

A Qualitative Meta-Synthesis of Family Experiences and Needs Regarding Health Care of
Newly Diagnosed Children with Traumatic Brain Injury in the Acute Care Setting

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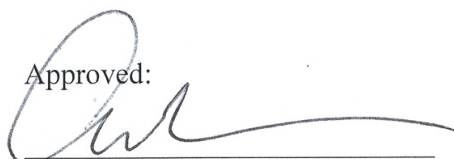
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Abstract

Children with moderate to severe traumatic brain injury (TBI) are often represented by their parents, who play a vital role in supporting their child. Minimal research captures the parents' experiences in the acute care setting, leading to a lack of evidence-based knowledge regarding the supportive needs they wish were available. This qualitative synthesis used the PRISMA guidelines to search for and assimilate peer-reviewed research on early parenting needs in the acute care setting following moderate to severe TBI. A total of 1188 studies were screened after searching three scientific databases (PubMed; CINAHL; PsycINFO). Inclusion criteria involved: (a) children \leq twenty-one years of age; (b) accidental moderate to severe TBI; (c) acute inpatient setting; (d) parent(s) views on support needs; (f) published within last eight years; and, (g) written in English. Eight articles met the inclusion criteria, and the following major themes were noted: emotional family burden, the child's protection from physical and emotional harm, the desire for parents' conservation of energy, the demand for frequent and thorough support and communication, and parents' varying coping abilities. Findings emphasize that a lack of understanding of early parenting needs following moderate to severe TBI can lead to substantial communication and support barriers. These obstacles gravely interfere with the distributed knowledge and physical, cognitive, or emotional assistance provided to newly informed parents. We used this information to inform the provision of future support materials for families. Prospective research needs be conducted to reveal unidentified parent(s) needs of newly diagnosed children with TBI.

Keywords: traumatic brain injury, pediatric, acute care, inpatient, parent, caregiver

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Introduction

One of the principal causes of death and disability throughout the world is traumatic brain injury (TBI), especially among children 21 years of age or younger (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015). It is reported that over ten million individuals sustain a TBI each year internationally with 2.5 million cases occurring in the United States (U.S.) alone (Centers for Disease Control and Prevention, 2017). Langlois, Rutland-Brown, and Thomas (2006) additionally report that of the 2.5 million injured, 600,000 incidents occur in U.S. children. Although only a small percentage (0.06%) occurs in children 21 years of age or younger when looking at the statistical data, attention needs to be applied to the pediatric population, because the long-term effects can be profound for the individual, their family, and the communities they live in (Gagnon, Swaine, Champagne, & Lefebvre, 2008).

According to Coco, Tossavainen, Jääskeläinen, and Turunen (2011), moderate to severe TBI can be classified as an accidental or inflicted injury to the brain, and can result from external mechanical forces, such as an impact, collision, object, blow, jolt, or penetration to the head (Centers for Disease Control and Prevention, 2017). These forces affect the brain in a way that leads to loss of consciousness or coma, and recovery is dependent on many, sometimes unpredictable, factors. According to Coco et al. (2011), copious amounts of research indicate that in addition to weakened bodily functions, moderate to severe TBI destructively impacts the physical, cognitive, emotional, and behavioral dimensions of child health and future development. Patient symptoms can often manifest with fear, anxiety, suffering, and depression.

Not surprising, however, is the substantial impact this diagnosis also has on the family of

these pediatric patients. Parents have a wide range of needs in different phases during the recovery of the child (i.e., acute care, rehabilitation, return to home, return to school, and long-term community reintegration) (Glang et al., 2008; McCarthy et al., 2006; Roscigno, Fleig, & Knafl, 2015). Growing evidence illustrates that many areas of burden are placed on families following a child's moderate to severe TBI. These burdens can include advocating for the child's complete needs in their medical, school, and social categories within their communities that lead to: stress and disorganization to prior family roles and relationships and a lack of emotional, informational, physical, and financial support to supplement these new stressors (Hawley, 2003; Youngblut & Brooten, 2006). Here, informational and emotional support from healthcare professionals has been shown to reduce stress among families and enhance reciprocal communication in the best interest of the child (Coco et al., 2011). Michelson and Rothschild (2015) supplement that families and patients, if able, typically value the option of being involved with decision-making. The injured child following a moderate to severe TBI is likely to be in a coma for hours, days, or weeks following the initial injury and should the child survive, they are then also at risk for secondary brain injury during that period (Salmani, Mohammadi, Rezvani, & Kazemnezhad, 2017). The child's early medical condition in the acute-care phase of recovery is tenuous for those several hours, days, or weeks following the initial injury. The child's legal guardian or parent(s) (henceforth referred to as parent(s)) will be asked to act as a proxy for the child, related to any decision-making regarding the initiation or the withdrawal of treatments, while the child cannot consent or assent (American Speech-Language-Hearing Association, 2017). The parents should be involved in early decision-making processes because they are most likely to be able to consider the wishes and values of the child, against the potential outcomes of any decision to the child, and the family will have to live with the intended or unintended

outcomes of any decision. Therefore, allowing them the opportunity to weigh in is critical (Brown, Whittingham, Sofronoff, & Boyd, 2013).

There are physical, cognitive, and emotional needs to be addressed for the parent(s) who are responsible for care decisions. Clinicians face multiple challenges in providing medical treatment for children with moderate to severe TBI with the intention of preventing further brain injury, but the team faces even more of a challenge in delivering precise information that will help parents to make such difficult decisions (Fassier & Azoulay, 2010). Additionally, there is a challenge in caring for the family of the patient as a whole unit (Moore et al., 2015). The unknown advanced-life care desires of the injured child, parents' moral beliefs about what it means to be a good parent, and our current inability to accurately and scientifically predict the child's long-term functional-outcomes, so early after injury, are not always recognized as strongly guided by a system of beliefs, attitudes, and symbols that also inform parents decisions in this critical family decision-making situation (Kirk et al., 2015; Moore et al., 2015; Reuter-Rice, Doser, Eads, & Berndt, 2017).

Despite research that has been conducted regarding parent experiences when caring for a family member with TBI in the community, there is less research regarding experiences in families following pediatric TBI. The closest attempts made to date to identify the acute-care needs of family members did so by enrolling a largely older adult sample, with only a small number of adolescents, so it is difficult to know how representative the findings are for the families of younger children or what factors, unique to children and young adults, might have been missed altogether by using a mostly older adult sample (Coco et al., 2011; Keenan & Joseph, 2010; Oyesanya & Bowers, 2017). For example, Keenan and Joseph (2010) qualitatively studied various needs of the family during the acute care phases of an adult family member's

care following TBI over two separate time periods. The first time period involved interviewing the parent(s) in the acute care setting within four days of being transferred out of an intensive care unit (ICU), and the second time period involved retrospectively interviewing the parent(s) at the time of the child's discharge or within one week of discharge, if the patient was in a rehabilitation or complex-care setting. The family participants in this study identified the need for information about their loved one's injuries and their prognosis as their greatest need during time period one as compared to the other reported needs, such as the following: direct involvement in their loved one's care, understanding the continued progress of the loved one, managing other family and community obligations, holding on to hope for recovery, and the need for professional and community supports (Keenan & Joseph, 2010). The majority of families not only reported wanting information updates the most, but also they expressed the need for communication and information to be "consistent, understandable, honest and updated on a frequent basis" throughout this phase of care (Keenan & Joseph, 2010, p. 29).

Purpose

Given a family's subsequent need for social support, as emphasized by Tramonti et al. (2015), this qualitative synthesis sought to analyze and contextually understand the current peer-reviewed literature thickly describing any family-member experiences and/or needs during the injured child's acute phase of care. We sought to provide evidence for the development of supportive materials for the physical, emotional, cognitive, and social needs of the families cared for in a Pediatric Intensive Care Unit.

Methods

To ensure an accurate and widely inclusive search of all current research literature addressing our purpose, inclusion criteria were defined as the following: (a) more than 50% of

participants were children aged twenty-one or younger; (b) diagnosed with accidental moderate or severe TBI, and (c) admitted to an acute inpatient hospital setting, such as an ICU, immediately after injury. Other general inclusion criteria for the studies included that they were: (a) written in English and (b) published since 2009 in a peer-reviewed journal, so that they were relevant to current acute care settings and their practices (Campbell et al., 2011).

In order to determine a comprehensive set of literature that defined and described the acute care support needs of families of children following moderate to severe traumatic brain injury, a research protocol was developed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009).

Search Strategy

This study was guided by the PRISMA guidelines and is reflected in Figure 1 of the appendix (Moher et al., 2009). Search strategies were developed by the two authors of the study and a university medical research librarian for each database that was included (Moher et al., 2009). Kelly and St Pierre-Hansen (2008) conducted a literature search comparison across commonly used medical databases and described how various search strategies affected their respective scopes, content, and organization. Using their results and considering our limited human and physical resources, we chose to select three of the largest and most relevant databases to conduct the search: PubMed, CINAHL, and PsycINFO.

Kelly and St Pierre-Hansen (2008) reported that PubMed, which contains over seventeen million articles from various life science journals, produced the most results, especially when combining text words and MeSH terms. Because this synthesis is focused on discovering results that are likely related to nursing care of these patients, CINAHL (Cumulative Index to Nursing

and Allied Health Literature) was determined to also be a relevant and applicable resource to capture those studies connected specifically to nursing practice. Lastly, PsycINFO was added to capture any missing articles that may not have been captured in PubMed or CINAHL. According to Kelly and St Pierre-Hansen (2008), PsycINFO, contains literature on psychology from more than 2200 periodicals, so it produces the most distinct results. Because this synthesis has the aim of capturing family and caregiver experiences, the psychological aspect was deemed important to include. Search terms used to capture the perspectives and support needs of families of children with moderate to severe TBI included “traumatic brain injury”, “mother”, “father” “caregiver”, “guardian”, “family”, “child*” for child or children, “parent*” for parent, parenting, or parental, “infant”, “teen”, “baby” or “babies”. Terms were entered in various formats and combinations in each of the databases by the research librarian (EM), as shown in Table 1A of the Appendix, to ensure an exhaustive exploration of research.

Retrieved indexed manuscripts were reviewed in various stages for recognition of duplicate retrievals in more than one of the databases and then according to our inclusion and exclusion criteria. For acceptance, articles needed to be research-based, focus on the families’ experiences, perspectives, or needs, and published between January 2009 and September 2017. At first, publication retrieval was limited to no more than five years old, but the retrieval of relevant results was scarce. Therefore, the search criteria were extended to encompass all literature within the past eight years. The search was performed in September of 2017, making it the end date in the range of study publication dates.

Resulting articles from all databases were uploaded into the computer software program, Covidence, for screening and selection (Covidence, 2018). Duplicate articles were then identified using Covidence and removed to avoid repetition in screening. The research literature was first

screened by title and abstract, when available. Those without abstracts or those not yet excluded were then read in full to decipher their eligibility for selection. Articles that met the inclusion criteria were then imported into F1000 where their reference list was also searched, commonly known as *reference harvesting* or *footnote chasing*. This helped us to identify other possible articles from the footnotes and bibliographies of the previously identified works (Version 35; F1000 Workspace, 2018).

Multiple articles were excluded for the following reasons: (a) not research; (b) more than 50% of the injured children were older than twenty-one years of age; (c) more than 50% of participants cared for non-accidental, intentional, or acquired brain injury; (d) the study was focused on the post-acute care setting or needs, including rehabilitation or in the community; or, (e) focused only on veteran participants, who have additional unique needs beyond the TBI. Additionally, it should be noted that quantitative studies were not exclusively dismissed from inclusion, but were only excluded if their context met our exclusion criteria and/or the findings did not provide rich and thorough detail regarding the perspective of families of children with moderate to severe TBI in the acute care phase of care.

995 of the 1188 total articles were rejected based on our exclusion criteria in the first round of exclusions (titles and abstracts), leaving 193 full-text articles to be assessed further for meeting our eligibility criteria. Together, two independent reviewers (TH and CR) evaluated the 193 articles for inclusion. As a result, 185 additional articles were excluded. Seventy-five of those articles involved research conducted in the wrong setting, forty-seven were not research based, twenty-five studied the wrong population, seventeen included adults only, fifteen operated under the wrong design (instrument development or survey study), three were incomplete in reference to reporting findings, one was in a language other than English, one included

interventions that were not applied to caring for a child with moderate to severe TBI, and, lastly, one produced an outcome that was not a result of caring for a child with moderate to severe TBI. After screening and assessing each result, eight total journal articles were deemed appropriate for inclusion. Table 1B of the Appendix summarizes the purpose and relevant study data for each of the eight included works.

Quality Assessment

To ensure that each study's findings were presented in context of any quality limitations, each study's level of quality was assessed according to Mays and Pope (2000) criteria. When assessing qualitative data using comprehensive conceptions, one must take into account the distinctive purposes and objectives of qualitative studies. To do so, Mays and Pope recommend utilizing the following criteria categories to determine the validity and quality of qualitative research: triangulation, respondent validation, clear elucidation of methods of data collection and analysis, reflexivity, attention to negative cases or limitations, and fair dealing.

Respectively, Mays and Pope (2000) argue that studies must: (a) have data that is collected via two or more sources for comparison (triangulation); (b) describe the correlation between its investigators and respondents to assist in reducing error (respondent validation); (c) clearly recollect on the precise methods of researching used (clear data collection and analysis); (d) clarify the sensitivity and bias in how data collection was designed (reflexivity); (e) describe limitations and any emergent contradictory elements that refute the phenomena being studied (negative cases); and, (f) ensure the study design incorporates multiple viewpoints, so one group is never offered as the sole truth of the results to be considered of quality (fair dealing). Each study that met inclusion criteria was assessed following these guidelines. Table 1C summarizes quality rankings for each study that was selected for inclusion in this qualitative meta-synthesis.

Extraction of Data

Extracting data from each of the included studies was based on the following criteria: research study authors, year published, methods of data collection, number of participants (including number of patients, number of total parent(s), and relationship to the patient), age of the child at time of diagnosis and acute care stay, limitations of the study, and the purposes of the research and findings (Lipsey, 2009). The results are concisely summarized and visually organized in Table 1B of the appendix to better represent and compare the literature.

Data Analysis

Data analysis followed the meta-ethnography method, as this is an effective method of synthesizing and analyzing qualitative research (Noblit & Hare, 1999). All selected articles were read multiple times and organized according to themes. Findings were reciprocally translated from each individual study into those from all other qualitative studies in the synthesis using a matrix to organize the findings (Ayres, Kavanaugh, & Knafl, 2003). Rigorous application of this method was accomplished using multiple independent reviewers (i.e., student investigator, faculty peer reviewer and co-investigator, and the medical research librarian), making the research findings and the context of the study the only informing sources of our conclusions, which helped to establish trustworthiness and credibility in our findings (Valentine, 2009). The rigor of our process ensures that qualitative data can reasonably be combined and compared because the data is rightfully considered in context, as reported by Campbell et al. (2011).

To begin, a list of the content to be extracted was developed after multiple read-throughs of each included article, which contained abstracts, purposes, designs, findings, and key concepts that focused on the needs of parent(s) of children with moderate to severe TBI. As each article was perused and read in full, notes were written and organizational separating of content (a form

of intuiting) was used to extract important contextual information. This process allowed for easy, simple, and quick referencing and categorization of data. From here, lists with the comparative information for each study was linked together for a more aesthetic and accessible document. This information was placed into tables, such as Table 1B and Table 1D in the appendix.

Results

The three database searches, which included PubMed, CINAHL, and PsycINFO, produced a total of 1186 articles after 522 duplicates were removed. Additionally, two references found in two separate articles that met our inclusion criteria were identified using the ancestry approach, commonly known as *footnote chasing*, to screen for inclusion (Cooper, 2015). Both articles did not meet our inclusion criteria, validating that the database searches were likely both comprehensive and thorough enough to capture results that covered the most significant articles. According to Ackermann and Hartman (2014), these results are considered to be of high precision/high recall, where all relevant documents are received after conducting a search. The PRISMA flow chart (Figure 1) presents the phases of the literature search and how we arrived at our final sample.

Identified Themes

While reading, evaluating, and analyzing all of the retrieved articles, it was noted that health care communication was described as a common critical need among parent(s) in the acute care phase of moderate to severe pediatric TBI. As a result, other articles were searched for using “communication” to compare similar findings. Supplemental emergent themes were discovered and recorded during the meta-ethnographic analysis, resulting in the compilation of the following family themes: (a) emotional family burden; (b) the child’s protection from physical and emotional harm; (c) the desire for parents’ conservation of energy; (d) the demand

for frequent and thorough support and communication; and, (e) parents' varying coping abilities. In addition, parents recommended suggestions for improving their comfortability and feeling fully supported while caring for their child with moderate to severe TBI in the acute care setting.

Emotional Family Burden

Within this category, findings display parental reports of emotional strife as a large part of caring for their child with moderate to severe TBI in the acute care initial stages. Two subcategories presented themselves to be common emotional subthemes among the included studies: dealing with fear and anxiety throughout their roles as caregivers and decision-makers for the child who is unable to do so for himself or herself and feeling anger, grief, and sadness toward their child's condition.

Fear and anxiety. Due to the ambiguous nature of care for pediatric moderate to severe TBI, it is evident that feelings of concern, fear, and anxiety are initially prevalent among parents caring for their injured child. Each of the eight articles mention the parental reporting of these manifestations. However, it is noted that persistent worry and anxiety may not always be visible to the healthcare team in the acute care phase because parents are still processing their child's injury (Aitken et al., 2009). As a result, Aitken et al. adds that interference in traditional routines and difficulties in concentration often manifest in families when their fears and anxiety go unnoticed and are, therefore uncontrolled, which may sometimes lead to depression and posttraumatic stress disorder (PTSD). Parents frequently mentioned the belief that providers focused only on the positive notions expressed by the family (i.e., 'I am glad they are doing better today' or 'He made it through surgery and that is a relief') and therefore determined that parents were out of touch with the reality of their child's condition, because the same providers did not also pay attention to the parents' expressions of fears and concerns (Roscigno, Grant,

Savage, & Philipsen, 2013). The fears and concerns among the parents of a child with moderate to severe TBI can be triggered by a multitude of factors. Roscigno and Swanson (2011) note that uncertainty about the child surviving and, if they do, what their future will entail and how the child will navigate the new world is a commonly reported cause of anxiety in parents. Regardless of the presenting symptoms among parents and how they arise, the main concern is that few parents recall having ever received any emotional support during the initial stages of acute care for their child. Because of this underlying, continuous state of overwhelming emotion in parents, information provided about their child's condition is challenging for parents to follow and absorb (Kirk et al., 2015; Reuter-Rice et al, 2017).

Anger, grief, and sadness. As previously mentioned, uncontrolled emotions can easily affect parents' abilities to care for their child in this context, often leading to additional negative feelings of discouragement, anger, grief, and sadness. Throughout the articles, parents reported not feeling entirely included in dialogue with providers and with additional healthcare team members related to decision-making for their injured child, which resulted in parents moving to emotional forms of coping, such as expressing anger, grief, sadness, demands, ignoring, and blocking because they felt disregarded (Roscigno et al., 2013; Roscigno, Savage, Grant, & Philipsen, 2013). As inadequate coping occurs, parents felt they had to work harder to persevere and endure the ongoing situation. As time passed, it was revealed that parents may resort to ignoring their "physical, psychological, and spiritual well-being" to utilize outside resources to overcome the overwhelming acute care barriers they encountered (Roscigno et al., 2013, p. 10).

Protecting Their Child from Harm

The relationship between moderate to severe pediatric TBI and parental burden is important to recognize and understand early, because burden on the family has a large impact on

the recovery of the injured child. It is also important to distinguish parents who experience much higher levels of stress because the stress not only affects the long-term health and recovery of the child, but also it can have negative effects on the parents' well-being both acutely and later in life (Aitken et al., 2009). Reuter-Rice et al. (2017, p. 84) described burden among the family as it is positively correlated with general "stress and psychological and emotional sequelae" in addition to unmet requests from providers for social service support and care regarding follow-up. Five of the eight studies directly address parents' desire for close attention to detail in attempting to locate and support family burden. The remaining three include statements from parents regarding their feeling extremely burdened at times, making it a commonality, but not necessarily deeming it a priority, as some parents felt they were ultimately responsible for controlling these feelings instead of burdening the providers (Kirk et al., 2015). Roscigno (2016) adds that burdens can present in many ways; however, the supposed responsibility of protecting their child from harm was reported by parents to be of utmost importance during the acute stages of care. This included harm from ignored symptoms that could lead to secondary brain injury, psychological harm from overhearing negative talk that might take away the child's drive to survive, or harm from not providing care or withdrawing care, which could negatively affect the child's long-term outcomes, should they survive.

The Need to Conserve Energy

Additionally, the burden on parents' energy primarily presented in the early acute care stages while caring and advocating for the child with the TBI (Roscigno and Swanson, 2017). During this stage, Moore et al. (2015) found that almost all parents sought staff members' support in demonstrating empathy and respect for the family's individual experience. Families made it clear that they wished to know that providers, and other healthcare team members

involved in their child's care, actually cared about their child as a valued person of their family and community (Moore et al., 2015; Reuter-Rice et al., 2017; Roscigno, 2016). Other sources of burden can encompass all aspects of health, including physical, emotional, social, cognitive, and financial. For example, energy expenditure is not only physical when discussing burden. Many families report struggling with work schedules and, therefore, finances, which Aitken et al. (2009) reports as being significant stressors for families of injured children, especially those with moderate to severe TBI. Aitken further elaborates that time, travel expenses, and scheduling difficulties, all of which are necessary for the child's recovery, added to families' stress and burden. These necessities often resulted in relational family issues and tension with role changes, which were reported to be ignored in the plan of care during the acute care hospital stay, making parents feel that care was not at all "family centered" (Roscigno and Swanson, 2011).

All levels of burden are important to consider in the presence of pediatric TBI, as care truly is for both the child and the family. It is an adjustment to a drastically new lifestyle for both parties, and it should be treated as such by healthcare professionals. The aforementioned patterns of burden demonstrated by these families is of high interest according to Aitken et al. (2009), because in many cases, the families reporting the most negative experiences were not only those with children who presented with severe physical hardship, but also they were those families and their child who suffered psychosocial dysfunction from loss of energy and emotional distress.

Support for Families

Support can be defined in a multitude of ways. Many families referenced in this synthesis deemed the idea of 'feeling important,' 'remaining involved,' and being 'listened to' as ways that providers could show support (Roscigno, 2016). It is prevalent in the majority of the family responses in this qualitative meta-synthesis that the following subthemes were of importance and

worth addressing, according to families: communication, limitations in support, and hope for recovery of their child.

Communication. It is without doubt that communication is one of the most important aspects of healthcare. When caring for a child with moderate to severe TBI and interacting with their family members, especially parents, communication becomes even more imperative. This is because that consistent flow of information on the child's condition is used by the parents for processing the child's current and ongoing medical state and consideration of their range of potential prognosis. This information helps the parents to decrease their uncertainty and make decisions that are in line with the child's and family's values for survival and recovery. Across each of the eight included studies, good and frequent communication with the parents was listed as the greatest priority from the perspective of the parent(s). Alternatively, Reuter-Rice et al. (2017) reported that caregivers reported communication, or rather, a lack thereof, as the most challenging and difficult need during the child's hospitalization. Furthermore, Roscigno et al. (2013) adds that parents feel that providers often fail to address the need for consistent and thorough communication because they likely struggle to understand the diagnosis from a parent's viewpoint, where making therapeutic decisions during the acute stage of recovery is difficult due to overwhelming emotions. Because overwhelming emotions can yield undesired and anxiety-producing settings, families who care for children with moderate to severe TBI desire a complete understanding of the extent of the injury. This includes understanding the possibility for secondary brain injury and comorbidities, the projected recovery time, and the projected ranges of the child's prognosis, including the scientific limitations of the ability to accurately and specifically predict outcomes in children at this early stage (Kirk et al., 2015; Moore et al., 2015; Reuter-Rice et al., 2017; Roscigno et al., 2013). Using a Life Course Trajectory (LCT)

theoretical approach, which illustrated the course of a child with moderate to severe TBI in the acute care phase of the hospital, Reuter-Rice et al. (2017) determined that there are three specific phases for both moderate and severe injury. These phases include: information seeking, watchful waiting, and decision making. From this, it is noted that information seeking is listed first, as it was found to be of highest significance. As each of these stages requires thorough and continuous communication with the healthcare team, it is no surprise that a lack of communication would increase the anxiety of parents who are needing to make critical decisions for their child and family. Roscigno et al. (2013) provides reason to believe that communication can both create alliances, if used appropriately, and create distrust, if not implemented well or at all. Overall, the parents' stories illustrate that any poor communication, no matter with whom, can hinder future interactions between the parents and the remainder of the healthcare team.

Limitations in support. Information and emotional needs should be geared in such a way as to provide families with as much information about the child's condition, what is being done, and why it should be done in a way that parents can absorb and process the knowledge. In this way, parents are provided the greatest support possible to promote recovery in both the family and the child. However, many families, from each of the eight studies, reported the following unmet support needs: emotional support, counseling, financial assistance, social services, information dissemination and discussion, environmental support, lack of a hospital-school liaison, and lack of educational support for both the family and the child (Aitken et al., 2009; Kirk et al., 2015; Moore et al., 2015, Roscigno, 2016). It should be made clear that support is provided to families in many aspects of healthcare. For some families, they felt supported even when providers actively involved them in care or teaching because this helped them understand and parent the child. Listening to the parent(s), without rushing them, allowed them to absorb

information, showed acceptance for their difficulties in learning such complex information under stressful circumstances, and provided practical assistance for their questions or concerns.

Hope for recovery. By definition, the stage of hoping for recovery can be described as the period of uncertainty where parents are attempting to make sense of their child's accident, while waiting for events to unfold, in either a positive (improving) or negative (declining) direction (Kirk et al., 2015). During this phase, parents often feel alone and helpless, because the healthcare team is focused on saving the child (i.e., medical stabilization). Roscigno and Swanson (2011) supplement this idea with the fact that parents initially focused on their injured child still being alive and having a small chance to recover and survive, hence the earliest stage of hope. Although feelings of hope come and go during this stage, as described by Kirk, such as when their child makes a significant improvement or parents see other ill or dying children on the unit, parents tend to lean more expressively toward the positive. Similarly, Roscigno and Swanson mention that parents focused on seeing the child for who they were before the injury, especially when the child was in a comatose state. As Moore et al. (2015) specifies, these parents' small glimpses of the child's formerly apparent personality were seen as random or meaningless to providers, but the parent(s) reported these moments as providing hopeful evidence for the child's progression towards healing, making them a large part of parents' coping and security (Roscigno et al., 2013).

Parents' Abilities to Cope

Although parents reported various reasons for coping and a multitude of strategies for doing so across each of the eight studies, Kirk et al. (2015) indicates that parents felt most concerned and unsupported when trying to cope with behavioral and psychological complications in their child due to the underlying injury. Some parents spoke about the

significance of spiritual faith and religion as a distinct coping strategy, while others referenced the receiving of updates on their child's prognosis and care from providers as their method of coping (Moore et al., 2015). Regardless of the strategies used in coping, providers should avoid negative prognostic talk that is offered with absolute certainty and in an authoritative manner, because parents argued that this behavior was not helping in their coping and ability to make decisions (Rosignano et al., 2013). Instead, parents wish for providers to be honest about their impressions and explain why they think those are true, while also explaining that predicting children's long-term prognosis, so early after injury, is fraught with imprecision because there are many factors that influence the outcomes (Rosignano et al., 2013).

It is important for providers to avoid making judgements about families' varying coping strategies; understanding context is critical. What providers believe is effective may not help a family that is experiencing added stressors other than the fact that their child is injured. This adjustment is forced on parents rapidly and without warning, causing the parent(s) to learn to cope quickly, while undergoing many additional stressors due to the sudden change in lifestyle. According to Rosignano (2016), it is entirely normal for parents to grieve and remain hopeful simultaneously without indicating a parents' misunderstanding of the magnitude of the situation at hand. Parents learn to cope in their own unique ways, and they should be able to talk about their experience without hesitation or judgement, so they can decompress from the trauma.

Family-Reported Suggestions for Improvement

While there are a number of suggestions provided by the parent interviewees to meet the needs of a family unit who is caring for a child with moderate to severe TBI, findings support interventions from the many categories. These interventions include the following: (a) empowering and encouraging direct participation in child care and decisions from parents; (b)

attention to physical, cognitive, emotional, and informational needs; (c) teaching and training parents to fully understand the care and treatment measures given to the child and the rationale and limitations of our knowledge; (d) providing resources to supplement verbal communications; and, (e) improving communication and support for the family as a whole via involving other relevant providers (chaplain, social workers, child life specialists, psychologists) and finding ways for all family members to be involved in supportive measures for the injured child (making get well cards/posters, selecting and providing the child's favorite things at the bedside, preparing parents to consider the unique impact on the individual family members and entire family as a unit, and involving the family in the preparation for the child to eventually return to home) (Moore et al., 2015; Reuter-Rice et al., 2017; Roscigno & Swanson, 2011)

Empowering parents to participate. Each study emphasized the desire from families to be active members in the direct care of their child during the acute stages of recovery. Parents universally described the importance of being participants in improving their own child's health. However, Kirk et al. (2015) adds that although these parents strive to be involved, they are often uncertain on how and when to contribute, if appropriate. Moore et al. (2015) further determined the great need for educated providers, where providers are able and willing, to teach, explain, and empower and encourage parents to participate in the care of their children directly even though the technologies attached to the child may be frightening.

Attention. Care is undoubtedly complicated for both the child and the parent(s) after a child experiences a TBI (Aitken et al., 2009; Roscigno et al., 2013). Moore et al. (2015) explains that the complications with care after a moderate to severe TBI often require staff to provide attention to families and be specially trained in assisting with education. Moore and Reuter-Rice (2017) indicate that there is much to be done, such that the healthcare teams should be extremely

flexible with taking families' needs and stressors into consideration, during the acute care stages, so that they are able to explain information and teach in a way that allows the parent(s) to understand the rationale behind the care being provided. Roscigno (2016) explains that this may need to be done in more than one way and done several times, because the family members are overwhelmed and find processing and remembering such detailed information difficult.

Care training. While parents desire the ability to comprehend and rationalize what care is to be provided to their injured child, it is recommended that specific capacity building techniques are including families. Moore et al. (2015) suggests that listening to families' questions and providing conformation that each individual patient holds a unique place among the hospital care team can lead to a positive experience for the parent(s), despite the current traumatic occasion. Some parents reported that the ability to intervene and assist in caring for their child was appealing, but they did not realize providers expected their involvement (Kirk et al., 2015). Other parents explain their fear of offending providers or making them feel alienated (Moore et al., 2015; Roscigno et al., 2013). However, Kirk provides evidence that involvement in direct care of the child is a way of regaining parent identity, which leads to parents playing a more active role in their child's recovery. In each study, parents accentuated the worth of receiving encouragement, instruction, and support in assuming and embracing the active role of being a part of the child's team of care (Kirk et al., 2015; Reuter-Rice et al., 2017). Overall, it is widely realized that caring for a child recovering from moderate to severe TBI can be daunting in the least, so providers should be knowledgeable, generous, and empathetic to encourage parents to actively participate and prevent parents from feeling judged or incompetent to keep up.

Resources. Aitken (2009) reports that educational and emotional support groups can play a large part in demonstrating promise to families that they are not alone and are able to move

forward, despite the outcome of their child's injury. Additionally, electronic and print resources regarding diagnostic and prognostic information for moderate to severe TBI has proven effective in improving problem-solving and reducing emotional stress among parents and within the family as a whole (Aitken et al., 2009; Roscigno et al., 2013). It is also recommended that families are offered local and affordable resources to help reduce the impact of the child's care on parental work schedules and to help consolidate follow-up visits in order to minimize physical distress (Kirk et al., 2015). Reuter-Rice et al. (2017) ultimately determined the three common phases that families move through: information seeking, watchful waiting, and decision-making. Understanding these phases can help respectively address parents' changing needs efficiently and in a timely manner. Given this information, these approaches could guide the development of best care protocols and facilitate the ability of the healthcare team to help ease parental burden by providing the appropriate physical, emotional, informational, or social support needed at each phase, while also encouraging the family's positive attempts to be involved, by not passing judgment on their abilities, needs, or noting any disagreement with their final decisions.

Communication and support. As communication was the most commonly discussed theme within each of the eight included studies, it is important to address strategies for improvement. In addition, Aitken et al. (2009) complements the need for assistance by stating that pediatricians are more thoroughly trained in handling physical needs versus emotional or social dysfunction, which makes recognizing and managing said psychosocial issues extremely difficult. According to Aitken, these facts present the need for routine screening and reassessment for such problem areas in the family during the acute care period. In standardizing a screening tool and using referral systems to recommend therapy or case management, families will likely endure a more tolerable and positive experience while in the hospital with their child.

Moore et al. (2015) supplements that case management can serve as a valuable tool for not only care during the acute care period, but also for transitioning from the acute care setting back home, where families would remain supported.

Discussion

While children with moderate to severe TBI only comprise 0.06% of the 2.5 million injured in the U.S., over ten million total are still affected worldwide (Centers for Disease Control and Prevention, 2017; Langlois et al., 2006). Given this statistic in conjunction with findings of this meta-synthesis, it is identifiable that several caregivers, often the parent(s), go without effective and complete support during times of need in the hospital while caring for acute moderate to severe TBI, especially parents of children with severe TBI (Rosigno et al., 2013). To think this many families are lacking supportive care and encouragement is enough reason to research further and expand options for supporting families undergoing such stress, so they can continue to support the child in the long trajectory of recovery from moderate or severe TBI. In the acute care inpatient setting, parents especially perceive an inherent demand to create standards of care that address aforementioned needs, which have been consistently reported, in slightly different variations, among countless family members (Fassier & Azoulay, 2010).

As a whole, the eight included research studies demonstrated the various supportive needs of the parent(s) who are associated with caring for a child who is receiving treatment for moderate to severe TBI in an acute care, hospital setting. Parent narratives emphasized the focus on vast differences among experiences with this pediatric population, including but not limited to: the desire to celebrate victories, the need for constant and complete support (emotional, physical, spiritual, and cognitive), the appeal to directly involve parents in the care of their child, the demand for consistent, thorough, and inclusive communication, and addressing social

barriers that limit the family's involvement in care and decisions, such as family visitation policies, parent involvement in decision-making processes, and considering and addressing the unique needs of the entire family (i.e., siblings and extended family members who will be involved with helping the parent(s)) (Hawley, 2003; Roscigno, Swanson, Vavilala, & Solchany, 2011). Despite the listed focuses, there were some inconsistencies in the findings across articles. These may be attributable to the various methods of studying parents' psychological understandings or the diverse data collection processes in describing and/or measuring these findings. Furthermore, depending on where the parent(s) lived or how long after diagnosis of the child's injury the parent(s) were interviewed, results may also be misrepresented. Yet we take parents' impressions not as objective reports of events (i.e., 'the truth'), but as important impressions that they use for their long-term creation of meaning. By understanding the elements that influence parents' and families' meaning, we can better serve them in future encounters.

The included articles were selected to be specific to pediatric populations only; however, many additional studies, involving both pediatric and adult populations, complement the findings supported in the results above. For example, a study by Grant and Starza-Smith (2016), which analyzed family functions of caring for children with TBI, determined that the ability of a parent to function comfortably while feeling supported by providers is an important factor in the prognosis of a child's recovery following TBI. In other words, families who recognize and understand the needs of their child can better advocate for and optimize the social environments for that child, compared with parents who do not appreciate the presenting difficulties.

From comparing these findings to available adult literature, we were able to surmise that regardless of the age of the injured individual, it is evident that families require continuous informational and emotional support, especially when the patient has severe cognitive or

behavioral difficulties (Coco et al., 2011; Oyesanya & Bowers, 2017). Especially in the case of TBI, where losses are often ambiguous, Boss and Couden (2002) agree that ambiguity creates powerful barriers to successful coping and grieving. Other adult studies similarly reasoned that, as a result of ambiguous loss and prognostic uncertainty, support for hope appeared as an imperative need among families. Said hope can either be used as an intervention for support and caring from providers or as a noticeable recognition among parents to let them know they are being cared for and their needs are appreciated (Schutz, Coats, Curtis, & Creutzfeldt, 2017). In the case of unmet or unappreciated needs, it is imperative to note that policies must be employed that involve support for these families. Similar to informational and emotional support and hope promotion, the highest priorities for families included information and assurance of their child's health first, followed by proximity to the child because this is where decisions are discussed and made, comfort measures, and further support (Al-Mutair, Plummer, O'Brien, & Clerehan, 2013).

One need, which was rarely mentioned among the studies in this meta-synthesis, was that of reducing cultural barriers. Grant and Starza-Smith (2016) explain the difficulties of working with families and children whose primary language is not English, which is noted to be a significant barrier in assessing the child and working with both the family and child in the later stages of rehabilitation and recovery. Culture is not only language related, however. Culture extends past language to also include families' belief systems and familial practices (Michelson and Rothschild, 2015). In combination with the fact that parents lack knowledge regarding their child's trajectory, making them reliant on healthcare providers, cultural awareness is an important piece of supporting these families and causing them to feel respected (Al-Mutair et al., 2013; Grant & Starza-Smith, 2016; Roscigno and Swanson, 2011). Generally, this kind of respect can allow families and individuals to cope, encourages them to be involved, and allows

for the parties to communicate easily, and with comfort, between members of the healthcare team, other family members, and the child, once able.

Dealing with perplexing behaviors in the hospital is certainly significant to healthcare systems, as challenges and trials in the hospital are inevitable. Often times, patients or family members may be challenging to healthcare personnel, given their needs, questions, and concerns, but in regard to TBI, these families need to be supported more exclusively (Hanks, Rapport, & Vangel, 2007). Healthcare team members may know what to expect in terms of some of the needs of families and their child with moderate to severe TBI, but their feelings and experiences should also be understood as a summation of many thoughts and challenges (Moore et al., 2015). Healthcare providers and healthcare systems must be able to understand parents' experiences from their points of view, as both Reuter-Rice et al. (2017) and Roscigno et al. (2013) mention. Communication measures may be vastly improved if providers learn and become comfortable with how prognostic ambiguity of severe TBI can affect those parents (Boss, 2006). Boss further reveals that supporting a family's efforts of resilience and moving forward while recognizing bouts of simultaneous grief and challenge is important among healthcare providers in order to encourage early positive coping strategies. These findings demonstrate why including qualitative research was vitally important during the search, because it delivers a unique set of information to explain why and how relationships are positively built or why they breakdown when the family's needs are not addressed appropriately.

Each one of the eight studies included in this synthesis used interviewing techniques at some point in their data collection methods. Data sources varied alongside the interviews in that some studies included retrospective data, surveys, and electronic health record searches. Surveys typically contain close-ended questions and answers are limited in that they are preprogrammed.

Therefore, the survey results may not entirely reflect or detect the true psychological implications in the same way an open interview would. However, due to the fact that parents often feel restricted from fully disclosing their feelings to avoid burdening healthcare providers from “doing their job,” interviews may limit the sensitivity to parents’ symptoms of stress and keep them from mentioning their true feelings and concerns regarding their experience, especially if conducted when the parent is too overwhelmed (prospectively while in the acute care setting). They are, indeed, in the midst of turmoil and have not yet been able to think about their experiences. Worrying about how it could affect their child’s care is also a concern (Roscigno, 2016). Roscigno further adds that not only do parents sometimes avoid burdening others, but also they may do so because they feel threatened or shamed by providers, who make them feel excluded or judged for their emotional capacities at times.

Limitations

Although the studies included in this qualitative meta-synthesis were rated to be of moderate to high or high quality (Table 1C), there were also limitations to utilizing their data, such as the following: their study of small, homogenous sample sizes, their use of self-selected samples, the limited ethnic diversity among participants in the studies, the retrospective nature, which may have contributed to recall bias, and the fact that they often covered a limited geographical range (one hospital or trauma center, etc). Despite the fact that no single study encompassed each of these limiting factors at one time, there is still room for over-simplifying and synthesizing results to also be true among the general moderate to severe pediatric TBI population. Additionally, our lack of access to the primary investigators, with the exception of one (CR), limited our capacity and capability of receiving further background information on the studies and having any questions answered.

Implications

The findings among these studies, with the abundant insight from parents' narratives, highlight that prospective research is needed to inform the development of early resources for families caring for a child in the acute care stages of recovery for moderate to severe TBI, especially resources that assist the parent(s) with information and decision-making regarding critical decisions for their child.

Conclusion

In reading, evaluating, and analyzing the included studies, it was noted that lack of healthcare communication regarding treatments and rationale, the trajectory of potential recovery, and explanation of the complexity of prognosis projections were the most prominent phenomena among parent(s) in the acute care phase of moderate to severe pediatric TBI. While this synthesis provides important information to cover and explain, we would suggest that any communicative interventions should be tailored to the specific needs of each parent and family. Parents know their own and their child's situations best, and as primary sources of this information, they should be included and involved as they want. Said involvement is critical so that healthcare providers can then support the specific needs of the family and foster all individuals' adjustment and adjustment of their family system as a whole.

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Appendix

Figure 1.

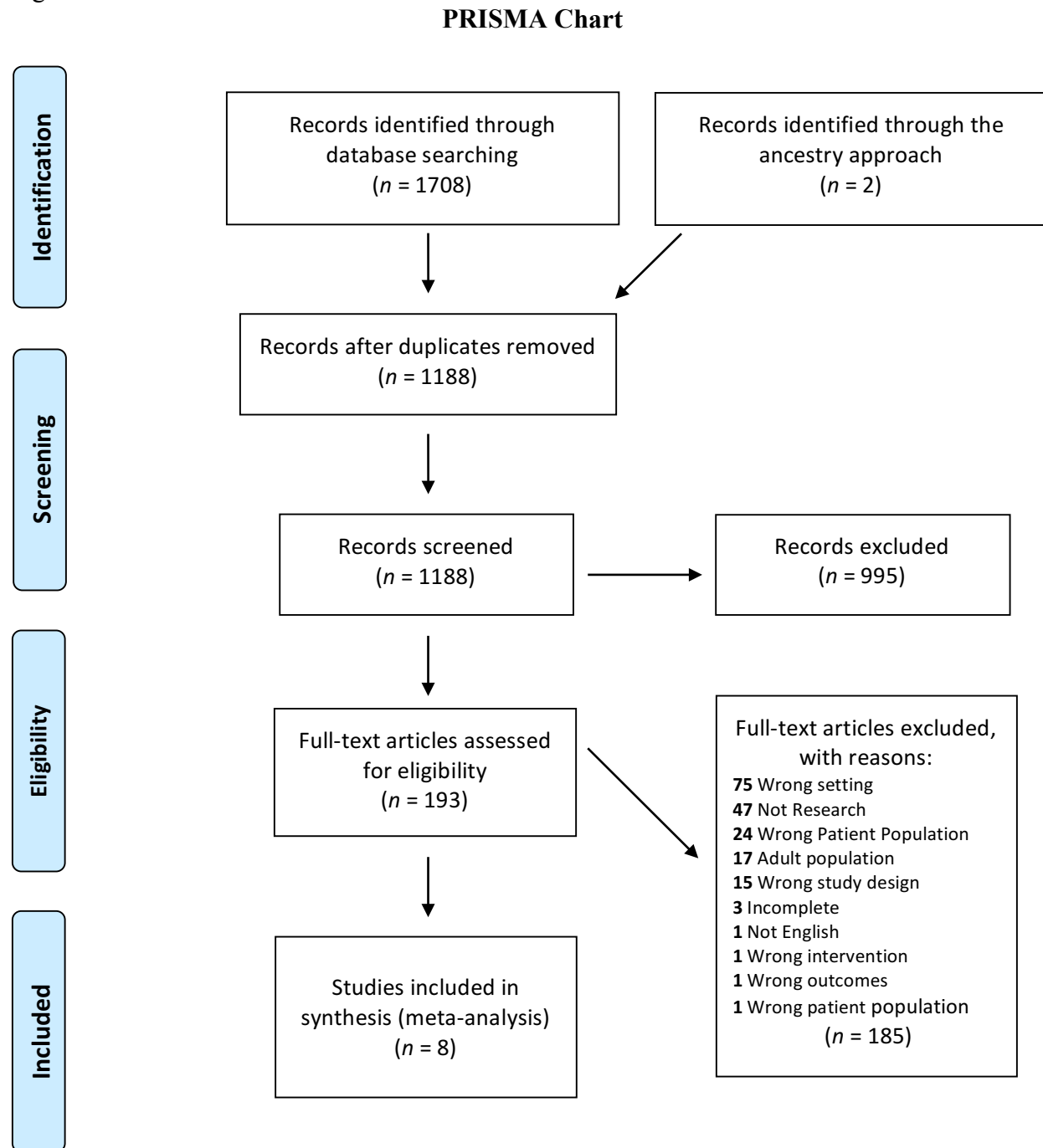


Table 1A: Search Terms by Database

PubMed	("Intensive Care Units"[Mesh] OR acute OR severe OR "intensive care" OR ICU OR "critical care" OR CCU OR "neuro ICU" OR neurolog* OR hospitaliz* OR inpatient* OR patient*) AND ("Family"[Mesh] OR famil*[title] OR parents[MeSH] OR parent*[title] OR mother*[MeSH] OR father*[MeSH] OR caregiver*[MeSH] OR "care giver" OR "care taker" OR caretaker* OR guardian* OR sibling* OR brother* OR sister*) AND ("Brain Injuries, Traumatic"[Mesh] OR "brain injury" OR "brain injuries" OR TBI)	542
CINAHL	((MH "Intensive Care Units+") OR acute OR severe OR "intensive care" OR ICU OR "critical care" OR CCU OR "neuro ICU" OR neurolog* OR hospitaliz* OR inpatient* OR patient*) AND ((MH "Family+") OR TI(famil*) OR (MH "Parents+") OR TI(parent*) OR (MH "Mothers+") OR (MH "Fathers+") OR (MH "Caregivers") OR "care giver" OR "care taker" OR caretaker* OR guardian* OR sibling* OR brother* OR sister*) AND ((MH "Brain Injuries+") OR "brain injury" OR "brain injuries" OR TBI)	581
PsycINFO	((DE "Intensive Care" OR DE "Neonatal Intensive Care") OR acute OR severe OR "intensive care" OR ICU OR "critical care" OR CCU OR "neuro ICU" OR neurolog* OR hospitaliz* OR inpatient* OR patient*) AND (DE "Family" OR DE "Biological Family" OR DE "Extended Family" OR DE "Stepfamily" OR TI(famil*) OR DE "Parents" OR DE "Adoptive Parents" OR DE "Fathers" OR DE "Foster Parents" OR TI(parent*) OR DE "Mothers" OR DE "Fathers" OR DE "Caregivers" OR "care giver" OR "care taker" OR caretaker* OR guardian* OR sibling* OR brother* OR sister*) AND (DE "Traumatic Brain Injury" OR DE "Brain Concussion" OR "brain injury" OR "brain injuries" OR TBI)	585
Total Records Identified		1708
Total Duplicate Records		522
Total with Duplicates Removed		1186

Table 1B: Summary of Articles Included in Meta-Synthesis

Study & Year	Data Collection Method	Sample (<i>n</i>)	Age of Child	Limitations	Purpose of Research	Findings
Aitken et al. (2009)	Telephone interview Child Health Questionnaire (emotional impact scale) Verbal caregiver perceptions	438 eligible children for the study 381 families of these children consented (87%) 330 families enrolled (75%)	5 to 15 years old at time of injury	Most subjects: white (68%) & male (69%) Unable to determine new vs. preexisting family burden Those with more severe TBI and those without health insurance were less likely to participate (underestimates family burden)	This study describes burdens experienced by families of children with TBI and examines relationships between child functioning and family burden during the acute post-injury phases	<ul style="list-style-type: none"> Families facing more severe TBI reported interference in routine and concentration and general worry Physical, emotional, and behavioral health were concerns Positive association between level of burden and whether or not parent's felt their needs were met during care Findings show that needs are modifiable through increased access to medical care, education, or other services (religious, social work, mental health, etc.).
Kirk et al. (2015)	Qualitative semi-structured interviews	29 parents or caretakers (from 19 families of a child with moderate to severe TBI)	16 years old or younger at time of injury	Participants were recruited from one children's tertiary hospital (limited setting) Children were discharged to a wide geographical area with different local service configurations	This study examines parents' experiences and support needs following childhood TBI from the time of their child's accident to discharge home	<ul style="list-style-type: none"> Parents reported a lack of information and support for care transitions Need for emotional support regarding watching their child's medical care and the loss of their child, if applicable Need to better understand the impact of TBI on children and how to cope Improvement in care transitions (i.e. education) can assist in continuity of care Need for a sense of hope and security and reassessment of their needs throughout their child's care
Moore et al. (2015)	Qualitative methods with semi-structured interviews Content analysis (interview transcription) Purposive sampling	15 mothers of children with moderate to severe TBI	Less than 18 years old at time of injury	Only two level 1 trauma hospitals; only one tertiary children's center used to gather data Need to test the FCC model proposed Data based on parents' recall of experience (recall bias) Only mothers volunteered to participate in the study	This study examines family experiences in an acute hospital stay after TBI within the last 5 years of critical care in order to develop a model of specific factors associated with family-centered care in an acute setting	<ul style="list-style-type: none"> Parental desire to be listened to and wanting support from staff that providers care about their child Preparation for outcomes decreased anxiety and distress Multiple communication methods (written, digital, print, demonstration, verbal, etc.) is an important intervention to enhance understanding of care Training in TBI care and enhancing their own physical comfort, such as their sleeping items in the room are needs parents wish to be addressed

Reuter-Rice et al. (2017)	Observational study Life course trajectory (LCT) approach Extraction of information from patients' electronic health record (EHR)	35 children with moderate to severe TBI	5 days to 15 years old at time of injury	Small sample size Studies from one large urban medical center only (limits generalization of results) Does not utilize a mixed-methods approach, where interviewing and surveying families could better describe interactions with the healthcare team	This study identifies common family-healthcare team interactions during the acute phase of hospitalization for children with TBI using a life course trajectory (LCT) theoretical approach	<ul style="list-style-type: none">• Different needs based on severity of child's injury• Need for information, emotional support, participation in decision-making, and care skills training – commonly reported among all injury levels• Need for proper timing of tailored communication and support to parents regarding their child's care for TBI• Healthcare professionals should approach joint decision-making using a communication framework when interacting with families	
Study & Year	Type of Study	Data Collection Method	Sample (n)	Age of Child	Limitations	Purpose of Research	Findings
Roscigno and Swanson (2011)	Primary Parent Study (Original)	Two ~90 minute semi-structured interviews (12-15 months apart) Transcripts: hand-coded; analyzed using a longitudinal, descriptive, phenomenologic approach	42 parents (from 37 families of a child with moderate to severe TBI)	6 to 18 years old at time of injury	Several recruitment methods used to obtain the sample (self-selection) Majority of families from Washington (n = 15) and Florida (n = 11) Sample is limited in racial, ethnic, and lingual diversity	This study aimed to gain understandings of a socially varied group of parents' experiences whose children were no more than 5 years past the date of injury	<ul style="list-style-type: none">• 4 themes identified during the acute phase of moderate to severe TBI care:<ol style="list-style-type: none">1. Gratefulness of child being alive2. Grief for the child they knew prior to injury3. Energy– running on nerves4. Struggle to get what the child & family needed• Parents explained often having to consult outside resources from a lack of trust for professionals• Parents seek 1-on-1 conversations, where medical language, education resources, procedures, and recovery are thoroughly explained by a nurse or physician who assesses their knowledge & answers questions
Roscigno et al. (2013)	Secondary Analysis of Roscigno and Swanson (2011)	Discourse analysis Ethnography of speaking applied to original study: Roscigno (2011) S-P-E-A-K-I-N-G Framework adaptation	Sub-group: 29 parents (from 25 families of a child with moderate to severe TBI)	6 to 18 years old at time of injury	No objective recall of prognostic statements provided Sample: self-participation Recollections of early acute care encounters may be biased by parents' hindsight of the child's later outcome (not interviewed at time of acute phase of injury)	This study aimed to analyze descriptions of prognostic encounters and their relation to parental attitudes, beliefs, notions and expectations regarding the provider's communication of information in early TBI	<ul style="list-style-type: none">• Providers often forget how parents respond to their child's injuries• Parents are affected physically, cognitively and emotionally, making it hard to synthesize or receive information regarding their child's prognosis and injury• Parents' assumed that providers are aware of a family's learning needs, so they expect all teams to work together to facilitate parent learning• Honest communication, even if it is negative, is something parents desired• Unbiased information given in a timely manner helped parents to cope and make decisions

Study & Year	Type of Study	Data Collection Method	Sample (n)	Age of Child	Limitations	Purpose of Research	Findings
Roscigno et al. (2013)	Secondary Analysis of Roscigno and Swanson (2011)	Discourse analysis Transcript data coded with discourse analysis in the framework of ethnography of speaking Semi-structured interviews	Sub-group: 27 parents of children with severe TBI (from 23 families)	6 to 18 years old at time of injury	Study did not re-interview the parents to confirm interpretations from the final findings (secondary analysis only) Included only parents whose child survived the TBI injury Possibility of recall bias	This study aims to understand the linguistic communication factors that parents used in all of their communication that could give understanding of their cultural expectations for early talk in these acute settings	<ul style="list-style-type: none"> Parents felt left out in decision-making regarding their child's care when physicians did not show 1-on-1 regular conversation Providers were claimed to be "too busy" or "unskilled" by intentionally avoiding the families Nurses often filled families in on the missing information, which helped parents get "back on track" <ul style="list-style-type: none"> Nurses play a large role in advocating for patients and their families when caring for moderate to severe TBI in the acute care stages Need for regular conversation with parents about their child's condition, treatments, and future plans of care
Roscigno (2016)	Secondary Analysis of Roscigno and Swanson (2011)	Secondary analysis Inductive analysis (to determine applicability for further theory analyzation) Directed content analysis Hand-coded transcription	Sub-group: 29 parents of children with severe TBI (from 25 families)	6 to 18 years old at time of injury	Only biological mothers ($n = 19$) and fathers ($n = 2$) or both biological parents ($n = 4$) were studied 93% identified as Caucasian and non-Hispanic Small, homogenous sample (small variability) No new themes of caring were discussed before ending parent enrollment	This study uses Swanson's theory of caring to document and categorize parents' descriptions in order to inform nursing care practices and family-centered care when encountering and caring for a child with TBI in the acute care setting	<ul style="list-style-type: none"> Partnerships between nurses and healthcare providers help bridge the gap between families and providers The partnership triad plays an important role in supporting a family's resiliency and supportive needs, because nurses are positioned to easily advocate for patients and their families Following Swanson's theory of caring, nurses are able to listen and empathize with parents' stages of grief, optimism, stress, and resilience in order to form a setting where an opportunity to make sense of the current situation is provided and encouraged → families can better heal, whether it be physically, emotionally, or cognitively

Table 1C: Rankings of Study Quality According to Mays and Pope (2000) Criteria

Study & Year	Quality Ranking	Rationale
Aitken et al. (2009)	High	This study directly addresses family burden while caring for a child with moderate to severe TBI in the acute care phase and follows the topic accurately. It also achieves Mays and Pope (2000) criteria. Three different methods of data collection were utilized to obtain results, and several limitations were directly addressed in detail in its own section, such as limits in the participants' perspectives and further exploration of certain health services that were addressed. Also, methods and data collection processes were explained thoroughly with time frames included, and many sources were referenced in conjunction with the study to proliferate findings and provide multiple perspectives.
Kirk et al. (2015)	Moderate to High	This study follows the trajectory of children diagnosed with moderate to severe TBI from the acute care stage until discharge home – examining families' experiences and support needs during this time. A parent advisory group was formed to provide feedback on study findings, meeting the respondent validation piece of the Mays and Pope (2000) criteria. Data collection and methodologies for designing and collecting the data were addressed such that semi-structured interviews were completed and participant safeguarding and distress protocols were even established during this period. The data analysis process was even developed into a figure divided into three stages for graphic display. Implications were also addressed. Although there was no section for limitations, the limiting factors were discussed in the conclusion. Attention to negative cases was also included such that some parents reported frightening or ambiguous experiences while the study includes some parental regard to positivity.
Moore et al. (2015)	Moderate to High	Though an in-depth interview guide was created using a multistep process, interviewing was the only method for collecting data. However, a literature review was first conducted to identify concepts and areas of interest for the interviews. This study used data to develop a model of elements associated with family-centered care for treatment of children with moderate to severe TBI. In doing so, they explained the precise levels of content analysis, limitations in their results, the need to further test the model of family-centered care, and their relationships with the patients. Multiple sources addressing care needs for this population were consulting in the results to further validate findings and strengthen the inclusion of factors for the family-centered care model that was created.
Reuter-Rice et al. (2017)	High	Following the Mays and Pope (2000) recommendation for validity, this study approached data collection from both an observational standpoint and extraction from the patients' electronic health record for the first eight days of hospitalization for moderate to severe pediatric TBI (triangulation). Also, proper timing of tailored communication and support and decreases in caregiver burden to improve functional outcomes were determined from careful explanation of data analysis, which was done in three ways. Additional studies were also referenced to support and supplement results. Limitations were explicitly stated as well, such as a small sample size and only including one study center. Lastly, negating cases were mentioned, when applicable, to address a more realistic idea for the trends in parents' needs by both the child's severity of injury and time in the acute care stage.

Study & Year	Study Type	Quality Ranking	Rationale
Roscigno and Swanson (2011)	Primary Parent Study (Original)	High	This study follows the guidelines discussed by Mays and Pope (2000) in that limitations, such as the need for further qualitative inquiry to support findings in greater measures or the limited diversity in the sample, are discussed directly and in detail. Also, data collection and methodologies were categorized to more appropriately display how exactly the study was configured and addressed. Feedback was asked during the second of the two interviews, which meets respondent validation or “member check” criteria. Also, data was obtained in the interviews and questionnaires to enhance triangulation. Results were arranged in distinct categories with many references to similar data to supplement their findings and allow for fair dealing. Lastly, reflexivity was also addressed in that biases, such as the idea that stronger opinionated families comprised the sample because it was self-selected, were mentioned.
Roscigno et al. (2013)	Secondary Analysis of Roscigno and Swanson (2011)	High	Prior to completing this secondary analysis from the original study, the researchers reviewed methodological considerations of qualitative data in secondary analyses, furthering the strength of the study. Mays and Pope (2000) criteria were met, such that limitations were identified from both the original study and its impact on secondary analysis data and limits in the secondary data. Also, recall bias was mentioned as a possibility for the study, demonstrating reflexivity. An extensive description of the researchers’ data collection processes and analyses were also discussed thoroughly. Parents of the original study were also contacted regarding information on the secondary analysis being conducted and were provided with a copy of the manuscript to achieve respondent validation.
Roscigno et al. (2013)	Secondary Analysis of Roscigno and Swanson (2011)	High	To follow Mays and Pope (2000) criteria, respondent validation was attempted by obtaining feedback on interviews from patients, but permission was not granted. However, manuscripts were provided to the participants in this secondary analysis. Ethical approval was also granted for the study, furthering its validity. Also, data collection and preparation and data analysis were organized accordingly to clarify the exact processes taken in this study. Triangulation was met with the interviews being both conducted and audio-recorded. Lastly, attention to negative cases were also disclosed and fair dealing was included by separating the purposes of each interview. The first interview focused on injury circumstances and family experiences, while the second interview focused on feedback of the synthesis and any experiences after the first encounter with the researchers.
Roscigno (2016)	Secondary Analysis of Roscigno and Swanson (2011)	Moderate to High	This secondary analysis uses the Mays and Pope (2000) guidelines to address how nurses’ behaviors can help accommodate family needs when in the acute care phases of moderate to severe pediatric TBI. First, the secondary analysis received Institutional Review Board (IRB) approval and was conducted in agreement with ethical criteria for studying human subjects. Patients were also made aware of the analysis from the original study. The design, sample, data collection, and analysis were all clearly exposed, including how the parents’ stories were linguistically structured. Also, attention to negative cases was addressed, such that the interviewing included both parent groups with strong positive and negative emotions. Results were organized using support from a wide range of sources with varying perspectives, helping improve findings and strengthen the quality of the secondary analysis. Limited biases were found, but limitations were discussed such as the sample being of small size and socially demographic data among the parent groups lacking diversity.

Table 1D: Emergent Themes and Factors that May Enhance Parent(s) Perceptions

Theme	Primary Concepts	Secondary Notions	Suggestive Needs
Family Burden	<p>“Holding a regular job is, you know, almost impossible without losing it, because your boss goes at some point, okay, you know, “You can’t keep walking out every... couple of days...” (Roscigno et al., 2011)</p> <p>“Having to pay for parking every day and knowing how long families are there for, I thought it was crazy... I just thought that that whole parking thing added more stress.” (Moore et al., 2015)</p>	<ul style="list-style-type: none"> Caregiver burden is more prevalent among parents who perceive that health care needs of their child are unmet (Aitken et al., 2009). Teams in healthcare could improve families’ abilities to cope and adapt to new needs of their child and own lifestyles. When functioning of family units (i.e., parents) improves, improvements in their own child’s recovery is more likely to occur. In some instances, there are even correlations between the two (Reuter-Rice, 2017). 	<p>Identification of the need for services (social, financial, mental health, etc.) and delivery of services to families experiencing care for a child with moderate to severe TBI is noted as a potentially modifiable factor that may decrease overall family burden and improve recovery after pediatric TBI (Aitken et al., 2009).</p>
Demand for Frequent and Thorough Support	<p>“And I was sleepin’ all bundled in a little chair on the side of her for like a week. I didn’t even never go home.” (Moore et al., 2015)</p> <p>“...[the doctor was] just so calm... his voice was just very calm... he wasn’t rushing, he wasn’t talking really quickly... [he answered] every question, even if we felt like it was dumb... [he was] giving us the time of day and not...ever treating us like we were-just another number.” (Moore et al., 2015)</p>	<ul style="list-style-type: none"> Parents described their time in the acute phase as an ‘emotional roller coaster’ with ‘ups and downs.’ Uncertainty was also a dominant feeling. Not only in whether their child would survive, but also uncertainty in their child’s degree of impairment (Kirk et al., 2015). According to Roscigno et al. (2013), parents often feel that providers forget how parents’ responses to their child’s injuries leave the parent “physically, cognitively and emotionally vulnerable” in the ability to take in and comprehend information and prognosis in the early acute care stage. 	<p>Families need to be educated on the idea that their feelings of helplessness, shock, and denial are normal. Findings display that it is recommended that helping families to associate their feelings with the context of the injury experience will better cater their support needs (Reuter-Rice, 2017). Additionally, it is conveyed that families also rely on support services to enhance their abilities to reengage in their communities (McCabe et al., 2007)</p>
Poor or Limited Communication	<p>“There isn’t anywhere to go to just to talk to, or just for that reassurance... you don’t feel like you can talk to them really because you’re putting them, you’re keeping them back from their job basically aren’t you, and that’s not a good feeling to be sat there thinking you know you can’t, don’t want to put on them because they’ve got so much to do.” (Kirk et al., 2015)</p>	<ul style="list-style-type: none"> Resources have been created that improve communication in acute care for moderate to severe TBI. These include integrated care pathways, transfer protocols, and case management (Kirk et al., 2015). Nurses act as a bridge of communication in the early stages of acute care (Adams et al., 2014; Bourhis et al., 1989). As parents have reported, nurses understand parents’ care needs better; therefore, nurses can bridge the gap between the family and provider. Parents believe this supports family resiliency (Roscigno, 2016). 	<p>It is recommended that explaining, in clear and understandable ways, the type of injury the child has sustained and the extent of the injury will better serve the parents needs for communication. Also, findings show that team meetings can ensure that all information given to families would be frequent and consistent, short, and concise regarding the child’s condition and treatment plan (Aitken et al., 2009).</p>

Patients' Protection from Harm	<p>"I don't think it's anything you'll ever get over, because just, he's not the same, if you know what I mean, he's not the same child... he's different in every way." (Kirk et al., 2015)</p>	<ul style="list-style-type: none"> • Safety concerns were discussed about when a parent's child was moved from an intensive care unit (ICU) to an acute phase, such as a medical-surgical floor. Parents report that their child's medical conditions were still medically fragile because of "seizures, brain storming, or disorders of consciousness (irritable, combative, and impaired judgment)." These are all important safety concerns that still should be monitored closely according to parents. They felt solely responsible for preventing and protecting their child from injury due to a perceived lack of education among nurses and other staff (Rosignano, 2016). 	<p>Nurses who integrate the parents in the care of the parents' child, and value doing so, are reported by families to help reduce stress among the family and improve their sense of trust and safety within the unit setting and among the healthcare team (Rosignano, 2016).</p>
Parents' Participation in Care	<p>"I think we just went with whatever they said. Yeah they didn't ask us, do you want to do this, they just said what they were doing and we just went along with [it]... Because I think if they give us the choice to say what [should happen], we're not medical people, we don't know what's going to happen, we could make the wrong decision... they know what they're doing... I think it'd be hard if they gave you the decision before they did anything. Because that decision that you could make could be wrong" (Kirk et al., 2015)</p>	<ul style="list-style-type: none"> • Involving the family in the child's everyday routine such as feeding, bathing, and changing bed linens can help families begin to assume control of care (Reuter-Rice et al., 2017). • Teaching plans for families allow parents to meet their own designated and discussed needs during the acute phase of their child's care. Here, family coping and adaptation to their new roles as caregivers is made clear (Reuter-Rice et al., 2017). 	<p>A holistic assessment of the family should be performed at each point of transfer in care to ensure that parents are being kept up to date and that the parents' needs are being conveyed to the healthcare team frequently. Also, parents should always be supported and encouraged to become involved in their child's care needs, when applicable and appropriate (Kirk et al., 2015).</p>