactions with the healthcare team as the team intervenes to stabilize the child. In the third and final phase, family interactions involve preparation for discharge home. The healthcare team reduces the frequency of interactions with the family as the patient becomes more stable and the functional status determines next steps for recovery.

The graph of children admitted for a severe TBI (see Figure 3). The severe TBI group reflects a very different graphic presentation as more events are distributed over a longer timespan. In the first phase, the interactions occur as the patient is admitted from the emergency department to a pediatric intensive care unit, and healthcare team interactions are frequent and focused primarily on communication of injury status, with no to limited prognostication. The first phase of family-healthcare team interactions is centered around patient status and resuscitation efforts. In the second phase, the interactions are mostly focused on stabilizing the child. This phase may take an increasingly emotional toll on the family because the child's improvement may be slow or complicated. In the third and final phase, the interactions increase as the healthcare team's treatment advances to prepare for sub-acute rehabilitation, or withdrawal of life support.

Three Phases Visualized

After examining the graphic depiction of each injury severity group, the text-based data was analyzed by the university's Data and Visualization Services. In this process, the descriptions of the interactions and their graphic appearance were interpreted and it was determined that three phases were present in each injury severity. The three phases were: information seeking, watchful waiting, and decision making. The first phase, *information seeking*, was based upon interactions that involved the family receiving information from the healthcare team regarding their child's injury status and expected treatment. The second phase, *watchful waiting*, occurred when the family interactions with the patient was based on watching and waiting for the healthcare team to stabilize the patient and their treatment. The final phase, *decision making*, consisted of the family beginning to give direction and feedback to the healthcare team while also initiating and facilitating the transition of their child's care from the healthcare team.

Discussion

The results of our research yielded a common trajectory for each injury severity group, as well as a timeline of three distinct phases of interaction between families and the healthcare team. In the first phase, we recognized that families' primary interactions are centered on the need for information, hence the term *information seeking*. This idea aligns with the adult TBI literature in which Coco et al. (2011) identified several support categories for families of patients with TBI. One of the primary support categories is receipt of information. Al-Mutair et al. (2013) also described that the highest priorities for families were information and assurance, followed by proximity, comfort, and support in the intensive care unit. Parents may become anxious, panicked, or be in a state of denial as they watch a team of

strangers take control of their child's compromised health (Rivara, 1994). Families must face being limited in their ability to gain as much information about the situation and their child's condition in this critical period. Most families do not have the skills necessary to take care of their child in this situation (Rivara, 1994). Therefore, families seek information about the patient's welfare, symptoms, and cognitive abilities (Coco, Tossavainen, Jaaskelainen, & Turunen, 2011). Families also desire a complete understanding of the extent of injury, including likely sequelae and outcomes (Lefebvre & Levert, 2006; Lefebvre, Pelchat, Swaine, Gelin, & Levert, 2005). As the patient's brain injury is better understood, families begin to seek further information regarding the day-to-day activities, limitations to their daily routine, and possible long-term, physical, behavioral, and cognitive problems (Arango-Lasprilla et al., 2010).

In the second phase, the family interactions consisted of *watchful waiting*. In this phase, the child's brain injury is becoming defined, and the healthcare team focuses on continued neuro-protective practices. After the initial surge of interactions, the decrease in interactions may provide the family with a sense of relief as their child appears to be getting better. If a child is getting better, families have the ability to adjust quickly, and they become optimistic and helpful to the healthcare team (Rivara, 1994). They also learn to cope with their child's injury with increased effectiveness. However, if the child fails to recover swiftly, families can have overwhelming feelings of sadness and ineptitude as they watch their child's acute stress and suffering (Rivara, 1994).

The last phase of the approach, *decision making*, again resembles the adult literature (Coco et al., 2011). Here, families want to participate in the decisions regarding their child's care and treatments. Families become more engaged with the day-to-day care of their child, as well as with the various therapies. In some patients, the families also begin to learn skills to provide care, such as feeding their child through a feeding tube, or managing various assistive devices to adapt the home environment to their child's limitations. During this phase, families rely on support services to enhance their ability to reengage in their community (McCabe et al., 2007).

In the patient with mild TBI, these three phases overlap, as the families experience *information seeking* while *watchfully waiting*, to see if their child continues to improve and demonstrate pre-head injury behaviors. In this brief time, families are also exposed to *decision making* regarding their child's reintegration into their family and community while watching for, or treating, symptoms associated with mild TBI, such as headaches, sleep disturbance, depression, and behavior change (McCabe et al., 2007; Prigatano & Gray, 2008).

Family interactions of a child with a moderate TBI are more staggered. In the first 3 days of care, the family is *information seeking* while also *watchfully waiting*. During this time, there are a number of interactions that provide the family with information regarding the child's injury, and their present and expected responses to treatments. Children also begin to become aware of their injury and possible limitations. Children of school age often require re-education about the injury and recovery period (Rosignano & Liew, 2008). In the *decision making* phase, the interactions most often involve participation in care, preparation for the

home environment, scheduling follow-up therapy visits, and for the school age child, development of individualized educational plans for school (Coco et al., 2011).

Families of children admitted with a severe TBI are stuck in the *information seeking* phase while the team is focused on resuscitation. This time is often confusing and overwhelming for families (Bond, Draeger, & Donnelly, 2003; Coco et al., 2011; Verhaeghe, Defloor, & Grypdonck, 2005). It is also the time period when it is important for families to get consistent information from the healthcare team (Bond et al., 2003; Lefebvre et al., 2005). The following days are occupied by interactions that focus on *watchful waiting* to get a better sense of the extent of the injury (Coco et al., 2011). In our sample, at day 5, patients began to stabilize and slowly recover; therefore, families began to become more engaged in *decision making* and in bedside caregiving. Family interactions include being taught new skills often associated with feeding, positioning for comfort, hygiene, and cognitive communication (Popernack, Gray, & Reuter-Rice, 2015).

As our findings show, the trajectories of pediatric patients are dependent upon severity, and the corresponding approach illustrates the uniqueness of the phases of family-healthcare team interactions. Preparing healthcare team communication with families based on the child's brain injury severity could allow for an increase in the effectiveness of informing and preparing families of children admitted for a TBI. The LCT approach also allows us to begin to consider communication patterns during a TBI hospitalization. This novel approach also enabled us to describe multi-dimensional data in a visual way that enhances our understanding of the family and healthcare team interactions.

Implications for Practice and Future Research

According to researchers and medical educators, healthcare professionals should use guidelines based on an approach of a joint decision-making and communication framework when interacting with families (Adams et al., 2013). The joint decision-making and communication framework consists of the elements of setting the stage, providing adequate information, responding therapeutically, avoiding too much medical jargon, and making recommendations about recovery (Adams et al., 2013). If healthcare team members structure their communication with families according to the elements above, they may be able to appropriately communicate with the families based on their needs during the specific phases we described. It could be recommended that this structure of communication should be considered as part of a child TBI treatment plan. We propose some consistent actions the healthcare team could take in the three different phases of a child TBI hospitalization (Table 2).

Healthcare teams often can be very patient-focused, rather than focusing on both the patient and their family. However, to provide holistic and collaborative care, the family and their needs should be included as an element of the patient's clinical care, as it has been shown that the family has a significant impact on a patient's recovery (Al-Mutair, Plummer, O'Brien, & Clerehan, 2014). In order to meet the needs of a family, a structured communication plan tailored toward the burden at various points during a child's hospitalization for TBI may be necessary. By adopting a teaching plan for families to meet

their needs during the three phases, healthcare teams could improve a family's ability to cope and to adapt to the new needs of their child. Improving family functioning may lead to an improvement in a child's recovery as it has been documented that family functioning and child's recovery may be correlated.

There are several opportunities for future research in this area. A study using a large sample size could better generalize findings and verify the use of the LCT approach. This study was conducted at one urban, tertiary care center, so there is need for this type of research to be performed in more locations to see if the trajectory we found could be applied more broadly. In addition, future studies could consider a mixed-methods approach, where interviewing and surveying families could better elucidate their interactions with the healthcare team while their child is hospitalized for TBI. Gathering this kind of qualitative data could also more conclusively identify the deeper understanding of the interactions between the families and the healthcare team during hospitalization for a TBI.

Limitations

One limitation of this study is that the sample size was small, particularly in the moderately severe TBI group (N=3), and taken from a single study center, thereby limiting the generalization of the results. However, the data collected allowed the authors to identify unique variations of hospital trajectory based upon TBI severity. By charting the events, a defined curve presented itself, and events were identified in each severity group. Bias was kept to a minimum as the events were not ranked by level of importance. Although we had a number of children whose mechanism of injury was a result of an abusive act, we specifically did not ascribe any difference to the family interaction events. It should be noted that children who were admitted for a mild TBI as a result of abusive head trauma were more likely to have a prolonged length of stay because of the medical-legal requirements surrounding their care and hospital course.

Conclusion

The findings of the study indicate there are unique differences in the hospital course of children admitted with TBI. The LCT approach illustrates that injury severity and family interactions require precise timing of communication and support systems. The results of our research also show that the role of the healthcare team truly requires a holistic approach. The opportunity to better understand children admitted with TBI and the interactions of the healthcare team and family are of importance if we are to promote best clinical practice, healthy and intact families, and optimal patient recovery.

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Highlights

- Pediatric traumatic brain injury (TBI) is leading cause of death and disability worldwide.
- TBI in a child can have life-long consequences.
- Life course trajectory approach provides a method to identify family and patient interactions with the healthcare team.
- Three phases emerged during hospitalization when families-healthcare team interacted.
- They were: (1) information seeking, (2) watchful waiting and (3) decision making.
- Being aware of the phases associated with the child's brain injury severity can assist the healthcare team better support the patient and family.

Figure 1. Mild Traumatic Brain Injury. The following graph depicts the trajectory of injury severity and family interaction phases for a child admitted to hospital for a mild traumatic brain injury.

Figure 2. Moderate Traumatic Brain Injury. The following graph depicts the trajectory of injury severity and family interaction phases for a child admitted to hospital for a moderate traumatic brain injury.

Figure 3. Severe Traumatic Brain Injury. The following graph depicts the trajectory of injury severity and family interaction phases for a child admitted to hospital for a severe traumatic brain injury.

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)
LOS in days, mean (SD)		9.0 (15.9)

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

^aMost participants had more than one finding on CT scan.

Table 2**Phases and Healthcare Team Actions**

Phases	Healthcare Team Action
Information Seeking	<ul style="list-style-type: none"> • Explain in clear and understandable way the type of injury the child has sustained and the extent of the injury • Conduct a team meeting to ensure that all the information given to family is consistent • Give short, concise information about child's condition and treatment plan often • Explain to the family that their feelings of helplessness, shock, and denial are normal, thus helping the family to associate their feelings with the context of the injury experience
Watchful Waiting	<ul style="list-style-type: none"> • Provide objective data when family incorrectly assume that body movements are signs of healing without hindering their optimism • Talk to the family about who their child is (i.e. pre-injury personality) and reinforce to family that their child may not behave, speak, move, play, etc. the way he or she did previously • Encourage families to express their feelings while encouraging them to remember that raising a child includes risks and protection may not always be possible
Decision Making	<ul style="list-style-type: none"> • Help parents arrange their social support network during the child's hospitalization to improve stress of post discharge transition and to support family • Involve family in routine ADLs such as feeding the patient, bathing the patient, changing the bed, etc. to help family start to assume control of care • Educate family on how they may have feelings of frustration, depression from time to time while providing family with access to social workers and psychiatric services • Support family's involvement in information and or support groups for families with a child who suffered a TBI • Remind parents or caregivers to not neglect the needs of their other children • Provide adequate follow-up with family

Adapted from *Family Functioning Following Pediatric Traumatic Brain Injury* by J'May B. Rivara, MSW, ACSW.

ADLs: Activities of Daily Living; TBI: Traumatic Brain Injury