The Experience of the Hospital Stay for Patients with Traumatic Brain Injury and Their Family Caregivers

By: Tolu O. Oyesanya

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy (Nursing)

at the UNIVERSITY OF WISCONSIN-MADISON

2016

Date of final oral examination: 04/26/16

The dissertation is approved by the following members of the Final Oral Committee:

Barbara J. Bowers, PhD, RN, FAAN, Professor, School of Nursing
Lyn S. Turkstra, PhD, CCC-SLP, Professor, Communication Sciences and Disorders
Mary (Molly) L. Carnes, MD, MS, Professor, School of Medicine and Public Health
Audrey Tluczek, PhD, RN, Associate Professor, School of Nursing
Barbara J. King, PhD, NP, Assistant Professor, School of Nursing
David J. Maiers, PT, Physical Therapist, UW Hospital and Clinics
Dedication

I dedicate this dissertation to my fiancé, my parents, and my siblings.

Thank you for your unconditional love and support throughout the years.

I couldn’t have done it without you.
Acknowledgements

Acknowledgements: Special thanks to dissertation committee members: Barbara Bowers, PhD, RN, FAAN (Chair); Lyn Turkstra, PhD, CCC-SLP; Barbara King, PhD, NP; Molly Carnes, MD, MS; Audrey Tluczek, PhD, RN; and David Maiers, PT. Thank you to School of Nursing faculty and staff and to staff at the participating study recruitment locations.

Funding: This research was funded by the National Institute of Nursing Research (NINR) and the Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD) (PI, T. Oyesanya), Grant #F31NR015398 and by the University of Wisconsin-Madison, School of Nursing. This project was partially supported by the NIH/NIGMS Initiative for Maximizing Student Development (PI, M. Carnes) Grant# R25GM083252 and by the Clinical and Translational Science Award (CTSA) program, through the NIH National Center for Advancing Translational Sciences (NCATS), Grant# UL1TR000427. The content is solely the responsibility of the author(s) and does not necessarily represent the official views of the NIH.

Conflicts of Interest: The author has no conflicts of interest to declare.
Table of Contents

Dedication ........................................................................................................ i
Acknowledgements ........................................................................................ ii
Dissertation Abstract ......................................................................................... iv

Paper 1: The experience of patients with ABI and their families during the hospital stay: A systematic review of qualitative literature

   Title Page ...................................................................................................... 1
   Abstract ....................................................................................................... 2
   Body of Paper ............................................................................................. 3-36
   References .................................................................................................. 37-41
   Figure ......................................................................................................... 42
   Tables ......................................................................................................... 43-54

Paper 2: “I’m trying to be the safety net”: Family protection of patients with TBI during the hospital stay

   Title Page .................................................................................................. 55
   Abstract ..................................................................................................... 57
   Body of Paper ............................................................................................ 57-78
   Figure ........................................................................................................ 65
   References ................................................................................................ 79-81

Paper 3: Managing visitors during the hospital stay: The experience of family caregivers of patients with TBI

   Title Page .................................................................................................. 82
   Abstract ..................................................................................................... 83
   Body of Paper ............................................................................................ 84-105
   Figure ........................................................................................................ 91
   References ................................................................................................ 106-107
Dissertation Abstract

Purpose: Patients with traumatic brain injury (TBI) and their family caregivers have unique experiences and needs during the hospital stay, and family caregivers regularly support these patient and are involved in their care. Yet, limited literature exists on patient/family experiences and family caregivers’ perceived roles during this time. The purpose of this dissertation is to describe the experience of the hospital stay for patients with TBI and their family caregivers (paper 1), including investigating the role of family caregivers during this time (paper 2 and 3).

Methods: Paper 1 describes a systematic literature review of qualitative literature, including content analysis to synthesize findings. Paper 2 and 3 describe research that used grounded theory to conduct twenty-four interviews with 16 family caregivers of patients with TBI.

Results: From paper 1, findings on the patient experience showed patients had negative perceptions of the rehabilitation environment and a perceived need for information. The family experience was multifaceted, including difficulty adjusting after the patient’s injury, a desire to be involved in the patient’s care, and high perceived need for information. Findings from paper 2 showed family caregivers saw their role as protecting the patient’s physical and emotional safety and used different strategies to do so. Findings from paper 3 further described family caregivers’ role, specifically discussing management of welcome and unwelcome visitors throughout the hospital stay to protect the patient’s physical and emotional safety.

Conclusion: These findings have practice implications for educating interdisciplinary healthcare providers on: 1) the multifaceted experiences of patients with TBI and their family caregivers during the hospital stay; 2) perceived roles of family caregivers during the hospital stay; and 3) strategies to improve support provided to patients and family caregivers during this time.
Paper #1

The experience of patients with ABI and their families during the hospital stay: A systematic review of qualitative literature

Author:

Tolu Oyesanya, PhD, RN
University of Wisconsin-Madison
School of Nursing
Abstract

Background: Patients with acquired brain injury (ABI) and their families have unique experiences and needs during the hospital stay; yet, limited literature exists on this topic. The purpose of this systematic review was to compile and synthesize literature on the experience of patients with ABI and their families during the hospital stay.

Methods: A systematic review of qualitative studies was conducted by searching for studies from seven databases. Content analysis was used to analyze and synthesize studies’ findings separately for the patient and family experience.

Results: The initial search provided 2,871 records. Ultimately, eleven studies relevant to the research question were included in this review. No studies were excluded based on critical quality appraisal. Findings on the patient experience showed patients had negative perceptions of the rehabilitation environment and a perceived need for information. Findings on the family experience included difficulty adjusting after the patient’s injury, desire to be involved in the patient’s care, mixed feelings about staff support, and high perceived need for information.

Conclusions: Findings provide awareness for healthcare providers on the multifaceted experiences of patients with ABI and their families during the hospital stay, strategies to make care more patient- and family-centered, and directions for future research.
Introduction

Acquired brain injury (ABI) may be defined as brain damage caused by events occurring after birth, as opposed to birth-related, genetic or congenital disorders [1]. Moderate-to-severe ABI encompasses brain damage with different etiologies, such as traumatic brain injuries (caused by a “bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain” [2]) and stroke (caused by cerebral vascular accidents) [3]. High incidence rates of ABI occur in the United States, with over 2.5 million people sustaining traumatic brain injuries, and over 800,000 people experiencing a new or recurrent stroke event annually [4,5]. Moderate-to-severe ABI causes cognitive impairments such as problems with memory, attention, and executive function; difficulties with speech, communication; and decreased capacity for new learning [6,7]. Millions of people are currently living with the cognitive impairments and disabilities caused by ABI, with more than 6.4 million people living with the impairments caused by traumatic brain injury and stroke combined [3]. ABI is a chronic disease [8], and the outcomes have tremendous lifetime implications for patients and their families.

Role and Needs of Family Members of Patients with ABI

Family members play a large role in supporting their loved one through the difficult recovery and rehabilitation process that is necessary after a moderate-to-severe ABI [9]. This process causes a crisis for family members, as the sudden onset of their loved one’s brain injury and critical and often changing status is overwhelming [10]. Throughout the hospital stay, family members support their loved ones with ABI by assisting with goal-planning and decision-making [9,11] and providing physical, instrumental, and emotional support during the hospital stay and after discharge [12]. Also, family members often transition to the role of caregiver once patients are discharged from the hospital.
As family members often become caregivers of patients with moderate-to-severe ABI and continue supporting them after discharge, it is important to consider family needs [13]. Consideration of family caregivers’ needs in the plan of care helps to ensure family caregivers are adequately prepared to care for their loved one after discharge. However, perhaps due to time constraints [14], the needs of family caregivers of patients with ABI are often not considered prior to the patient being discharged, as much of the focus is on the patient [15]. Consequently, some family caregivers perceive that they are not prepared to care for the patient with ABI when they are discharged home from the hospital [16]. The long-term care needs of both patients with ABI and their family caregivers suggest family caregivers’ needs should be addressed as soon as possible, particularly during the hospital stay, as this will provide insight into how healthcare providers can meet their needs [17]. Thus, it is important to understand family caregivers’ needs before they are discharged from the hospital to assist with adequate preparation for the caregiver role.

Research on the Experience of Patients with ABI and their Families

While limited studies have examined the experience of patients with ABI and their family during the hospital stay, research exists that examines the patient and family experience after discharge. Research has shown that patients with ABI report unmet needs relating to support from healthcare providers after discharge [18,19], specific to the transition from hospital to home and help with emotional and behavioral problems. Other studies have shown that patients with ABI report needing more assistance from healthcare providers to address neuropsychological problems, such as emotional lability, memory, and problem solving [20-22]. A systematic literature review focusing on needs of family caregivers of patients with ABI after discharge found families reported unmet needs, which were linked to a perceived need for more
information [23]. Families also had unmet needs relating to emotional support and management of the patient’s behavioral problems [23].

However, the majority of studies on the needs of patients with ABI and their families collected data on their experience long after the patient was discharged from the hospital (e.g., 3 months to several years) [23,24]. Collecting data long after the patient has been discharged from the hospital limits applicability to the patient’s and family’s experience and needs during the hospital stay for multiple reasons: 1) collecting data long after discharge may not accurately capture patient and family thoughts, feelings, and concerns as events occurred during the hospital stay [25]; 2) the needs of patients and families during the hospital stay are much different than their needs once discharged home, as research has shown their needs change over time [26]; 3) research has shown that when someone is asked to recall events that have long passed, bad memories are remembered more strongly than good memories, also known as negativity bias [27], so waiting until long after discharge to interview patients and families about their experience during the hospital stay may negatively influence their responses. Conversely, collected data on the experience of patients with ABI and their family members during the hospital stay can help healthcare providers understand their needs and adequately prepare them for discharge by making care more patient- and family-centered.

**Research on the Experience of Patients with Spinal Cord Injuries and their Families**

Spinal cord injury, defined as either “loss of voluntary movement (paralysis) [or] loss of sensation [28, p. 289], is a complex injury that, similar to ABI, causes physical, psychological, and social difficulties for both the patient and their family [29]. Spinal cord injuries commonly co-occur with traumatic brain injuries. Approximately 60% of people who sustain a spinal cord
injury simultaneously sustain a brain injury, and up to 20% of those traumatic brain injuries are moderate-to-severe in nature [30].

Research on the experience of patients with spinal cord injuries and their families during the hospital suggests there may be more to learn about the experience of patients with ABI and their families during this time. Similar to patients with ABI, patients with spinal cord injuries report unmet needs during the hospital stay, including perceived the need for more information [31], desire to build stronger relationships with healthcare providers [31], desire to participate in rehabilitation planning [32], the need for more emotional support [32], and the need for family involvement in care [33,34]. After discharge, unmet needs for patients with spinal cord injury and their family members continue, including difficulty communication with healthcare providers [35], lack of post-discharge care [36], limited support from healthcare providers [36], and difficulty adjusting [37]. As there is limited research on the experience of the hospital stay for patients with ABI and their families, this body of research specific to spinal cord injury can be used to provide direction to researchers and healthcare providers on the patient and family experience after ABI.

**Research Recommendations from Prior Literature on ABI**

Although research, albeit limited, is available about the experience and needs of patients with moderate-to-severe ABI and their families both during and after the hospital stay, scholars have emphasized the need for more research. Even though the majority of research on this topic has been quantitative, findings of both quantitative and mixed-methods reviews emphasize the need for qualitative research to reinforce existing quantitative knowledge. For instance, a quantitative systematic review on the needs of patients with brain injury after discharge recommended that more research be done to help healthcare providers understand the needs of
patients with ABI, specifying that “in-depth interviews could provide a clearer image of the actual needs and care required by patients” [24, p. 1204]. A systematic review that synthesized quantitative literature focusing on the needs of family caregivers of patients with ABI after the hospital stay emphasized that more research is needed “to determine whether current methods of analyses reveal an accurate representation of family needs” [23, p. 670]. Yet another systematic review, which was mixed-methods in nature, focused on the long-term care needs of patients with ABI and their families recommended more research be conducted to elucidate areas that patients and their families deem are important, which could be better understood through the voices of the patients and families [17]. These authors also noted that “more qualitative approaches to exploring TBI [traumatic brain injury] are an invaluable addition to the evidence base” [17, p. 606], and that this knowledge could help healthcare providers to learn about strategies to best support patients and families, which is vital to service planning and development [17]. These published recommendations for research emphasize the need for qualitative research methodologies to assist researchers and clinicians to better understand patient and family experiences and needs during the hospital stay.

Qualitative research methodologies are suitable to help researchers and clinicians to improve the accuracy and relevance of quantitative studies by helping to identify appropriate variables that are important to the population being studied and by providing explanations for findings that are unexpected or that were previously unexplainable [38]. As quantitative research alone may be unable to fully describe the experience of patients with ABI and their families during the hospital stay, qualitative research can be used to reinforce quantitative research and to provide directions to healthcare providers on how to make care more patient- and family-centered. Therefore, there is a need to do a systematic literature review of qualitative research
focusing on the experience of patients with moderate-to-severe ABI and their families during the hospital stay.

To address these gaps in knowledge and the above-listed research recommendations, it is important to capture and synthesize findings from qualitative research on the experiences of patients with ABI and their families during the hospital stay to build new knowledge and to provide directions for future research. As partnerships between patients, families, and healthcare providers “need to be forged as early as possible” [39, p. 23], this research can provide new knowledge in this area, which may assist healthcare providers to do the following: 1) understand the overall experience of the hospital stay for patients with ABI and their families; 2) improve how patients and families are prepared for discharge; 3) make care more patient- and family-centered; and, in turn, 4) improve self- and family-management of ABI after discharge.

However, to do this, common themes among patients’ and families’ experiences are required and the needs of both should be identified [23]. To this end, a systematic literature review was conducted with the following aims:

1. To synthesize qualitative research on the experience of patients with moderate-to-severe ABI during the hospital stay;
2. To synthesize qualitative research on the experience of family members of patients with moderate-to-severe ABI during the hospital stay.

**Methods**

**Study Design**

This systematic literature review was conducted following guidelines put forth by the Centre for Review and Dissemination and by Butler (2016) [40,41]. The author used PRISMA
(Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines to report findings [42]. The PRISMA flow diagram in Figure 1 describes the selection process.

Eligibility Criteria

General inclusion criteria were set for selecting studies from all databases. All literature searches were restricted by: period of publication (1990-2015), type of journal (academic peer-reviewed), language (English), research subject (human), and subject age (18 years or older). Specific inclusion and exclusion criteria governed the overall screening process, and were set for patients, family members, patients’ diagnoses, study focus, type of studies, and setting. These criteria are listed in Table 1.

Search Strategy

The literature search was conducted between October 28 and November 11, 2015. The following electronic databases were searched: CINAHL, PsycInfo, PubMed, SocIndex, Academic Search Premier, Family Studies Abstracts, and Family and Society Studies Worldwide. An example of key words and phrases used in each database is listed in Table 2.

Study Selection

After obtaining all of the studies resulting from searching the seven electronic databases, the author saved all citations in a citation manager (Zotero). Prior to applying the inclusion/exclusion criteria, duplicates were removed. The author and a research assistant independently screened the title and abstract of each study. Next, the author and research assistant discussed whether to include each study that met inclusion criteria by reading the full-text. Reference lists of each study that met inclusion criteria were hand-searched for additional studies on the topic.

Data Extraction
Data extraction were performed by the author and research assistant. All studies were coded deductively for the stated: a) author(s); b) year of publication; c) country; d) study purpose; e) study design; f) sample strategy; g) sample characteristics; h) data collection techniques; i) data analysis techniques; j) findings for patients’ and families’ experience relevant to the review.

**Critical Appraisal of the Quality of the Studies**

The author and research assistant used the QualSyst Tool for Qualitative Studies [43] to assess the quality of each study in this review. When discrepancies occurred, both discussed rationale for including or excluding studies until consensus was reached. The QualSyst Tool contains an individual checklist detailing criteria specific to qualitative studies [43]. Psychometric information for this tool has yet to be established.

**Analysis of Findings from Studies in this Review**

Findings across all studies were analyzed and synthesized using conventional content analysis, which was suitable to use as research on this experience is limited [44]. Following the steps outlined by Hsieh & Shannon (2005), the author and research assistant first immersed themselves in the data by reading through each article to obtain a sense of the whole, writing notes while reading through to indicate first impressions. Next, codes were developed that were reflective of the data. Themes were developed by grouping codes based on similarities and differences and organizing codes into meaningful clusters [44]. Analysis for the patient and family experience occurred separately, resulting in two separate syntheses. Information on each study is presented in Table 4 to allow for comparison across articles.

**Results**

**Search Outcome**
The initial search identified 2,871 studies. A flow diagram describing the selection of studies is shown in Figure 1. After the initial search, all studies were imported into a citation manager, and 590 duplicates were removed. The first author and research assistant independently screened titles and abstracts for the remaining 2,286 studies. There were 76 studies that met inclusion criteria during this screening phase and were reviewed in full. Next, during the preliminary review of full-text of each study, 65 studies were excluded due to not meeting inclusion criteria for the following reasons: a) being a quantitative study (n=5); b) conducting interviews greater than one month post-discharge (n=28); c) lacking patient/family perspectives (n=2); d) not separating patient/family perspectives (n=1); e) lacking focus on brain injury (n=3); f) lacking focus on hospital experience (n=9); and g) being grey literature (n=17). Ultimately, 11 studies were included in this systematic literature review, including 5 studies identified through hand searching. The chosen studies varied based on design, population, aims, and findings.

**Quality of Study Methodology**

The QualSyst Tool was used to assess the quality of methodology in each study on 10 criteria items, which were scored as 0 (no), 1 (partial), and 2 (yes) [43]. Each study was given a total score and a summary score. A maximum total score of 20 and a maximum summary score of 1 is possible for each study (see Table 3). Instructions for scoring indicated by the QualSyst Tool were: 1) to obtain the total score, add all the criteria items together; and 2) to obtain the summary score, divide the total score by the total possible score. Studies that did not meet the minimum summary score of 0.55 defined by the QualSyst Tool’s inclusion threshold were excluded [43]. Five studies received a summary score between 1.00 and 0.90; three studies ranged from 0.75 and 0.70; and three studies ranged from 0.65 to 0.55. No studies were excluded based on critical quality appraisal.
Study Characteristics

All studies were qualitative in nature, using the following study designs: unspecific qualitative approach (n=4), phenomenology (n=3), and grounded theory (n=4). Data collection techniques included: semi-structured interviews (n=10) and mixed-methods (n=1; i.e., interviews and surveys). All studies focused on at least some portion of the experience of the hospital stay for patients with brain injury (n=4), their family members (n=7), or both (n=3). Each sample included at least one of the following: 1) patients that were hospitalized primarily for care relating to their ABI or had been discharged ≤ one month post-discharge at the time of the study; and 2) family members of these patients. The sample sizes varied from one participant (a case study) to 38 participants.

Patient diagnoses included moderate-to-severe traumatic brain injury (n=3), specified and unspecified acquired brain injury (n=3), and stroke (n=5). Samples included family members with the following relations to the patient: spouses/partners, parents, children, siblings, uncles, grandparents, or unspecified. When specified, ages of patients ranged from 18 to 64 years. Ages of family members were more commonly reported and ranged from 24 to 93 years. Although participants in each study were interviewed during the hospital stay or ≤ one month post-discharge, there were large variations in data collection time points. Data collection time points included: pre-discharge, post-discharge, and over the course of the patient’s recovery. Finally, studies were conducted in various countries or areas around the world, including: United States (n=6), Australia (n=2), United Kingdom (n=2), and Canada (n=1).

Synthesis of Studies

Patient Experience
Four studies [45-48] in this review had findings relevant to the experience of the hospital stay for patients with brain injury. There were two main themes synthesized from the literature, which included: 1) perceptions of rehabilitation and 2) perceived need for information. An overview of themes specific to the patient experience based on the synthesized literature is listed in Table 5.

**Perceptions of Rehabilitation**

Three studies [45,46,48] reported patients’ experiences during inpatient rehabilitation, including their thoughts about the rehabilitation environment, relationships with healthcare providers, and excitement for discharge. This theme included sub-theme findings that focused on the patients’ perceptions of: a) expectations for recovery; b) impact of the rehabilitation environment; c) perceptions of rehabilitation activities; d) perceived support; and e) perceptions about discharge.

*Expectations for recovery.* After being stabilized, patients with ABI began to look toward the future regarding their next step in the recovery process, including completing inpatient rehabilitation [46]. Some viewed inpatient rehabilitation as an extension of their hospital stay, while others assumed that engaging in inpatient rehabilitation would help them return to their pre-injury functioning prior to discharge [46]. As rehabilitation began, patients realized that their expectations for recovery were incongruent with the expectations staff held. Patients wanted to return to their pre-injury functioning, while staff wanted to see "small, but notable change in function" [46, p. 791].

*Impact of the rehabilitation environment.* Patients who were interviewed during inpatient rehabilitation reported negative perceptions of the rehabilitation environment, often referring to their stay in inpatient rehabilitation as “prison” [45]. Many of these negative connotations arose
due to limited personal privacy, minimal privacy with visitors, and lack of outside space on the rehabilitation unit [45]. Noises and regulated mealtimes also felt unnatural to the patients. However, some patients regarded the rehabilitation environment as a place to build community and socialize. While positive comments were made about rehabilitation staff, patients that had negative comments perceived rehabilitation staff did not treat them with respect [45].

*Perceptions of rehabilitation activities.* Fleming [45] described how many patients undergoing rehabilitation felt that their time was not used meaningfully. While patients reported that engaging in therapy and rehabilitation activities was beneficial to their recovery, some patients reported feeling bored and stated rehabilitation activities did not have much meaning; many said much of the day was unstructured during rehabilitation. Patients reported being bored and frustrated as they spent time watching TV and socializing with other patients or visitors while waiting for their next therapy activity to begin. However, patients that were able to find other ways to occupy their time did not report these feelings [45].

*Perceived support.* During inpatient rehabilitation, patients with ABI reported that visits from family members and friends made their experiences positive [45]. Visitors often provided support in different ways, including "providing a connection to current events outside the rehabilitation unit, knowing and understanding the person, and providing emotional support" [45, p. 190]. In contrast, not having any visitors had a negative effect on patients.

*Perceptions about discharge.* Three studies [45,46,48] described patients’ perceptions of discharge. Many patients reported perceiving discharge as an escape from inpatient rehabilitation [45]. Patients reported that preparing for discharge was a relief, with feelings of excitement and anticipation [46,48]. However, prior to discharge, patients had to determine their post-discharge
destination, including returning home, going to live with someone, or going to a nursing home [46].

**Perceived Need for Information**

One study [47] detailed patients’ need for information throughout their hospital stay, specifically indicating the types of information desired at specific times, including the following sub-theme time frames: a) immediately after injury; b) during acute care/rehabilitation; and c) before discharge.

*Immediately after injury.* Within two days of the ABI, patients who were cognizant wanted information that would help them to understand their diagnosis. Patients wanted to know the results of tests and "investigations" that were conducted, including seeing scans and x-rays. In particular, patients wanted to know about staff’s recovery predictions. Patients with ABI reported that they wanted this information delivered by medical staff, both verbally and in writing to be able to reference later. Patients also reported that they wanted information about control of symptoms, such as pain, but requested that nurses, in no specific format, deliver this information [47].

*During acute care/rehabilitation.* Approximately 20 days post-injury, patients reported wanting much of the same information that they received immediately after injury. Patients recognized that they were likely “out of it” when staff initially provided them with information about test results and diagnosis. Patients also requested information detailing whether further tests were needed. Information about test results and the need for further testing was requested from anyone with sufficient knowledge, verbally and in writing. Patients also had concerns about long-term problems, wanted to speak with the nurse about pain control, and wanted advice on financial matters from social services staff [47].
Before discharge. Prior to discharge, at approximately 90 days post-injury, patients who were still undergoing inpatient rehabilitation wanted information about long-term recovery and recovery predictions from their general practitioner. Patients also wanted to know about caregiver support and benefits from social services staff, but did not have any preferences on the manner of delivery of this information. Finally, patients also wanted to hear first-hand from other people who had survived an ABI to learn about their experience [47].

Family Experience

Ten studies [10,15,25,39,45-47,49-51] in this review had findings that were relevant to families’ experiences of the hospital stay after their loved one had an ABI. Multiple themes for the family experience were synthesized from the literature, including: 1) adjustment after loved one’s injury; 2) involvement in care; 3) dealing with the event; 4) perceptions of the patient’s rehabilitation; 5) perceptions of relationships; 6) preparing for the upcoming caregiver role; and 7) perceived need for information. The majority of the themes have sub-themes that provide a deeper description of the family experience. An overview of themes specific to the family experience based on the synthesized literature is listed in Table 5.

Adjustment after Loved One’s Injury

Five studies [25,45,46,49,50] in this review discussed the theme “adjustment after loved one’s injury,” including descriptions of family members’ negative emotions, and problems with decision-making. This theme had three sub-themes: a) emotional reactions; b) uncertainty; c) decision making; and d) difficulty with transitions.

Emotional reactions. Emotional reactions began for family members after the patient was admitted to the hospital for critical or acute care [46]. Many emotions surrounded the event of "getting the news,” which left vivid memories for family members [50]. As the family members
began to understand what happened, they experienced shock, disbelief, anxiety, stress, anger, confusion, loss of control, guilt, blame, and fear [25,46,49]. Many family members reported feeling relief that their family member survived and hoped that they would return to their pre-injury functioning [46]. Some family members reported blaming the patient, the patients’ primary family caregiver (e.g., wife of patient) or medical personnel for lack of immediate recognition of the symptoms, especially when a stroke occurred [46]. Family members’ emotions fluctuated over the course of the patient’s hospital stay up until discharge from rehabilitation [49]. Emotions fluctuated depending on the time since injury and personality of the family member [25]. Many primary family caregivers had difficulty coming to terms with adjusting to life post-injury, with feelings of sadness and grief [45,49].

**Uncertainty.** After the patient was admitted to the hospital, family members felt uncertainty surrounding the patient's survival. Uncertainty was composed of: a) not knowing whether the patient would survive; b) waiting for information on the patient's injury and for the patient to wake up; c) uncertainty regarding the patient's prognosis and how much the patient's and family members’ lives would change; and d) uncertainty about the patient’s quality of life [50].

**Decision-making.** Decision making for these families was particularly difficult as families were uncertain about the prognosis of the patient's recovery. Many family caregivers reported having to make life-changing decisions in a short period of time with limited information [46]. Most families were concerned with the potential for cognitive deficits and changes in behavior. Given the difficulty predicting patient prognosis, many family members wanted to wait to make ethical decisions. If ethical decisions were made before it was clinically
necessary, family members perceived this to mean they were "giving up hope and abandoning the injured family member" [25, p. 233].

**Difficulty with transitions.** According to Keenan and Joseph [50], transitioning to different levels of care was hard for families because they had to adjust to different staff, unit cultures, and a perceived delay in care as the patient was being assessed. Being on one unit for many weeks bred familiarity, and moving to a new unit with new staff was a big adjustment [50].

**Involvement in Care**

Three studies [10,25,50] showed that many family members wanted to be directly involved in the patient’s care in multiple ways such as physical presence and assisting staff with the patient. Involvement in care included the sub-themes: a) physical presence; b) hands-on actions; and c) other ways of involvement.

**Physical presence.** Because survival was questionable, the family members wanted to be physically present with their injured loved one [50]. Family members rushed to their loved one's bedside and had a difficult time leaving immediately after the injury. Many wanted to be present when their family member regained consciousness [25,50]. Family members reported wanting to be able to stay as long as possible, even though some hospital policies restricted amount of visitors and length of their stay, particularly in ICU [25]. This physical closeness made some families feel that they were involved in their loved one’s care [50].

**Hands-on actions.** As the time progressed in the patient's ICU stay and as family members stayed long hours to support the patient, many family members expressed wanting to participate in the patient’s care by doing hands-on actions. For instance, many wanted to assist with the patient's bath. However, some families reported never being given instructions on how
they could help [10]. Family members that participated in "hands-on actions" for the patient reported that they felt involved in the patient’s care [50].

*Other ways of involvement.* Families reported that being involved in the patient's care was meaningful to them. Family members were involved in multiple other ways, such as attempting to help staff understand the patient. Others attempted to be a patient advocate and to plan for the patient’s future [50].

**Dealing with the Event**

Five studies [10,39,49-51] discussed the theme “dealing with the event.” After making sense of the news, family members attempted to deal with the patient’s brain injury in many different ways, such as receiving support, and using spirituality and acceptance, which was described in the following sub-themes: a) perceived support from the community; b) perceived support from staff; c) taking it one day at a time; d) spirituality; and e) accepting.

*Perceived support from others in community.* During ICU, other family members and friends gave emotional support to the patient’s primary family caregiver and to the patient by visiting, calling, and sending cards with prayers and optimistic messages [39]. However, primary family caregivers reported phone calls from friends and family were overwhelming due to the volume. Having to spend time dealing with friends' and family members' questions left family caregivers fatigued as all of their energy was already going to the patient. Staff were able to assist with this issue by limiting the number of calls at the hospital and limiting visitation with extended family and friends [39].

As few primary family caregivers felt they obtained a full understanding of their family member's injury, many turned to their informal social network of healthcare providers composed of family and friends to seek advice, if available [39]. Primary family caregivers were also
grateful when these family members and friends came to the hospital to visit and asked the "right" questions of staff [39].

During ICU, community members also provided instrumental support by delivering meals, providing transportation for primary family caregivers and other family members to and from hospital, transporting the patient’s and/or primary family caregivers’ children to activities, helping with home chores, and giving money [50]. During acute care, emotional support from friends and other family members ensured that the patient's primary family caregiver(s) did not feel alone. Instrumental support from insurance and work accommodations were also very helpful at this time [50].

*Perceived support from staff.* Primary family caregivers reported that support received from staff had a positive influence on their experience [50]. Some spoke positively about their interactions with staff, especially the nurses in the ICU. Family caregivers felt reassured when staff presented themselves as confident, knowledgeable, and honest. In contrast, family caregivers had concerns when they perceived staff to not know the patient, which made them feel "insecure about the care that was being given" [50, p. 29]. During acute care, support often came from the healthcare team as a whole. Some primary family caregivers reported nurses provided the most support, as nurses spent many intimate hours with the patient and family [50].

*Taking it one day at a time.* Throughout the recovery process, family members reported facing the unknown, as they did not know what was going to happen to the patient or themselves. Family members felt overwhelmed when they thought too far into the future, so they reported taking it one day at a time by focusing on the immediate and the known [49].

*Spirituality.* Primary family caregivers reported that their strong faith and spirituality helped to bring them through the ongoing crisis, maintain hope, and give them strength. They
relied on their faith, even when they didn't have all the answers [10]. Camaraderie was also used to maintain hope, and primary family caregivers called on others with similar spiritual beliefs for help in maintaining hope [51].

**Accepting.** Families whose loved one's were severely injured began to accept that their lives would be forever changed by this injury. This was especially influenced by staffs’ prognosis was that the patient would never be able to care for him/herself again and by the patient’s marked cognitive changes, particularly because both would change roles and social interactions with family members [50].

**Perceptions of the Patient’s Rehabilitation**

Eight studies [10,15,25,39,46,49-51] discussed the theme “perceptions of the patient’s rehabilitation,” which encompassed the family member’s experience of the patient’s stay in inpatient rehabilitation, particularly focusing on family members’ involvement in the patient’s care. This theme had multiple sub-themes, including: a) expectations for recovery; b) observing the patient’s recovery; c) knowing the patient better; d) monitoring the patient’s care; e) holding on to hope; and f) managing needs of the family.

**Expectations for patient’s recovery.** After the patient was stabilized, family members began to look towards the future, particularly at the next step in the recovery process [46]. Both patients and their primary family caregivers were given the option of having the patient go to an inpatient rehabilitation unit, be placed in a nursing home, or go to sub-acute rehabilitation facility. Nursing home placement was not seen as a suitable option by most family caregivers [46]. Many families perceived that if the patient went to inpatient rehabilitation, they would not be discharged until they returned to their pre-injury abilities. Unfortunately, many family
members “did not understand the scope of the decision to which they were committing” [46, p. 790].

*Observing the patient’s recovery.* Family caregivers described a perceived association between involvement of family and the patient’s recovery. For instance, family members noted that the perception that if family was present and involved, the patient seemed to recover faster [51]. Many families wanted to be present to monitor the patient closely for indicators of progress, which was sometimes inhibited by restrictions on the length of time they could spend visiting their loved one [10]. The patient's daily behaviors also influenced the family’s feeling about the patient’s recovery, with families reporting feeling positive when the patient progressed and disheartened when the patient regressed [50].

*Knowing the patient better.* Many family caregivers reported observation of daily improvements to use in determining the patient's progress. Family caregivers often reported that they believed that they knew the patient better than staff; some stated that they had the ability to identify behaviors that were present pre-injury as they emerged during the patient’s recovery, such as mannerisms, subtle movement, and comments. This helped to reaffirm that progress was being made. Family caregivers felt that this "inside" knowledge helped them to see improvements that the nurses and other staff could not see, as staff did not know the patient pre-injury [51]. Other family members felt the information they provided to staff about the patient's pre-injury abilities and problems with their ongoing care were not actively used [39]. Some caregivers with active healthcare experience took a more active approach to try to convince staff to use the information they provided, while those without experience often did not know what to do and became concerned about the quality of care their family member was receiving [39].
**Monitoring the patient's care.** Some family members reported being very vigilant with the patient's care and progress [50]. Many relied on staff to provide the best care for their loved one but often found the patient was frequently waiting for care because staff were busy. This led to family caregivers monitoring how staff provided care to the patient, causing family caregivers to spend long hours at the hospital [39].

**Holding on to hope.** Family members attempted to maintain hope throughout the patient’s hospital stay and recovery process, particularly during inpatient rehabilitation. Various levels of hope were held: where some families had a positive outlook, others lost hope and felt that things would not improve [50]. For many family members, specific events or interactions influenced their levels of hope. Family caregivers reported observation of the patient daily and recognition of the patient’s improvements reinforced the caregiver's hope [51]. By focusing on the known rather than the unknown, hope was also fostered [49]. Families often relied on staff to maintain hope and were very cognizant of staff’s words of encouragement [50].

All family members expressed hope for their loved one's future, including completing school or being able to regain employment. However, no caregivers expressed hope for the patient to resume activities of daily living, implying that activities of daily living were an automatic expectation [51]. As time went on, thoughts changed from hope for specific things to a general hopefulness that the patient would continue to get better [49].

**Managing needs of the family.** Immediately after the patient's injury and the first weeks following, family members reported focusing solely on the patient and postponing or delaying other responsibilities [50]. When it was clear the patient would survive, often when the patient began inpatient rehabilitation, the families adjusted and realized "other family obligations, work, and community life must take precedence" [50, p. 29], including sleeping and eating [25]. Many
families reported role reversals, where primary family caregivers took on the pre-injury roles of the patient in addition to assuming their own prior roles [15]. Some also took on additional responsibilities, such as caring for the patient’s children. As family functioning was disrupted [39], new routines needed to be developed for caring for other children at home [15].

Many family members gave up activities and commitments that were scheduled pre-injury, such as going on vacations and trips, volunteering, attending church activities, and socializing with friends [15]. Financial decisions changed, particularly if the injured person was the primary wage earner prior to injury. Many family members worried about what their life would be like after discharge, especially as it related to money [25].

**Perceptions of Relationships**

Four studies [10,25,50,51] discussed the theme “perceptions of relationships,” including multiple types of relationships with family, staff, and friends, with the following sub-themes: a) family-family; b) family-friend; and c) family-staff.

*Family-family relationships.* Family-family relationships played a significant role in this experience. The stressful events, including the uncertainty of the patient’s recovery, created interpersonal conflict in the family. For families that already had interpersonal conflicts prior to injury, this situation intensified their conflicts. Presence of interpersonal conflicts made it even more difficult to deal with the patient’s injury [50]. Strong marital relationships with clear communication were present, but the stress of the patient’s injury created tension [25,51].

*Family-friend relationships.* Relationships with friends and other acquaintances were important, particularly in the first few days after injury. However, some family members reported wanting to be alone at this time. As the patient's recovery progressed, the continuing presence of friends became tiring to family members [25].
During critical care, relationships with other families began to form. Many of these relationships were built as families sat in the waiting room patiently awaiting the next time they could go into their family member’s hospital room for a short visit [25].

**Family-staff relationships.** Many family members reported disappointment if they did not have the opportunity to talk with their loved one's physician each day [25], and some even reported not being able to speak with the patient’s physician for a few days after the hospital stay began [10]. Many wanted regular updates on the patient's condition, even if there were no changes [25]. However, some families reported that the less they saw the patient’s physician, the less discouraging news they would have to hear [25]. Regarding family-nurse relationships, many families reported positive relationships with nursing staff [25]. Nurses were often helpful in filling in missing information after discussions with physicians [25]. However, visiting restrictions in the ICU created conflicted between families and nurses [25]. Family-staff trust was established when information was delivered in a consistent, caring, and understandable manner. Positive interactions reinforced trust, while negative interactions diminished it [50].

**Preparing for Upcoming Caregiver Role**

Three studies [39,46,49] discussed the theme “preparing for the upcoming caregiver role.” While discharge was highly anticipated by both the patient and family caregiver, much work was required of family caregivers before the patient was discharged, including gaining knowledge and skills and preparing to accommodate the patient post-discharge. Sub-themes included: a) attempting to gain knowledge and skills; b) gaining confidence; and c) crisis of discharge.

**Attempting to gain knowledge and skills.** Primary family caregivers were motivated to seek the best care for their loved one, leading to a desire to be competent as a family caregiver.
After realizing they would need to care for the patient post-discharge, family caregivers wanted to become actively involved in the patient's care but often felt that doing so was infringing on staff’s territory. Family caregivers felt that their attempts to gain knowledge and skills necessary to care for their loved one were unheeded. However, some family caregivers reported they were able to overcome resistance from the staff [39].

**Gaining confidence.** Primary family caregivers' gained confidence to care for their injured loved one when staff whom caregivers perceived to be confident taught them skills. However, most family caregivers reported limited time to prepare them for their loved one’s discharge, which led to additional stress and lack of confidence [39].

**Crisis of discharge.** The patient’s impending discharge caused a crisis for family members, particularly primary family caregivers [49]. It was often not until one or two days prior to discharge that caregivers began to realize that the patient was going to be discharged even if they had not met the family caregiver’s initial recovery expectations. Family caregivers had to quickly determine what was needed to accommodate the patient after discharge and who would be able to do help. An endless list of tasks and responsibilities was determined, including physical, emotional, and instrumental support. Family caregivers were also expected to attend the patient's therapy and rehabilitation sessions before discharge to receive training on how to care for the patient. The sheer amount of preparation and training made most family caregivers exhausted [46].

**Perceived Need for Information**

Six studies [10,25,39,45,47,50] discussed the theme “perceived need for information.” Throughout the patient’s hospital stay, families reported an intense need for information, wanting to know about their loved one's injury and their prognosis [10,25,39,45,47,50]. Families reported
wanting information that was consistent, easy to understand, specific to their relative (not probabilities or statistics), with frequent updates [50]. Many family members reported the following sub-themes: a) lack of understanding of information; b) wanting certain types of information; c) problems accessing staff and information; and d) wanting no assumptions.

*Lack of understanding of information.* Information in many forms (given, received, perceived, interpreted) played a large role in the decisions made by family members [25]. Although family members could repeat information on the patient's status, some reported that they “had not grasped the meaning of the information” [25, p. 233].

*Wanting certain types of information.* Many family caregivers were uncertain about the injury and what it meant for the patient and themselves. Family members sought knowledge and understanding relating to the injury [39,50], including verbal and written information about diagnosis, prognosis, results of tests, prescribed medications, and possible interventions [10,47]. Others wanted knowledge about expectations of the rehabilitation process, treatment goals and outcomes, available resources [45], information about long-term consequences (e.g., recovery of speech, sexual needs) and the impact these consequences would have on the patient’s discharge [47]. Some families reported wanting this information from a single doctor, especially early in the patient’s care [10]. Regardless, family caregivers wanted this information to be truthful and consistent and having to ask for this above-listed information led to more stress [10]. Family members wanted this information communicated freely, without having to ask for it, as asking felt intrusive [10]. Often times, when this information was not given, family members became concerned that they lacked knowledge and would be unable to fulfill the role of caregiver [45].

*Problems accessing staff and information.* In regards to attempts to receive information, some families felt that staff were easily accessible, while other family members who were
unavailable during business hours reported difficulty gaining access to information they desired from staff due to communication barriers. Those who had difficulty communicating with staff had doubts about their own abilities to provide effective care to the patient after discharge [45]. Sometimes, when it was not easy to access desired information, family members used both subtle and explicit techniques to obtain information, such as asking direct questions, observing, or even eavesdropping on patient-staff interactions. Having to seek information in this manner made family members feel as if they were going it alone [39]. Finally, family members reported that family meetings with staff were very helpful in receiving information. However, families stated more family meetings were necessary to make sure there was clear and consistent information being communicated [45].

Wanting no assumptions. Many family members reported being overwhelmed, even if they had prior experience visiting other sick family members in the hospital, or even if they had healthcare experience (e.g., practicing nurse). Family caregivers with healthcare experience reported that their healthcare experience was a barrier, as staff made assumptions about their levels of knowledge about ABI, thus limiting information provided to them [39]. Family caregivers reported that, regardless of healthcare experience, they wanted as much information as possible to help them become knowledgeable about the patient’s status and necessary future care [39].

Discussion

The purpose of this systematic literature review was two-fold: 1) to compile and synthesize the research on the experience of patients with moderate-to-severe ABI during the hospital stay; and 2) to compile and synthesize the research on the experience of family members of the same patients during the hospital stay. Across qualitative methodologies, very similar
themes were present when patients and families were allowed to speak for themselves. Although
the experience for patients with ABI compared to family caregivers varied, common themes
were present among each group. Findings specific to the patient experience showed that patients
with ABI had negative perceptions of the rehabilitation environment and had a perceived need
for information. Findings specific to the family experience were multifaceted, characterized by
family members reporting difficulty adjusting after the injury, a desire to be involved in the
patient’s care, mixed feelings about support from and relationships with staff, attempts to
become prepared for the caregiver role, and a high perceived need for information.

The two main themes that characterized the literature on the patient experience were
perceptions of rehabilitation and perceived need for information. While these findings are similar
to the experience of the hospital stay for patients with spinal cord injury [31-33], these findings
differ from literature on the experience of patients with ABI post-discharge. A systematic review
on the care needs of patients with ABI after discharge showed patients reported different types of
needs, including cognitive, emotional, and behavioral needs [24]. Cognitive needs included
assistance with memory problems. Emotional needs were reported as wanting help with
controlling one’s moods, while behavioral needs focused on controlling one’s temperament [24].
Taken together, this study’s findings of the need for information during the hospital stay and
findings from prior research on patients’ long-term care needs are likely indicative of the
patients’ desire for self-management of injury after discharge. These findings emphasize the
need for patient-centered care to increase patient’s preparation for discharge, which aims to
develop a partnership between patients and healthcare providers, increasing patient participation
and patient-provider collaboration [52].
Only four studies on patients’ experience were included in this study. Although patients with ABI are the ones spending all of their time at the hospital when receiving care immediately after a brain injury, few studies exist detailing their experience. Patients with ABI may have been systematically excluded from research on about their experience during the hospital stay due to the perception that the cognitive impairments caused by the injury inhibit them from providing meaningful information [53]. However, depending on the severity of patient’s injury, patients may still be able to share their experience. Researchers’ and healthcare providers’ negative perceptions about the abilities of people with cognitive impairments to meaningfully participating in research have been documented in the literature, such as with people with intellectual disabilities or dementia [53,54]. Yet, research has shown that strategies can be used to facilitate effective interviewing with people with cognitive impairments, such as using shorter questions with active verbs and avoiding abstract concepts [54]. Question development should also take into account the patient’s level of communicative competence, based on first- and second-order theory of mind (first-order: ability to understand another person’s thoughts; second-order: ability to conclude what one person is thinking about another person’s thoughts) [55]. The findings from this study provide evidence that researchers were able to successfully interview patients with ABI during the hospital stay, as patients provided meaningful information on their experience. These patients’ perspectives can be used to improve the rehabilitation environment to make care more patient-centered.

In contrast to themes about patients’ experience, this study’s findings on the family experience during the hospital stay were characterized by multiple themes, including: 1) adjustment after loved one’s injury; 2) involvement in care; 3) dealing with the event; 4) perceptions of the patient’s rehabilitation; 5) perceptions of relationships; 6) preparing for the
upcoming caregiver role; and 7) perceived need for information. However, two themes from the family member’s experience were also present in the patient’s experience: perceptions of rehabilitation and perceived need for information. Many of these themes detail families’ experience of fluctuating emotions, heightened uncertainty regarding decision-making, positive support from family and friends, and mixed feelings on support from healthcare professionals. These findings also emphasize families’ use of multiple strategies to cope with their loved one’s injury and apprehension about and difficulty with preparing for their upcoming caregiver role. These findings are similar to results from other studies, which focused on the needs of family members of patients with ABI after the hospital stay, as well as studies detailing the experience of family members of patients with spinal cord injuries [34-37]. For instance, a mixed-methods systematic literature review on support needs of family members of patients with ABI showed that families reported multiple support needs, including informational, emotional, and practical support [56]. Examples of their needs included wanting: 1) quality information about the patient’s symptoms [12,57]; brain injury care [58,59] and prognosis [60]; 2) their emotions to be taken into account by healthcare providers [61]; and 3) to participate in the patient’s care [62] and decision making [63].

Findings on the family experience from this systematic review can also be used to reinforce results from other studies, particularly studies using quantitative methodologies. The themes relating to the family experience in this review, such as “preparing for the upcoming caregiver role” and “perceived need for information,” truly emphasize that family members have a desire to be adequately prepared to care for the patient after discharge. These findings provide depth to quantitative research on this topic. More specifically, research has found after a patient with ABI leaves the hospital, family members report that 30-60% of their needs go unmet
relating to care and support of the patient [21,22,64]. After discharge from inpatient rehabilitation, other studies show family members stated they felt that their needs were unmet because the service system was unorganized, uncaring, and unresponsive [62], limiting the family’s ability to support the patient. Taken together, our findings and those from prior research emphasize family members’ desire to be adequately prepared to support and care for their loved one after the hospital stay, suggesting a need for care to be more family-centered during the hospital stay to assist with meeting family members’ needs. In addition, these findings shed light on areas that need further research and provide direction for researchers on new variables to test.

Perhaps our most interesting finding was that family members’ reported a desire to be more prepared to care for their loved ones after discharge, which emphasizes the need for family-centered care. A family-centered care model can help to meet families’ needs through family-provider partnerships focusing on emotional, social, and developmental support and promoting the well-being of the patient and the family [52]. As families play a significant role in supporting the patient during the hospital stay [9,11], a family-centered model of care can begin to address both patient and family needs before the patient is discharged [52].

**Practice Implications**

Taken together, findings from this study and prior research provide awareness for healthcare providers on the multifaceted experiences of patients’ with ABI and their families during the hospital stay, providing direction on how to make care more patient- and family-centered. Patient- and family-centered care emphasizes the importance of having a partnership between patients, their families, and healthcare providers in goal setting and decision-making [52], throughout the hospital stay and especially during rehabilitation. As patients and families move through their experience of the hospital stay, it is clear that they have expectations of
healthcare providers, including being listened to, receiving support, receiving information, and being prepared for self- and family-management of injury. Healthcare providers’ awareness of these expectations can be used as a first step in making care more patient- and family-centered for patients with ABI and their families.

More specifically, knowledge that patients perceive the rehabilitation environment lacks privacy and that unstructured activities cause boredom and frustration may provide direction on how to improve inpatient rehabilitation for patients with ABI. Discrepancies in expectations in recovery for patients’ and their families compared to healthcare providers may suggest a need for more inclusion of patients and families in goal setting and interdisciplinary team meetings, particularly during inpatient rehabilitation. Understanding of how family members attempt to deal with their loved one’s injury may give healthcare providers insight into strategies some families use to cope, which providers may be able to directly apply to their own practice. Cognizance of family caregivers’ attempts to become adequately prepared for the caregiver role may suggest a need for more focused family caregiver training throughout the hospital stay, in conjunction with typically scheduled family caregiver training during the patient’s rehabilitation therapy sessions. Awareness of patients’ and families’ perceived need for information throughout the hospital stay may provide guidance on exactly what information to provide to patients and families and the appropriate timing to do so.

**Limitations**

This systematic literature review only included studies published in English in peer-reviewed journals, which may have excluded relevant studies published in other languages. However, the findings of this study provide direction for future research on this topic. This review focused on studies that collected data on the patient and family experience *during* the
hospital stay or less than one month post-discharge. While this may have excluded other studies on this topic that collected data more that one month post-discharge, the author chose this data collection time frame as it captured an accurate portrayal of the literature on this topic by collecting data from participants while they were actively engaged in the events. This study also combined literature on moderate-to-severe ABI, including specified and unspecified ABI, traumatic brain injury, and stroke and also did not include other causes of brain injury in the search strategy. Although these injuries have different etiologies, much of the care provided to patients with ABI and their families after injury and over the recovery trajectory is similar.

**Future Research**

Future research is needed to provide more depth to current literature on the experience of the hospital stay for patients with ABI and their families. First, more studies are needed to better understand patients’ and families’ experiences of the hospital stay, including studies focusing on differences based on age of the patient and cause of injury (e.g., TBI vs. stroke). The results of this review provide evidence that patients with ABI are able to provide meaningful information about their experience *during* the hospital stay. Instead of minimizing patient’s abilities after ABI, researchers should determine questions patients are able to answer and work to capture their experience. While studies about patients with ABI and their families can be applied to the experience of patients with TBI and their families, more research is needed to elucidate the experience of patients with TBI and their families during the hospital as only three studies in this review focused specifically on TBI. Additional research on this topic will help to increase both healthcare providers’ and researchers’ knowledge of specific their needs during this time.

Second, more rigorously conducted research is needed as many studies had flaws in study aims and objectives, data collection techniques and time frames, and data analysis. Some studies’
findings in this review did not specify timeframes for the participant experiences, including not specifying the hospital units participants were on or were referring to during interviews and not specifying the patient’s time since injury.

Similarly, few studies in this review detailed the actual questions asked of participants during interviews; some provided examples of a few interview questions, others provided information on topics discussed during interviews, and others provided no information. To improve existing and forthcoming knowledge on the patient and family experience, researchers need to detail the interview questions asked of participants so researchers and clinicians can understand what was specifically asked about their experience, how this relates to patient and family needs, and what questions are left to be asked. Third, while it is beneficial to ask patients and families about their experience, it is essential to determine exactly what patients and families want or what would have been helpful to them, which could be asked as a direct question. For instance, towards the beginning of inpatient rehabilitation, a clinician could ask the family caregiver, “What are your concerns for when your family member returns home from the hospital?” In addition, three to five days before discharge, a researcher or healthcare provider could ask the family caregiver, “What hasn’t been done so far that would be helpful to you before your family member is discharged?” Finally, as family members report spending long hours at the hospital to support their loved one physically and emotionally [25,50], more research is needed to determine the work that the family perceives they are doing during the hospital stay.

Conclusions

Patients with moderate-to-severe ABI and their families spend a significant amount of time at the hospital immediately after the patient’s injury and throughout recovery and rehabilitation. Both patients and family members have perceptions about the events they face, as
well as expectations of healthcare providers, including receiving support from professionals, providing information, and being prepared for discharge. Understanding more about patients’ and families’ experiences can assist healthcare providers in meeting the needs of patients with ABI and their families during the hospital stay.
References


47. Garrett D, Cowdell F. Information needs of patients and carers following stroke. Nursing Older People. 2005;17(6):14-16.


Figure 1. PRISMA Flow Chart
Table 1. Eligibility Criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Inclusion/Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients</strong></td>
<td>Patient participants must: a) be age 18 years or older; b) be diagnosed with an acquired brain injury (e.g., moderate-to-severe traumatic brain injury or some form of acquired brain injury [stroke, aneurysm, etc.]); c) be hospitalized or ≤ one month post-discharge at the time of the study; d) have had a qualitative interview conducted during the hospital stay or ≤ one month post-discharge; and e) be fluent in English language. <em>Exclusion criteria for patients</em>: a) age 17 years or younger; b) sustained some sort of brain injury but did not receive hospital care; and c) diagnosis of brain injury but are part of a drug trial or intervention study.</td>
</tr>
<tr>
<td><strong>Family Members</strong></td>
<td>Family member participants must: a) be age 18 years or older; b) have a family member who was diagnosed with an acquired brain injury (e.g., moderate-to-severe traumatic brain injury or some form of acquired brain injury [stroke, aneurysm, etc.]); c) be an immediate or extended family member of patient; d) have a family member who was hospitalized or ≤ one month post-discharge at the time of the study; e) have had a qualitative interview conducted during the patient’s hospital stay or ≤ one month post-discharge; and f) fluent in English language. <em>Exclusion criteria for family members</em>: a) age 17 years or younger; b) non-family member (e.g., friends, bystanders, strangers).</td>
</tr>
<tr>
<td><strong>Patients’ Diagnoses</strong></td>
<td>This systematic review included studies with samples of patients diagnosed with: a) specific or unspecified moderate-to-severe ABI; b) moderate-to-severe TBI; and c) stroke. <em>Exclusion criteria for patients’ diagnoses</em>. The following exclusion criteria were applied for diagnoses: a) mild TBI; b) severe TBI with diagnosis of persistent vegetative state; and c) non-brain injury related condition/disease.</td>
</tr>
<tr>
<td><strong>Study Focus</strong></td>
<td>Studies focusing on these topics relevant to the patient’s and family’s hospital stay experience were included: a) views or experience of; b) attitudes; c) perspectives or perceptions; d) needs or wants; e) thoughts or feelings. <em>Exclusion criteria for study focus</em>. Studies focusing on the following topics were excluded: a) views/experience that did not relate to the hospital stay; b) healthcare providers’ perspective; c) patient/family views/experience of the therapy patients receive while hospitalized.</td>
</tr>
<tr>
<td><strong>Types of Studies</strong></td>
<td>All qualitative research studies published as a journal article, including qualitative findings from mixed-methods studies were included. All quantitative research studies and grey literature (e.g., dissertation studies, books, clinical guidelines, published abstracts, newsletters, conference proceedings, etc.) were excluded.</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td>Studies focusing on following hospital settings were included in this review: a) intensive or critical care; b) acute care; c) general care; d) [acute] inpatient rehabilitation; and e) tertiary care settings. <em>Exclusion criteria for settings</em> including the following settings: a) outpatient; b) community; and c) home.</td>
</tr>
</tbody>
</table>
Table 2. Search Terms

<table>
<thead>
<tr>
<th>Focus</th>
<th>Key words and phrases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (Patients)</td>
<td>Clients OR Patients OR client* OR patient*</td>
</tr>
<tr>
<td>Population (Family Members)</td>
<td>Family OR “Family Members” OR Caregivers OR famil* OR husband* OR wife OR wiv* OR child* OR parent* OR relative*</td>
</tr>
<tr>
<td></td>
<td>OR grandparent* OR grandmother* OR grandfather* OR aunt* OR uncle* OR cousin* OR sibling* OR sister* OR brother* OR niece*</td>
</tr>
<tr>
<td></td>
<td>OR nephew*</td>
</tr>
<tr>
<td>Patients’ Diagnoses</td>
<td>&quot;Traumatic Brain Injury&quot; OR brain injur* OR TBI OR traumatic brain injur* OR head injur* OR &quot;traumatic brain injury&quot; OR ABI OR “acquired brain injury” OR &quot;brain injury&quot; OR &quot;head injury&quot;</td>
</tr>
<tr>
<td>Study focus and type of studies</td>
<td>&quot;Qualitative Research&quot; OR Attitudes OR Emotions OR view* OR experience* OR perspective* OR attitude* OR perception* OR need* OR want* OR feeling* OR qualitative* OR story OR stories</td>
</tr>
<tr>
<td>Setting</td>
<td>Hospitalization OR Hospitals OR Rehabilitation OR Intensive Care OR Treatment OR hospital* OR inpatient* OR inpatient OR ICU OR rehabilitation OR &quot;intensive care&quot; OR &quot;acute care&quot; OR therap* OR therapy</td>
</tr>
</tbody>
</table>

1 Table 2 details an example of search terms from the PsycInfo literature search. Subject headings were used where applicable and available. An ‘*’ denotes a truncated term. Some phrases have quotation marks around them as a signal to the database to provide studies that used that exact phrase.
Table 3. Quality Assessment with QualSyst Tool (Qualitative Studies)

<table>
<thead>
<tr>
<th>Studies</th>
<th>Quality Assessment Criteria for Qualitative Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Question/Objective</td>
</tr>
<tr>
<td>Fleming (2012)</td>
<td>2</td>
</tr>
<tr>
<td>Turner (2012)</td>
<td>2</td>
</tr>
<tr>
<td>Mirr (1991)</td>
<td>2</td>
</tr>
<tr>
<td>Bond (2003)</td>
<td>2</td>
</tr>
<tr>
<td>Gebhardt (2011)</td>
<td>2</td>
</tr>
<tr>
<td>Keenan (2010)</td>
<td>2</td>
</tr>
<tr>
<td>Lutz (2011)</td>
<td>2</td>
</tr>
<tr>
<td>Garrett (2005)</td>
<td>2</td>
</tr>
<tr>
<td>Silva-Smith (2007)</td>
<td>2</td>
</tr>
<tr>
<td>Fraser (1999)</td>
<td>2</td>
</tr>
<tr>
<td>Brereton (2002)</td>
<td>2</td>
</tr>
</tbody>
</table>

2 = yes; 1 = partial; 0 = no.
<table>
<thead>
<tr>
<th>Author, Year, County</th>
<th>Study Design</th>
<th>Purpose</th>
<th>Sample Size and Description</th>
<th>Data Collection Relevant to Study/ Data Analysis</th>
<th>Findings Relevant to Patients with ABI</th>
<th>Findings Relevant to Family Members of Patients with ABI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fleming 2012, Australia</td>
<td>Phenomenological approach</td>
<td>To describe and interpret the inpatient brain injury rehabilitation experience from the perspectives of patients and their family caregivers</td>
<td>20 patients with ABI; 18 family caregivers&lt;br&gt;Patients: Injuries: 16 with traumatic brain injury; 4 with stroke/aneurysm&lt;br&gt;Sex: 15 males, 5 females Mean age: 40.2 years&lt;br&gt;Family caregivers: Sex: 13 females, 5 males Relation: 11 spouses 6 parents, 1 daughter Mean age: 46.6 years</td>
<td>Data Collection: Semi-structured interviews pre-discharge, and 1 month post-discharge&lt;br&gt;Data Analysis: Content analysis</td>
<td>Most patients had negative views of the rehabilitation environment (stating that it lacked privacy and had no outside space), while some felt the environment built community. Patients felt the unstructured time while waiting for therapy activities was boring and frustrating. Some patients perceived that staff did not treat them with respect. Patients viewed visitors as supportive and positive to their experience.</td>
<td>Family caregivers wanted information and their loved one’s injury, expectations of the rehabilitation process, treatment goals and outcomes, and available resources. Families that were unable to be at the hospital during business hours reported healthcare providers were inaccessible, which made them unconfident for the caregiver role. Family members had feelings of sadness and grief after their loved one’s injury.</td>
</tr>
<tr>
<td>Turner, 2011, Australia</td>
<td>Phenomenological approach</td>
<td>To explore the perspectives of individuals with ABI and their family caregivers concerning recovery and adjustment during the early transition phase from hospital to home</td>
<td>20 patients with ABI; 18 family caregivers&lt;br&gt;Patients with ABI: Injuries: 16 with traumatic brain injury; 4 with stroke/aneurysm&lt;br&gt;Sex: 15 males, 5 females Mean age: 40.2 years&lt;br&gt;Family caregivers: Sex: 13 females, 5 males Relation: 11 spouses 6 parents, 1 daughter Mean age: 46.6 years</td>
<td>Data Collection: Semi-structured interviews pre-discharge, and 1 month post-discharge&lt;br&gt;Data Analysis: Followed approach of Liamputtong &amp; Ezzy (2005), using open, axial, and selective coding. (Liamputtong &amp; Ezzy, 2005)</td>
<td>Patients had feelings of excitement and relief while preparing for discharge.</td>
<td>N/A</td>
</tr>
<tr>
<td>Mirr, 1991, USA</td>
<td>Exploratory, descriptive qualitative approach</td>
<td>To determine factors affecting decisions made by families of patients with severe head injury during the first two stages of recovery</td>
<td>19 family members of 11 patients with traumatic brain injury&lt;br&gt;Family members: Sex: 11 female; 8 male Relations: 6 mothers; 7 fathers; 2 daughters; 2 wives; 1 husband; 1</td>
<td>Data Collection: Interview guide for family members were submitted to a content expert to ensure content validity&lt;br&gt;Interviews were</td>
<td>N/A</td>
<td>Emotions fluctuated immediately after injury and throughout the hospital stay. Family members rushed to the patient’s bedside after receiving news of the injury. Many wanted to be present when the patient regained consciousness.</td>
</tr>
<tr>
<td>Study</td>
<td>Approach</td>
<td>Methodology</td>
<td>Participants</td>
<td>Data Collection</td>
<td>Data Analysis</td>
<td>Findings</td>
</tr>
<tr>
<td>-------</td>
<td>----------</td>
<td>-------------</td>
<td>--------------</td>
<td>----------------</td>
<td>---------------</td>
<td>----------</td>
</tr>
<tr>
<td>Bond, 2003, USA</td>
<td>Exploratory, qualitative, approach</td>
<td>To explore the needs of families of patients' with severe brain injury through individual interviews during the course of the patients' stay in the ICU</td>
<td>7 family members of patients with traumatic brain injury: 2 mothers, 1 daughter, 1 father, 1 grandmother, 1 sister, and 1 uncle</td>
<td>Interviews conducted all of the interviews for consistency. Interviews were conducted in a nearby waiting room or over the phone.</td>
<td>Content analysis</td>
<td>Families reported a need to know about the patient’s status, stating they were disappointed when they were not being able to speak to their loved one’s physician for a few days after the patient was admitted. Families wanted truthful and consistent information, as inconsistencies added to stress. When possible, families wanted to be physically involved in the patient’s care, including bathing. Some reported wanting fewer restrictions on the amount of time they could spend in their loved one's room. Many family members reported using their faith to cope with the event.</td>
</tr>
<tr>
<td>Gebhardt, 2011, USA</td>
<td>Qualitative. No specific design is stated</td>
<td>1) To explore the caregiver's hopes for recovery of his 21 family caregivers associated with 21 patients with ABI</td>
<td>Interviews with family caregivers</td>
<td>N/A</td>
<td>Family caregivers expressed hope for their loved one’s future, including regaining pre-injury abilities.</td>
<td></td>
</tr>
</tbody>
</table>
or her family member who has experienced an ABI, and 2) to identify what caregivers and nurses do to maintain hope during the rehabilitation period.

[21 nurses were included in this sample, but nurses’ characteristics will not be recorded in this paper.]

Family caregivers were the anticipated primary caregivers after discharge.

Family caregivers: Relation: 19 parents, 1 relative, and 1 stepmother Sex: 20 female, 1 male Mean age: 45 years

occurred within 2 weeks of the patient’s admission to inpatient rehabilitation and were conducted in a private, quiet location that was convenient for the family caregiver.

Data Analysis: Authors read all interviews and coded the transcripts independently for themes associated with hope.

Keenan, 2010, Canada Qualitative approach To identify the needs expressed by family members as patients with severe traumatic brain injury progress through their recovery.

25 family members associated with 15 injured patients with traumatic brain injury

Family members: Relation: 40% mothers Sex: 84% female Mean age: 44 years

Patients: Cause of Injuries: 2 falls, 1 construction accident, 12 motor vehicle accidents Sex: 14 male, 1 female Mean age: 30.7 years

Data Collection: 44 interviews were conducted during ICU (time 1) and discharge from acute care to home or rehabilitation (time 2).

Time 1 interviews occurred within 4 days of the patient being transferred out of ICU. Time 2 interviews occurred within one week of discharge.

Data Analysis: Thematic analysis (Streubert Speziale & Rinaldi Carpenter, 2007)

N/A

Family caregivers perceived a positive association between family presence and patient recovery.

Family caregivers observed the patient’s recovery daily, and felt that they knew the patient better than staff as they were able to identify behaviors that were present pre-injury as they emerged. This fostered hope for family caregivers.

Family caregivers reported relying on their faith and spirituality to cope. They often called on others with similar spiritual beliefs for help in maintaining hope.

Family members reported many emotions surrounding getting the news of the event and wanted to know specific event details.

Family members wanted to be physically present with the patient and wanted to be involved in the patient’s care, including “hands-on activities.”

Family interpersonal relationships and support from the community and healthcare professionals influenced their experiences.

Much of the focus was on the patient immediately after injury. After the patient was discharged from ICU, families began to shift focus to managing the needs of the family and returning to self-care and work, family, and community obligations.

Families had an intense need for information, which was expected to be provided by healthcare providers. Families expected healthcare providers to be knowledgeable and
<table>
<thead>
<tr>
<th>Lutz, 2011, USA</th>
<th>Grounded theory</th>
<th>To explore the needs of stroke patients and their family caregivers as they transition through the stroke care continuum from acute care to inpatient rehabilitation to home.</th>
<th>19 patient/family units, consisting of 38 participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Patients: 19 stroke patients  Sex: 11 male, 8 female  Mean age: 64 years</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family Caregivers: 19 family caregivers  Relation: 14 spouses, 1 mother, and 4 children  Mean age: 58 years</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Data Collection:  Patients and family members were interviewed twice while the patient was undergoing inpatient rehabilitation or as close to discharge as possible.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Data Analysis:  Dimensional and constructivist analysis (Strauss &amp; Corbin, 1998)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patients who were cognizant recall feeling very emotional.  After being stabilized, patients looked toward the next step in the recovery process.  Patients had to decide if they would go to inpatient rehabilitation, a nursing home, or sub-acute rehabilitation. Most did not view nursing home placement as suitable option.  Patients who lived alone pre-injury had to identify family members or friends who could help them post-discharge.  Patients assumed they would not be discharged from inpatient rehabilitation until they reached their pre-injury functioning levels. This was not the case.  Patient’s expectations for recovery were incongruent with those of healthcare providers.  Discharge was highly anticipated by patients.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| | Family members reported shock and disbelief upon receiving the news.  After the patient was stabilized, family members looked toward the next step in the recovery process.  Family members assisted patients in making decisions on their next phase in recovery, including going to inpatient rehabilitation, a nursing home, or sub-acute rehabilitation.  Families perceived patients would not be discharged from inpatient rehabilitation until they reached their pre-injury functioning levels. This was not the case.  Discharge occurred prior to patients returning to their pre-injury functioning, so upon realization of this, family caregivers realized they needed to quickly find ways to accommodate the patient at home.  Family caregivers who were able attended the patient’s therapy and rehabilitation sessions to receive training on how to care for the
<p>| Garrett, 2005, United Kingdom | Modified grounded theory approach | To discover the perceived information needs of patients and family caregivers at 2-, 20- and 90-days post-stroke, including preferences about when, by whom, and in what format information should be delivered. | 16 patients with stroke and their family caregivers | Data Collection: A researcher who was not a member of the hospital stroke team conducted the interviews to reduce bias. Interviews were conducted at 2-, 20- and 90-days post-stroke. Data Analysis: Constant comparative analysis | At 2-days post-stroke, patients wanted information to help them understand their diagnosis and wanted results of tests, including scans and x-rays. This information was requested verbally and in written form. Patients also wanted pain control information from their nurse. At 20-days post-stroke, patients wanted much of the same information that was given at 2-days post-stroke, realizing they were likely “out of it” when the information was delivered. Patients also wanted to discuss long-term problems and wanted advice on financial matters from social services staff. At 90-days post-stroke, patients who were still in rehabilitation wanted information about long-term recovery and recovery predictions from their general practitioner. Patients also wanted information on caregiver support and benefits from social services staff. Finally patients wanted to hear first-hand experiences from other stroke survivors. | A 2-days post-stroke, family caregivers wanted information about the patient’s prognosis, diagnosis, and prescribed medication. This information was requested verbally and in writing. At 20-days post-stroke, family caregivers wanted information about results of tests and possible interventions from medical staff. This information could include drawings, pictures, and scans. Family caregivers also wanted information about the future and social support from any one with expertise. At 90-days post-stroke, family caregivers requested information about long-term consequences of stroke (e.g., recovery of speech, sexual needs) and the impact consequences would have on discharge. This information was requested from someone who was knowledgeable with no preferences for the delivery method. |
| Silva-Smith, 2007, USA | Grounded theory | To generate a grounded theory to describe the experience of preparing for and beginning a new caregiving role following a family member's stroke. | 12 family caregivers of stroke survivors | Data Collection: Two interviews: pre-discharge and post-discharge. Data Analysis: Constant comparative analysis | N/A | Family caregivers reported the patient’s stroke resulted in changes to the family routine, role reversal, and the addition of new responsibilities. Plans for the future, such as vacation, were cancelled or postponed. Activities such as volunteering, attending church activities, and socializing with friends were given up. Financial security became an issue, especially if the family caregiver or stroke survivor was laid off after the patient’s stroke. |</p>
<table>
<thead>
<tr>
<th>Author</th>
<th>Year, Location</th>
<th>Study Type</th>
<th>Research Questions</th>
<th>Methodology</th>
<th>Findings/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fraser, 1999, USA</td>
<td>Phenomenological, longitudinal case study</td>
<td>To describe the experience of transition for a daughter caregiver of a stroke survivor</td>
<td>1 daughter caregiver of a stroke survivor</td>
<td>Data Collection: Began after the mother was hospitalized and continued every two weeks as the participant was available until the participant felt her experience has become more orderly and predictable (interviews ended 8 months after mother's stroke). Data Analysis: Followed steps outlined by Colaizzi using a time-ordered matrix to identify themes over time (Colaizzi, 1978)</td>
<td>Family caregivers avoided thinking too far into the future to help cope with the situation. Immediately after injury, the family caregiver felt a strong desire to become the family caregiver for her mother, which later changed to feeling a sense of obligation to be the caregiver. The family caregiver mourned the pre-death loss of her mother, as she began to feel disconnected from her mother after she had personality changes. The family caregiver attempted to take things one day at a time by not looking too far into the future. The family caregiver initially hoped her mother would return to her pre-injury function. Hope diminished over time for the family caregiver as her did not meet her recovery expectations.</td>
</tr>
<tr>
<td>Brereton, 2002, United Kingdom</td>
<td>Longitudinal, grounded theory study</td>
<td>To explore the experience of new family caregivers of survivors of stroke</td>
<td>14 family caregivers of patients with stroke</td>
<td>Data Collection: In-depth, semi-structured interviews every 2-3 months over 18 months from the following locations: 1) general acute medical admission ward; and 2) specialist stroke unit Data Analysis: Grounded theory following Glaser &amp; Strauss, 1967 and Charmaz, 2000. (Charmaz, 2000; Glaser &amp; Strauss,</td>
<td>Many family caregivers sought knowledge about stroke and its consequences from healthcare providers. Family caregivers with healthcare experience (e.g., nurses) also sought this information, but reported difficulty in obtaining it due to healthcare providers’ assumptions about their levels of knowledge about stroke. Family caregivers used subtle and explicit techniques to obtain information, including asking a direct question or eavesdropping on patient-staff interactions. Family caregivers turned to their informal healthcare provider network</td>
</tr>
</tbody>
</table>
family members’ stroke.

Family caregivers had to juggle usual roles, take on new roles, and attend to multiple outside responsibilities, in addition to visiting the patient in the hospital.

Family members wanted the best care for their loved one, but often found that staff were too busy, which led them to monitor patient’s care. Family caregivers wanted to gain knowledge and skills to be a competent caregiver, but often felt that they were infringing of staff territory and received resistance from staff when attempting to learn.

Limited time was allotted for family caregivers to learn knowledge and skills to care for the patient post-discharge, leaving caregivers feeling stressed and lacking confidence.
Table 5. Overview of Themes of Patient and Family Experience based on Synthesized Literature

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Experience Themes and Sub-themes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceptions of Rehabilitation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Expectations for recovery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Impact of the rehabilitation environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Perceptions of rehabilitation activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Perceived support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Perceptions about discharge</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived Need for Information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Immediately after injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• During acute care/rehabilitation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Before discharge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Experience Themes and Sub-Themes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjustment after Loved One’s Injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Emotional reactions</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Uncertainty</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Difficulty with transitions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involvement in Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Physical presence</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Hands-on actions</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Other ways of involvement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dealing with the Event</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Perceived support from others in community</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Perceived support from staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Taking it one day at a time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Spirituality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Accepting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>------------------------</td>
<td>---------------------------</td>
<td>--------------------------</td>
<td>-------------------------------</td>
<td>----------------</td>
<td>-------------------</td>
<td>--------------------------</td>
<td>--------------------------</td>
<td>----------------------------</td>
<td>-----------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td><strong>Family Experience Themes and Sub-themes (continued)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceptions of the Patient’s Rehabilitation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Expectations for patient’s recovery</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Observing the patient’s recovery</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Knowing the patient better</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Monitoring the patient’s care</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Holding on to hope</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Managing needs of the family</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceptions of Relationships</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Family-family relationships</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Family-friend relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Family-staff relationships</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Family-other relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Preparing for Upcoming Caregiver Role</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Attempting to gain knowledge and skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Gaining confidence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Crisis of discharge</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td><strong>Perceived Need for Information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Lack of understanding of information</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Wanting certain types of information</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Problems accessing staff and information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Wanting no assumptions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Paper #2

“I’m trying to be the safety net”:

Family protection of patients with TBI during the hospital stay

Authors:

Tolu Oyesanya, PhD, RN
University of Wisconsin-Madison
School of Nursing

Barbara Bowers, PhD, RN, FAAN
Professor & Associate Dean of Research
University of Wisconsin-Madison
School of Nursing
Abstract

Purpose: Family caregivers of patients with moderate-to-severe TBI regularly support the patient during the hospital stay and are involved in their care. Research has shown that one of family caregivers’ perceived roles during this time is to protect the patient; however, research has described what caregivers are attempting to protect the patient from or the strategies they use to do this. The purpose of this paper is to describe family caregivers’ experience of protecting patients with moderate-to-severe TBI during the hospital stay.

Method: Grounded theory was used to conduct twenty-four interviews with 16 family caregivers associated with 13 patients with TBI.

Results: Findings showed caregivers worked to protect the patient’s physical and emotional safety. Strategies to protect the patient’s physical safety include: 1) influencing the selection of staff; 2) attempting to prevent overstimulation; 3) breaking the patient’s bad habits; and 4) anticipating how to orchestrate the home environment. Strategies to protect the patient’s emotional safety include: 1) connecting on an emotional level and 2) managing visitors.

Conclusion: The findings have practice implications for educating interdisciplinary healthcare providers about the experience of caregivers during the hospital stay to improve support provided to family caregivers during this time.
Introduction

Each year, more than 2.5 million people sustain a traumatic brain injury (TBI) in the United States (Centers for Disease Control and Prevention, 2014). Moderate-to-severe TBI causes both immediate and chronic impairments in cognitive and physical functioning and verbal communication (Brain Injury Association of America, 2015b). These impairments often prohibit the injured person from having decision making capacity (Kahler & Davis, 2001), setting goals for him or herself (Levack, Siegert, Dean, & McPherson, 2009), and from providing care for him or herself during their hospital stay (Brain Injury Association of America, 2015b). To assist the injured patient, family members often play a role in supporting the patient during the hospital stay (Rotondi AJ, Sinkule J, Balzer K, Harris J, & Moldovan R, 2007).

Support and Involvement from Family Members during Hospital Stay

Family members are generally the main support system for the injured patient during the hospital stay (Verhaeghe, Defloor, & Grypdonck, 2005), but families use different support strategies. For instance, many families support the patient by being physically present at the hospital as much as possible, and even hope to be within view of the patient when they regain consciousness (Keenan & Joseph, 2010; Mirr, 1991). Some families are supportive of the patient by assisting them with goal setting and attempting to make decisions on the patient’s behalf (Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005; Pegg Jr et al., 2005). Families also support the patient by taking on some of the patient’s pre-injury responsibilities, including caring for the patient’s children (Silva-Smith, 2007). Other family members support the patient emotionally and financially (Rotondi AJ et al., 2007). The above listed support and involvement strategies suggests that family members take on the role of an informal caregiver during the patients hospital stay (Family Caregiver Alliance, 2009; Sapountzi-Kreopia et al., 2008).

Family Caregivers’ Perception of Their Role
In addition to supporting the patient, research has also shown that some family caregivers’ perceive their role during the patient’s hospital stay to be multifaceted, including being vigilant of the patient. Family caregivers may be vigilant and monitor the patient’s care patient to ensure the patient is kept safe (Brain Injury Association of America, 2015a; Keenan & Joseph, 2010). Family vigilance, defined as “close protective involvement with a hospitalized relative,” (Carr & Fogarty, 1999, p. 1), has been investigated broadly in family caregivers of adult patients hospitalized for various health conditions. However, limited research of this nature exists in family caregivers of patients with moderate-to-severe TBI.

In studies of caregivers of patients hospitalized for various conditions, family caregivers wanted to be physically present at the hospital to protect the patient (Carr, 2014; Carr & Fogarty, 1999). Information on what family caregivers were attempting to protect the patient from was not specified. Research on caregivers of patients with neurological conditions showed family caregivers reported being vigilant of the patient’s care to ensure the patient received the best care possible and to maintain a connection with them (Lam & Beaulieu, 2004). Studies conducted with family caregivers of patients with TBI found that family caregivers kept “bedside vigil” by being physically present at the patients beside to watch over the patient (Duff, 2002); other family caregivers of patients with TBI monitored the patient’s care due to perceptions that staff were too busy to provide care to the patient (Brereton & Nolan, 2002; Keenan & Joseph, 2010).

Even though family members are involved in the patient’s hospital care (Verhaeghe et al., 2005), there is limited literature detailing their experience during this time. In addition, while some studies show that family caregivers perceive their role is to protect the patient during the hospital stay, no research is available that describes: 1) what family caregivers of patients with moderate-to-severe TBI are attempting to protect patients from or 2) strategies family caregivers use to protect the patient.
Thus, the purpose of this paper was to describe family caregivers’ experience of protecting patients with moderate-to-severe TBI during the hospital stay.

**Methods**

This study was conducted using grounded theory. The findings reported in this manuscript are part of a larger study focusing on the experience of the hospital stay for family caregivers of patients with moderate-to-severe TBI. Protection of patients with TBI during the hospital stay was a large component of the families’ experience.

After receiving approval from the participating institutional review boards, family caregivers were recruited from three facilities in one, Midwestern state. Purposive sampling was used to target family caregivers with specific criteria. Family caregivers were eligible to participate if the associated patient: 1) was age 18 years or older; 2) had been diagnosed with moderate-to-severe TBI; 3) had a Glasgow Coma Score between 3 and 12 upon admission to inpatient rehabilitation; and 4) had no history of pre-injury medical or neurological disease affecting the brain, language, or learning disability. Specific caregiver eligibility criteria included: 1) age 18 years or older; 2) a fluent speaker of English, by self-report; and 3) self-identified anticipated primary family caregiver after discharge. Other family members were allowed to participate if they received permission from the anticipated primary caregiver.

The nurse manager at each facility approached caregivers to inform them about the study and to determine interest in participation. Next, the first author went to the rehabilitation facility to schedule interview times with interested and eligible participants and to explain consent forms, which were completed before the start of the first interview.

**Study Participants**
The sample included 16 family caregivers associated with 13 patients with TBI. Caregivers were all white, mostly women (n=14), and mostly primary caregivers (n=14). The average age of caregivers was 55.56 years (range=22-76). Patient-family relationships included: parents (n=5); spouses (n=7); and other (n=4) (i.e., grandparent, child, sibling, and cousin). Patients were all white and were mostly male (n=11). Causes of injury included falls (n=8), motor vehicle accidents (n=3), and other (n=2; e.g., sports related injury). The average age of patients was 47 years (range=19-79). Patients’ average length of hospital stay at the time of the first interview with the family caregiver was 26.30 days (range=8-40). Finally, patients’ average length of stay at the inpatient rehabilitation facility was 17.09 days (range=5-33).

As the level of cognitive functioning of each patient with TBI may influence the strategies family caregivers use to protect the patient, we used the Level of Cognitive Functioning Scale (Ranchos Los Amigos Scale) to measure each patient’s level of awareness, cognition, behavior, and interaction with the environment (Gouvier et al., 1987). Rehabilitation teams providing care to patients with moderate-to-severe TBI often use this scale to guide the patient’s plan of care (Gouvier et al., 1987). Level of Cognitive Functioning Scale scores range from Level I (1) to Level X (10), which characterizes the level of recovery for the patient with moderate-to-severe TBI, with Level I being comatose (no observed neurological response) and Level X being modified independent (Gouvier et al., 1987). For patient’s whose caregivers were enrolled in the study, patients’ average level of cognitive functioning was Level 7, ranging from Level V (5) to Level IX (9).

Data Collection

Data were collected between February 2015 and July 2016. Twenty-four interviews were conducted via one to two interviews per participant; second interviews were used to ask more questions, adding depth to the conceptual model. Interviews averaged 68 minutes.
The first author collected the data, interviewing each participant one week after the patient was admitted to inpatient rehabilitation. The second interview occurred 48-72 hours before the patient was discharged, usually 4-7 days after the first interview. Caregivers were interviewed in private location of their choosing, and interviews were recorded and transcribed.

The first interview question was “Can you tell me about what things have been like for you while your family member has been in the hospital?” This question was intentionally non-directive so that caregivers could lead us in a direction that was important to them. Other topics of discussion initiated by caregivers during some of the first interviews included involvement in the patient’s care, concerns about the care the patient had been receiving, strategies used when care concerns arose, and protection of patients’ safety during the hospital stay. In addition to the use of purposive sampling, theoretical sampling was used, achieved through revision of interview questions to explore directions indicated by participants (Strauss & Corbin, 1998). During subsequent interviews, topics discussed with family caregivers included whether the patient has had visitors, their experience of visitors, and visitors’ influence on patients.

Data Analysis

Data were collected and analyzed using grounded theory, useful for understanding social processes and obtaining an in-depth view of participants’ experiences (B. Bowers, 1990; Strauss & Corbin, 1998). The basic underpinning of grounded theory is symbolic interactionism, which focuses on social processes (Blumer, 1969). Following analysis procedures outlined by Strauss and Corbin (1998), data analysis began immediately after the first interview (Strauss & Corbin, 1998). The research team met regularly to analyze data using the following structure: 1) weekly meetings with first and last authors; 2) monthly meetings with the authors and nursing doctoral students well-versed in grounded theory.
Although interview questions were purposely open and initially focused broadly on the experience of the hospital stay, caregivers immediately began discussing protecting the patient during the hospital stay without prompting. As grounded theory directs the research to follow participants’ perspectives, we revised interview questions based on the participants’ directions to gain in-depth information about their experience. An example of how the researcher followed the direction of participants is illustrated in the first interview of this study. A caregiver shared, “Keeping her safe is most important... I’m trying to be the safety net... You have to protect them from certain things” [Caregiver #1]. The quote from this caregiver indicated her concern about protecting the patient’s safety. The first author asked a subsequent interview question (below) to follow the direction indicated by the caregiver and gain more in-depth knowledge about safety concerns:

“From what you shared in the first interview, I see one of the things you did as protecting your daughter—making sure she’s safe here. Talk to me about all the ways you do that. Could you tell me some times where you did that?” [First author interview question]

This question allowed the caregiver to elaborate on her concerns about the patient’s safety encouraging her to describe specific events or instances where her actions were directed toward protecting the patient’s safety. The specific event examples shared by the caregiver provided data to construct categories and identify strategies used to protect the patient during the hospital stay.

Analysis of the first four interviews showed the dimension of protecting the patient’s safety, which was a sub-dimension of family work. The following 20 interviews provided depth to our understanding of caregivers’ experiences particularly as it related to protecting the patient.

All coding procedures began early and were done continuously (Strauss, 1987). Analysis began with open coding, consisting of line-by-line analysis of each transcript (B. Bowers, 1990; Charmaz,
2000), used to examine, compare, conceptualize, and categorize the data (Corbin & Strauss, 2008). For example, a caregiver said,

“I wanted to be here with her to keep her safe because I was just so afraid that some fluke thing is gonna happen and she’s gonna bang her head on something.” [Caregiver #1]

This was coded as: 1) physical presence, 2) keeping her safe, and 3) fear about re-injury. Specific happenings were labeled and were grouped based on similarities, also known as categories (Strauss, 1987). Authors determined properties, which are characteristics that pertain to a specific category (Strauss & Corbin, 1998). This led to identification of salient dimensions of caregivers’ experience (B. Bowers, 1990). In constant comparative analysis, dimensions identified during coding were used to compare the perspectives of caregivers, where the sample was compared between units (events and participants) and as a whole (Corbin & Strauss, 2008). Similarities, differences, and interrelations in dimensions were determined, as well as new concepts that may not have appeared in the previous data (Strauss & Corbin, 1998). For instance, authors read through each family caregiver’s transcript that had been collected to date to determine similarities, differences, and interrelations, which led to the conceptual distinction between protecting the patient’s physical safety and emotional safety.

Next, axial coding occurred, where authors pieced the data back together in new ways and made connections between categories (Strauss, 1987). Conditions were identified, providing context to caregivers’ experiences (Corbin & Strauss, 2008). For example, a condition influencing caregiver’s protection strategies was their perception of threats to the patient’s safety and whether those threats related to the patient’s emotional or physical safety. Finally, authors used selective coding to identify the core category, integrate all categories, and develop the conceptual model (Strauss, 1987). The authors continued data collection and analysis until saturation on selected categories was reached,
specifically that “the researcher cannot discover new dimensions in the data being collected” (B. Bowers, 1990, p. 48).

**Rigor**

The authors used multiple strategies to increase rigor, based on evaluation criteria outlined by Charmaz (2014). To ensure credibility, the authors chose categories that covered a wide range of participant observations and provided sufficient evidence for findings by using quotes from multiple participants (Charmaz, 2014). Second, the authors achieved originality by choosing categories that offered new insights and refined current ideas and clinical practices (Charmaz, 2014). Third, we achieved resonance by developing a conceptual model that is representative of our participants’ experience through member checking (Charmaz, 2014). The first author used member checking during data collection and analysis to determine whether participants’ experiences were accurately described by showing pieces of the conceptual model to them and asking them to if their experience was included, missing, or could be better described. Participant feedback was used to both elaborate on and confirm the conceptual model (Charmaz, 2014). Finally, we achieved usefulness by ensuring that our analysis offered “interpretations that people can use in their everyday worlds” (Charmaz, 2014, p. 338).

**Results**

The core category that emerged from the analysis was *family work*, detailing work that family caregivers engaged in during the hospital stay. The purpose of family work was to protect the patient’s physical and emotional safety. Caregivers worked to protect the patient’s physical safety to prevent re-injury, fatigue, or over-stimulation. Family caregivers worked to protect the patient’s emotional safety to stabilize the patient’s emotional state. Family caregivers spent a significant amount of time at the
hospital to protect the patient. Some caregivers perceived their presence would help mitigate any impending threats to the patient’s safety (see Figure 1).

**Figure 1. Conceptual Model: Family Work**

**Protecting the patient’s physical safety**

Family caregivers worked to protect the patient’s physical safety by: 1) influencing the selection of staff; 2) attempting to prevent overstimulation; 3) breaking the patient’s bad habits; and 4) anticipating how to orchestrate the home environment.

*Influencing the selection of staff.* Throughout the hospital stay, many caregivers wanted to be physically close to the patient, desiring to be present when the patient woke up. Initially, caregivers did not know they had to be physically present to protect the patient; their physical presence was only to support the patient. However, while being physically present, some caregivers began casually observing the patient’s care, including observing how the patient responded to staff. By doing so, caregivers began to have concerns about the patient’s care, specifically noticing threats to the patient’s physical safety, including that some staff did things the right way while others did not.
“I was in the room when I saw her holding her walking belt incorrectly. I thought, ‘Hmm, just this one finger? You’re gonna hold her like that? Cause that, I know for a fact that’s not how you’re taught to do it.’ It put a little fear in me.” [Caregiver #2]

Caregivers concerns about care caused them to begin monitoring the patient’s care. When monitoring the care, caregivers observed evidence of inadequate care. This included perceptions that a staff member seemed inattentive, used an ineffective technique, or appeared to be inexperienced. Caregivers deemed this as a threat to the patient’s physical safety, with the anticipated consequence of re-injury or even death.

“She couldn’t breathe anymore. I didn’t feel like the nurse was experienced enough to be handling such a critical case. I’m like, I need someone else in here. You know it’s a weird situation to be in because I’m not a doctor, I have no medical training whatsoever. I’m a mom whose daughter is possibly going to die right in front of me because I’m too afraid to speak up? I can’t have that happen.” [Caregiver #5]

When some caregivers determined that certain, assigned staff provided inadequate care, they attempted to influence the selection of staff by finding a new, replacement staff to care for the patient. They did this by describing their concerns about the patient’s care to staff members’ supervisors, or by having another family member or friend speak on their behalf. Speaking up typically led to a staff replacement.

“I talked the RN that was on that night about the nursing assistant. I asked her if we were going to be assigned the same person again. And she said, ‘yup!’ I told her what happened and I said, ‘do I have the right to ask for somebody else?’ And she said “absolutely!” ...So I don’t know if they pulled somebody from another unit or what they did but we got someone new.” [Caregiver #1]
The perception that the patient’s physical safety was in danger due to staff’s performance led caregivers to increase the time they spent at the hospital.

**Attempting to prevent overstimulation.** Another strategy caregivers used to protect the patient’s physical safety was ensuring the patient had the opportunity to rest and sleep as much. A major source of overstimulation was external (e.g., visitors), as visitors were perceived to keep the patient from resting and often overstimulate them. Thus, caregivers attempted to manage visitors. Caregivers communicated with potential visitors via phone calls, texting, or social media, notifying them about whether and when to come, how long to stay, and how many visitors could come at once. “Okay, two can come in, and just have it be a short amount at a time to not overwhelm him. He definitely needs his downtime” [Caregiver #5].

After visitors arrived, some caregivers reminded them to limit their stay. However, visitors often stayed longer, as they thought the patient looked ‘just fine.’ Some caregivers did not want to seem impolite, so they did not ask visitors who stayed longer than expected to leave; others took no issue with asking visitors to leave when they felt it was time.

“I have the information on Facebook. And when I say that you can come visit him on the weekends, I say please limit your visits to 15 to 20 minutes, 30 minutes top, because he needs to rest. Nobody leaves before an hour, because he looks fine. And I need to say, okay, really, I need for you to allow him to rest.” [Caregiver #8]

**Breaking the patient’s bad habits.** Some caregivers perceived the patient’s bad habits were a threat to their physical safety, seeing these habits as the cause of the TBI. For example, when drinking alcohol or hanging with the wrong crowd was identified as the cause of the patient’s current injuries, caregivers took the hospitalization as an opportunity to make significant life changes. To prevent the
bad habit from causing future injury, caregivers of older adult patients often spoke to patients about their concerns. During inpatient rehabilitation, when the patient was more cognizant, caregivers talked to the patient about past or ongoing problems, encouraged the patient to “start fresh.” “I told him don’t drink as often, you're going to hurt yourself. You're hurting our family” [Caregiver #7].

In contrast, caregivers of younger adult patients felt they had the parental or legal authority to block bad influences to protect the patient. This included blocking visitors perceived to have a negative influence on the patient, particularly those with negative involvement in the patient’s injury, with the hopes of decreasing the patient’s risk for future injury.

“I know the things they do, like alcohol or whatever, is really bad for a brain injury. It could push him back to old thinking and old ways, in a negative way. It's been a big concern. If he was involved with any friends that a negative influence in the past, it was kind of hard to initially let them come.” [Caregiver #5]

**Anticipating how to orchestrate the home environment.** Caregivers also planned how they would orchestrate the patient’s home environment to prevent future harm. Some caregivers planned to use strategies they learned during the patient’s hospital stay to protect the patient once they were discharged, such as observing the patient’s interactions with other people. Caregivers also discussed anticipating what might go wrong once the patient was discharged, and what they would do preemptively to prevent the patient from being re-injured. For instance, a caregiver stated that once the patient returned home, she would ask him “to stay within hollering distance” in case anything happened [Caregiver #6].” Caregivers also stated that they would provide directions to the home visitors to ensure the visitor would not allow the patient to be re-injured.
“I'm going to have some bullet points for visitors to help him. Like how to like softly correct him...And, you know, how to assist him down the stairs or how to help him if he needs to get off the toilet or whatever.” [Caregiver #8]

Other caregivers stated they would monitor the patient’s interactions with others and make sure to redirect the patient if someone gave the patient ill advice.

“And be careful that your loved ones don't get poor advice from well-wishers. There are people that love to gossip and push their opinions around... I'll probably be monitoring him pretty close to keep him safe. I know I can't be there 24/7, nobody can, but hopefully we'll discuss things if somebody does try to advise him badly.” [Caregiver #6]

Still other caregivers stated they would completely take over at home to protect the patient, such as hiding the patient’s car keys to prevent premature return to driving.

“I was afraid...the car would be an example that he's not supposed to drive. And I think in three or four days after being home from the hospital, he will say, ‘Guess what? I can drive. I'm much better now.’ Well, I've already hidden the keys. And we have a riding lawn mower; we're going to hide that key too.” [Caregiver #10]

**Protecting the patient’s emotional safety**

When protecting the patient’s emotional safety, caregivers attempted to control the patient’s hospital environment to stabilize the patient’s emotional state by: 1) connecting on an emotional level and 2) managing visitors.

**Connecting on an emotional level.** Caregivers connected with the patient on an emotional level by verbally and physically reassuring the patient and by managing emotions in front of the patient. When reassuring the patient verbally, the caregiver attempted to talk to patient through the ongoing
situation by using personal information about the patient to take them to a place that was known to be calm and peaceful, using information known to reassure them in the past. One mother took her daughter to a “happy place,” which was a strategy used in the past when the daughter became upset. Other caregivers told the patient select details about what happened to them when they were asked or were scared, and by telling the patient they were loved and that everything was going to be okay.

“Well my daughter wanted to know what had happened to her. But we weren’t ready to tell her the full story. She said, ‘What happened?’ I said, ‘Well, you fell. You hit your head. And you broke your leg. But you’re gonna be fine!’” [Caregiver #1]

Throughout the hospital stay, when reassuring the patient physically, caregivers reported holding the patient’s hand, bringing the patient water, surrounding them with familiar, comforting objects, being physically present, and engaging in activities with the patient. “I tried to bring in pictures and activities for her to do. We read to her. Just holding her hand. Just being there. Sometimes just sitting there in the same room, doing nothing, while she naps” [Caregiver #11]. Some caregivers attempted to lighten up the environment by being silly or purchasing things that they felt would improve the patient’s emotional state.

“We just did silly things to encourage her to get better. She loves all this marvel stuff. The Wonder Woman, the Bat Woman. I went out and I found pajamas that would fit her that was Wonder Woman and Bat Woman. I put them out and said, now you’re a Wonder Woman. You’re going to wear this and you’re gonna make it through.”[Caregiver #4]

Caregivers also worked to protect the patient’s emotional safety by managing their emotions in front of the patient. Caregivers tried to control their emotions in front of the patient at all times for fear that their display of negative emotions would negatively influence the patient’s emotional state. “You got to pick your moments to cry” [Caregiver #4]. Many caregivers found other places to release their
emotions. “You can cry all you want out in the hallway, as long as she can’t hear you. Go outside and cry or do something like that. But just trying to be strong for her when you’re in here” [Caregiver #9].

**Managing visitors.** Caregivers managed visitors to protect the patient’s emotional safety, to ensure the patient was in a positive environment and to eliminate any bad influences on the patient. Caregivers used multiple strategies to manage visitors, though some strategies were successful and others were not. Throughout the hospital stay, caregivers managed the number, frequency, duration, and timing of visits. Many families reported multiple visitors were present at one time throughout the hospital stay.

“There were a lot of people in the waiting room. I think it was only day 2 for my daughter. My brothers and my sisters were all here and, my daughter’s brother and sister and her dad and her boyfriend and a couple of her friends from school and some of her lifetime friends. They were all in the waiting room.” [Caregiver #2]

Some caregivers reported using social media, such as Facebook, to notify family members and friends whether and when to come and how long to stay.

“And I just try to do my best through social media. I had her friends join my friends list on Facebook, and then I just started putting updates, like, ‘Please don’t come to the hospital right now, I’ll post everything that I know so you know what’s going on with her but now it’s just not the time to have tons of people going through.’” [Caregiver #3]

Caregivers who did and did not use Facebook attempted to manage the flow of visitors through phone calls and texting. It was common for caregivers to enlist another person (e.g., other family members or friends) to assist them if they became overwhelmed. Regardless of the method used, some caregivers attempted to assign visitors specific times to visit to prevent too many people from showing up at once. Yet, with all the work put into managing visitors, people often showed up unannounced. “A lot of
times they would show up, and, you know, I didn't get the opportunity to really say anything. And, you know, I just had to trust that it was all good” [Caregiver #5].

Although caregivers managed groups of visitors, family members also attempted to manage individual visitors. Caregivers did not let allow any and all visitors into the patient’s hospital room, especially while the patient was receiving critical care. To protect the patient’s integrity, family caregivers first assessed the motivation of the visitors. In particular, caregivers assessed the motivation of people they had never met. They determined the nature of the visitor’s relationship to the patient (e.g., friend, acquaintance, or stranger) and their prior involvement with the patient, particularly when they perceived blocking visits from specific visitors would prevent the patient from future danger.

“So there was only one person that I had trouble with in the beginning. My son was very upset with her before he fell and I wasn't sure if he'd come to and get real upset when he saw her. So that was hard at first, the first day I just said no family or friends and didn’t allow her to come in.” [Caregiver #5]

People who appeared to only want to see the patient in bad shape and gawk at the patient were asked to leave or never let in. “It was just frustrating because it seemed like it was a parade of people and it’s like, hey guys, this isn’t helpful for right now” [Caregiver #3]. People who the caregiver perceived to have been involved with the patient’s injury were often not allowed to visit because some caregivers wanted to reduce negative influences on the patient. “I'd have to say if he was involved with any friends that maybe were a negative influence recently or in the past, it was kind of hard to let them come in” [Caregiver #5].

*Lack of staff involvement in managing visitors.* Some caregivers reported minimal assistance from staff to manage visitors throughout the hospital stay and grew frustrated with having to ask unwanted visitors to leave. This frustration was often projected onto visitors.
“That gentleman, they pretty much just let him up. It was one of her friends, but it’s like,
‘What’s the point in letting him up here? She’s in ICU.’ So I was a little angry that they were letting other people aside from family just hanging, standing right next to the door of her room. And so I lashed out at him, and I feel bad about it, but at the time, I just, because I was angry about a lot of things. [Caregiver #3]

*Types of visitors.* Caregivers also identified visitors who might pose emotional threats to the patient. Family caregivers characterized visitors in two ways: safe and dangerous. Safe visitors were often other family members and close friends who were trusted to not cause the patient emotional harm. Dangerous visitors were people claiming to be friends of the patient who were unknown to the caregiver or people who may give the patient unpleasant information.

As the patient became more cognizant, he/she asked questions about their accident. Most caregiver wanted to wait for the right time and place to tell the patient what happened to them as they knew the traumatic story would evoke an emotional crisis for the patient. To prevent this from happening, some caregivers asked visitors not tell the patient what happened, even if the patient asked. Anyone who might tell the patient what happened was perceived as threat to the patient’s emotional state, labeled as dangerous, and blocked from seeing the patient. Some caregivers attempted to discourage specific visitors who they suspected would tell the patient what happened, and even disallowed visitors if they told the patient what happened.

“I actually got into a fight with my daughter’s boyfriend. I was trying to not tell her about what happened to her. I had been telling everybody, ‘let’s wait until she’s out of the hospital. But no, he decides to take it upon himself to tell her the whole thing and then he left. It’s like, how dare you, I was trying to avoid this issue.” [Caregiver #3]
Some caregivers only allowed visitors with a positive demeanor into the patient’s hospital room. “Nobody was allowed in her room unless they had a happy face and a happy voice! Happy thoughts. Positive energy. This is what we try to keep going in her room” [Caregiver #2]. Caregivers also reported the intent to use many of these same strategies to protect the patient’s emotional safety after discharge.

**Discussion**

These findings describe the work that family caregivers did to protect patients with moderate-to-severe TBI during the hospital stay, specifically protecting the patient’s physical and emotional safety. Strategies for protecting the patient’s physical safety included influencing the selection of staff, attempting to prevent overstimulation, breaking the patient’s bad habits, and anticipating how to orchestrate the home environment. Strategies used for protecting the patient’s emotional safety were connecting on an emotional level and managing visitors.

Multiple concepts were included in these findings, including family work and in-hospital caregiving. Limited mentions of family work occur in the literature, but when discussed, family work describes the effort of caregivers to assist patients in health care settings (Bischofberger & Spirig, 2004; Vandal-Walker & Clark, 2011). The concept of in-hospital family caregiving seen in these findings is also present in the literature (Sapountzi-Krepi et al., 2008; Stavrou, Ploumis, Zyga, & Kotrotsiou, 2014). In prior research, in-hospital family caregivers perceived their role was to help maintain the health of the patient, manage their disease, and assist with their rehabilitation and recovery (Lavdaniti et al., 2011). Family caregivers typically assisted the patient with activities of daily living or monitored portions of the patient’s care (Sapountzi-Krepi et al., 2008; Stavrou et al., 2014). Some in-hospital family caregivers discussed concerns and fears about the course of the patient’s care and health status with staff (Stavrou et al., 2014).
Many family caregivers in this study had the perception that the patient’s safety was in danger, resulting in protective caregiving mechanisms conducted by spending long hours at the hospital, which has been documented in the literature (Carr, 2014; Carr & Fogarty, 1999; Lam & Beaulieu, 2004). Like this study, research has shown that caregivers also monitored patient care to make sure the care provided by staff was appropriate, termed “vigilant observation” (Hupcey, 1999; Jamerson et al., 1996; Salmond, 2011; Vandall-Walker & Clark, 2011). However, unlike our study, the literature does not provide nuanced strategies used to protect the patient.

The protective caregiving mechanisms used by caregivers to protect the patient were perceived to be invisible to staff. Although staff involved in patients’ care were not interviewed, the reports of minimal assistance from staff implies that staff may be unaware of the work family members are doing. The “invisibility” of the work of caregivers to protect the patient has also been documented in the literature, including work of caregivers of patients with cognitive impairments (B. J. Bowers, 1987; Choi & Kang, 2016; Hasselkus, 1988; Wilson, 1989).

**Implications for Practice**

The findings that family caregivers work to protect the patient’s safety during the hospital stay emphasize the need for person- and family-centered care (Lor, Crooks, & Tluczek, 2016), which directly relates to guidelines for development of an adversarial alliance, or a therapeutic relationship, between family caregivers and staff (McLaughlin & Carey, 1993). Some attributes of both person- and family- centered care and development of an adversarial alliance relevant to these findings include: 1) inclusion of the person’s and family’s interests and needs in the plan of care; 2) effective communication between person/family and staff; 3) self-awareness; 4) empowerment of the person and family; and 5) viewing the family as a unit of care (Lor et al., 2016; McLaughlin & Carey, 1993).
Furthermore, these findings suggest the need for education of staff regarding to caregivers’ concerns and perspectives. More specifically, awareness of what the families’ concerns are, how they’re watching, and their reaction to what they’re seeing is something staff are unaware of. Cognizance that some caregivers feel they need to protect the patient’s physical safety due to perceptions of staff members’ performance suggests that staff need to do more to build trust. Caregivers’ perceptions that visitors threatened patients’ physical and emotional safety imply that staff need to increase assistance given to caregivers to manage visitors. Knowledge that caregivers perceive their protective role to begin during the hospital stay suggests that staff need to assess caregivers’ needs on a more frequent basis to ensure their needs are being met. Taken together, these changes could help to improve person- and family-centered care and increase the safety of the patient during the hospital stay.

**Implications for Theory Development**

These findings have implications for theory development and adaptation as the results of this study are closely related to current models and theory focusing on family systems. The Calgary Family Assessment Model and the Family Systems Theory discuss multiple attributes of the family structure including: the roles of family members in the family structure; family role changes and adjustment after trauma and impairment of children; family dynamics and dysfunction; and the emotional and social influences of family members on one another (Rosenblatt, 1994; Wright & Leahey, 2012). Many of the above-listed attributes could influence families’ experience during the hospital stay. Additional understanding of how family systems models and theories influence families’ experience during the hospital stay could expand on existing knowledge, which could improve the support healthcare providers can lend to this population. In addition, these findings can be used to adapt existing family systems models and theories to further describe how family systems influence families’ experience during the hospital stay.
Limitations

Despite the enhanced knowledge described in this study, limitations are present. This sample can be considered homogenous because all participants were white, most family caregivers were female, and most patients were male. Although this sample’s homogeneity may limit application to the experiences other groups, these findings still provide depth to caregivers’ experiences. The patient’s cause of injury was not considered, and the perception that patient’s injury was serendipitous or due to a poor decision could alter caregivers’ perceptions. However, our findings showed the protective actions did not differ based on the cause of injury. Finally, no data were collected on whether caregivers’ prior experience with caregiving, which may have influenced the strategies used. Nonetheless, these findings provide new knowledge on family caregivers’ experience during the hospital stay.

Future Research

Researchers may wish to compare the experience of family caregivers of patients with TBI to caregivers of patients with other conditions to determine differences protective caregiving strategies. As our study did not ask family caregivers if they had caregiving experience, additional research is needed to determine if the strategies used by caregivers with caregiving experience differ compared to those without experience. Future researchers could investigate how patient characteristics specific to severity of injury [e.g., Glasgow Coma Scale score at admission to intensive care and rehabilitation, functional independence measures (FIM), Level of Cognitive Functioning Scale] may influence family protection strategies, as it may be possible that families of patients with more severe cognitive impairments enact more protection strategies. Finally, future researchers may wish to investigate patients’ and providers’ awareness and perceptions of family caregivers’ efforts to protect the patient during the hospital stay.
Conclusion

This study describes family caregivers’ experience of protecting the patient with moderate-to-severe TBI during the hospital stay. Caregivers reported protecting the patient’s physical and emotional safety and put considerable effort into doing so. These findings support the need for staff awareness of this phenomenon to assist with making care more family-centered and meeting the needs of family caregivers.
References


Salmond, S. W. (2011). When the family member is a nurse: The role and needs of nurse family members during critical illness of a loved one. *Intensive and Critical Care Nursing, 27*(1), 10–18.


Paper #3

Managing visitors during the hospital stay:

The experience of family caregivers of patients with TBI

Authors:

Tolu Oyesanya, PhD, RN
University of Wisconsin-Madison
School of Nursing

Barbara Bowers, PhD, RN, FAAN
Professor & Associate Dean of Research
University of Wisconsin-Madison
School of Nursing
Abstract

Family caregivers of patients with moderate-to-severe traumatic brain injury (TBI) regularly visit the patient during the hospital stay and are involved in their care. As impairments caused by the TBI often preclude the patient from stating preferences for visitors, family caregivers often make decisions about visitors during hospitalization. However, limited literature investigates this process. The purpose of this paper was to describe family caregivers’ experience of visitors while the patient with moderate-to-severe TBI is hospitalized. Authors used grounded theory to conduct 24 interviews with 16 family caregivers. Findings showed family caregivers manage welcome and unwelcome visitors throughout the hospital stay to protect the patient’s physical and emotional safety and to conserve their own energy. Staff had limited involvement in management of unwelcome visitors. These findings have practice implications for educating hospital staff about assisting families to manage unwelcome visitors and policy implications for improving hospital visiting policies.
Family Involvement during the Hospital Stay

Family caregivers are often involved in the hospital care of the patient (Rotondi AJ, Sinkule J, Balzer K, Harris J, & Moldovan R, 2007). After spending long hours at the hospital, some family caregivers expressed a desire to help staff with patient care, such as assisting with the patient’s bath (Bond, Draeger, Mandleco, & Donnelly, 2003). Other family caregivers are involved in the patient’s care by sharing information with staff to help them understand the patient better (Keenan & Joseph, 2010). Still others are involved by advocating for the patient and attempting to plan for the patient’s future (Keenan & Joseph, 2010). Caregivers’ involvement in the patient’s care often occurs while visiting (Keenan & Joseph, 2010).

Hospital Visiting Policies

Research on hospital visiting policies has focused on a narrow range of issues, including frequency and duration of visits. Changes over time in thinking about the influence of visiting led to revisions in hospital visiting guidelines and policies (Farrell, Joseph, & Schwartz-Barcott, 2005; Whitton & Pittiglio, 2011). Former evidence-based practice guidelines from the U.S. Public Health Service on hospital visiting directed healthcare providers to limit visitors due to perceptions that visitors increase stimulation and infection risk for the patient (Whitton & Pittiglio, 2011). New guidelines simply state that families should be allowed to visit the patient at any time (Davidson et al., 2007).

Visiting policies are often determined at the national-, institutional-, and sometimes hospital unit-level (Halm & Titler, 1990), which leads to considerable variation. Institutions and individual hospital units often restrict visitors inconsistently based on: a) patient status, b) patient preferences, c) nursing staff preferences, and d) how busy the unit is (Halm & Titler, 1990; Hart, Hardin, Townsend,
Ramsey, & Mahrle-Henson, 2013). These inconsistencies often cause confusion and conflict between hospital staff and families (Ciufo, Hader, & Holly, 2011; Roland, Russell, Richards, & Sullivan, 2001; Slota, Shearn, Potersnak, & Haas, 2003), as nurses and families have differing perceptions of visitors during the hospital stay.

Nurses’ Perceptions of Visitors during the Hospital Stay

Research on hospital visitation has focused mainly on nurses’ perceptions of visitors and primarily addressed patients in critical care (Ciufo et al., 2011). The research seems divided between studies suggesting that visitation has either a negative or positive influence. Studies of negative influence focus on the perceived effect of visitors on nurses and patients, identifying that some nurses perceive visitors make the environment unsafe by interfering with nurse roles/procedures (Nuss et al., 2014), increasing risk of infection for patients (Hart et al., 2013), and over-stimulating the patient (Farrell et al., 2005). Studies showing a positive influence identify visitors as valuable resource, particularly when family members assist in taking a patient history (Cappellini, Bambi, Lucchini, & Milanesio, 2014; Slota et al., 2003) and provide the patient with emotional support (Marco et al., 2006). However, there is no research available about what nurses discuss with families about visitors.

Families’ Perceptions of Visitors during the Hospital Stay

The general literature on visitation shows that most family members have preferences about visitors, preferring immediate and extended family members over significant others, friends, co-workers, and church members (Halm & Titler, 1990). Research shows that family caregivers attempt to support the patient during the hospital stay through physical presence and comfort (Gonzalez, Carroll, Elliott, Fitzgerald, & Vallent, 2004). Family caregivers’ perception that their physical presence is beneficial to the patient increases their desire to be physically present with the patient on regular and frequent basis (Gonzalez et al., 2004).
Knowledge Gaps in Visitation Literature

Despite the plethora of research on hospital visitation, gaps in knowledge exist because most literature focuses on issues such as frequency and duration of visitors. First, much of the literature focuses on visits to the patient while in critical care. However, visitors are present throughout the hospital stay, regardless of the unit or phase of recovery. Second, few studies have taken quality or appropriateness of visiting into account (Halm & Titler, 1990). Third, limited research is available about visitation concerning patients with cognitive impairments, including patients with moderate-to-severe TBI. The available literature on visitation for patients with moderate-to-severe TBI provides limited direction due to inconsistencies in the negative (Turkstra, 2013) and positive (Abbasi, Mohammadi, & Sheaykh Rezayi, 2009) effects of visitors.

Fourth, the number, frequency, and duration of visitors are often determined based on patient and staff preferences. However, patients with cognitive impairments, including people who have unconsciousness, amnesia, and limited awareness caused by moderate-to-severe TBI are unable to make decisions (Long et al., 2011), including decisions about visitors. Thus, family caregivers often make decisions about visitors on the patient’s behalf. Yet, no research on this topic could be found. Therefore, the purpose of this paper is to describe family caregivers’ experience of visitors while the patient with moderate-to-severe TBI is hospitalized.

Methods

We conducted this study using grounded theory. The findings reported in this manuscript are part of a larger study that focused on the experience of the hospital stay for family caregivers of patients with moderate-to-severe TBI. Managing visitors was the core category of the families’ experience. After receiving approval from the participating institutional review board, participants were recruited from three inpatient rehabilitation facilities in a Midwestern state.
Family caregivers were eligible to participate if the patient: 1) was age 18 years or older; 2) was diagnosed with moderate-to-severe TBI; 3) had a Glasgow Coma Scale score between 3-12 on admission to inpatient rehabilitation; and 4) was currently undergoing inpatient rehabilitation. Each family caregiver was eligible to participate if they: 1) were age 18 years or older; 2) spoke English fluently, by self-report; and 3) identified as the anticipated primary family caregiver after discharge. Other family members who were not the primary caregiver participated after receiving permission from the primary caregiver.

The nurse managers from each site approached all primary family caregivers to determine interest in participation and distributed a study information sheet with the first author’s contact information. The first author gave all interested participants detailed information about the study, including the study purpose and necessary studies activities. After reading the informed consent and asking any questions, all participants signed the informed consent prior to the first interview.

Study Participants

The final sample included 16 family caregivers associated with 13 patients with TBI. All caregivers were white, most were women (n=14), and most self-identified as the caregiver after discharge (n=14). The average age of family caregivers was 55.56 years (range= 22-76). Biological relationships included: parents (n=5); spouses (n=7); and other (n=4) (i.e., grandparent, child, sibling, and cousin). Patients were all white and were mostly men (n=11). Causes of injury included falls (n=8), motor vehicle accidents (n=3), and other (n=2; e.g., gunshot wound). The patients’ average age was 47 years (range=19-79) and average length of hospital stay at the time of the first interview with the family caregiver was 26.30 days (range=8-40). Finally, patients’ average length of stay at the inpatient rehabilitation facility was 17.09 days (range=5-33).

Data Collection
Interviews with family caregivers occurred between February 2015 and April 2016. The first author conducted all 24 interviews with family caregivers. Each family caregiver was interviewed one (n=16) or two times (n=8); second interviews were used to add depth to the conceptual model. Interviews averaged 68 minutes (range 48-150). The first interview occurred 7 days after admission to inpatient rehabilitation. The second was held 48-72 hours before discharge, which was 4-7 days after the first interview. Interviews were conducted in private locations of family caregivers’ choosing and were audio recorded and transcribed verbatim.

During the first four interviews, family caregivers were asked, “Can you tell me about what things have been like for you while your family member has been in the hospital?” allowing family caregivers to determine the direction of the interview. Most family caregivers spontaneously identified concerns about visitors, specifically their influence on the patient. To add depth to the conceptual model, subsequent participants were asked, “What is your experience with visitors while your loved one has been hospitalized?” Follow-up interview questions became more focused to identify all dimensions, conditions, and interactions among categories.

Data Analysis

The authors followed tenets of grounded theory to conduct data collection and analysis. Symbolic interactionism is the basic underpinning of grounded theory, which focuses on social processes (Blumer, 1969). The authors followed analysis procedures outlined by Strauss and Corbin (1998), which direct the researcher to begin data analysis early (i.e., immediately after the first interview) and continuously (Strauss & Corbin, 1998) with a research team (Charmaz, 2014). Interview questions began with a broad focus on the experience of the hospital stay. However, participants immediately began discussing management of visitors to protect the patient’s safety without prompting. As grounded theory directs the research to follow the direction of the participants’
perspectives (Strauss & Corbin, 1998), we revised interview questions to gain an in-depth understanding of the participants’ experience focusing on managing visitors. For instance, during an interview, a caregiver shared, “we didn’t want a parade of people going and coming through her hospital room because it wasn’t safe.” This quote indicated the caregiver had concerns about visitors and how they influenced the safety of the patient. In a subsequent interview with the same caregiver, the first author asked follow-up interview questions focusing on visitors, including:

“1) You said a parade of people coming to see your daughter would be unsafe. Could you please tell me why this would be unsafe?
2) What could’ve happened if the wrong people came to see your daughter?; and
3) How do you choose who should come see your daughter and who shouldn’t?”

These questions elicited new data about the process of managing visitors, allowing the first author to obtain detailed data that was related to the core category, managing visitors.

Analysis of our data began with open coding, consisting of line-by-line analysis of each transcript (B. Bowers, 1990; Charmaz, 2000). For example, a caregiver shared:

“When people came unannounced, we told them that we would contact people when she was actually conscious, and when it would actually mean something to her because then it would be familiar faces. But what’s the point of sitting there staring at her, unconscious in a bed with a ventilator going?” [Caregiver #4]

This quote was related to the time frame of having visitors and was coded as: 1) unannounced visitors; 2) visitors are inappropriate while unconscious; and 3) visitors are appropriate / meaningful when conscious. Specific events were coded and were grouped together based on similarities, also known as categories (Strauss, 1987). Next, authors identified properties, detailed characteristics that pertain to a specific category, leading to identification of salient dimensions of caregivers’ experience (Strauss & Corbin, 1998).
Constant comparative analysis was used to compare participants’ experiences and events (Corbin & Strauss, 2008). Next, we used axial coding to look for similarities and variations in categories and determined how they related to one another (Strauss & Corbin, 1998). For instance, after identifying that caregivers focused on managing visitors, with the purpose of protecting the patient’s safety, we used axial coding to dichotomize safety into two conceptually distinct subdimensions that were related to one another: physical safety and emotional safety. Conditions were identified, which provided context to the events family caregivers experienced (Corbin & Strauss, 2008). Conditions that appeared frequently throughout our data related to the caregiver’s perception of visitors’ threat to the patient’s safety, specifically relating to threats to physical and emotional safety. Finally, authors used selective coding to confirm the core category and integrate all categories, resulting in a conceptual model (Strauss, 1987). In this case, the core category was managing visitors, which was associated with two other categories: welcome visitors and unwelcome visitors. Data collection and analysis continued until saturation on selected categories (i.e., managing visitors) was reached, whereby it was determined that “the researcher cannot discover new dimensions in the data being collected” (B. Bowers, 1990, p. 48).

Results

The core category in our findings was managing visitors. Many family caregivers focused on managing visitors and there was considerable effort involved. Managing visitors was intended to: 1) protect the patient’s safety and 2) to conserve caregivers’ energy. Caregivers were concerned about two types of safety for the patient: physical and emotional. Protecting the patient’s physical safety focused on preventing re-injury, fatigue, or overstimulation; protecting the patient’s emotional safety focused on stabilizing the patient’s emotional state. Caregivers attempted to conserve energy to have enough energy to focus on the patient.
Managing Visitors

Family caregivers characterized visitors in two ways: welcome or unwelcome (see Figure 1). Welcome visitors included people who were believed to have a positive influence on the patient, the family caregiver, or both. Unwelcome visitors were people perceived to have a negative (or potentially negative) influence on the patient, the family caregiver, or both. Some visitors were initially welcome but were shifted to unwelcome based on visiting behavior.

Figure 1. Conceptual Model: Managing Visitors

Welcome Visitors

Welcome visitors were considered safe people. For instance, safe visitors: 1) did not (or had not) cause the patient any physical harm; 2) had a positive attitude or demeanor; 3) had a positive effect on the patient, such as making the patient smile and laugh. “Nobody was allowed in her room
unless they had a happy face and a happy voice! Happy thoughts. Positive energy. This is what we try to keep going in her room.” [Caregiver #1]

Welcome visitors could also benefit the caregiver by providing: 1) emotional support, 2) tangible support (such as bringing food or clothes), or 3) assistance with the caregiver’s hospital work. These visitors were often the caregivers’ family members and close friends.

“We have great group of friends. It may not help at the time for the patient, but what a difference for me. I wasn't even thinking about food. My friends brought in baskets of food, not for my husband, but for me. So that made a difference.” [Caregiver #10]

Managing Welcome Visitors

**Approach #1: Managing Welcome Visitors Alone**

Most family caregivers were able to manage welcome visitors alone. Welcome visitors were often encouraged to visit throughout the hospital stay. Only the number and frequency of welcome visitors, as well as the timing and duration of their visits needed to be managed. This included sequencing visitors to avoid over-stimulating the patient and to allow the caregiver to rest in between visitors in effort to conserve energy. Family caregivers also managed visitors as a group and individually before and after visitors arrived to the hospital.

*Before welcome visitors arrive to the hospital.* When managing welcome visitors alone, family caregivers attempted to manage visitors as a group before they visited. Family caregivers who regularly used social media used Facebook to communicate with visitors. This involved posting daily status notifications to inform welcome visitors whether to visit that day, instructing them on frequency and duration of visits, and coordinating visits. “I had put messages out on Facebook saying that, ‘Okay, well this is what her status is. And the rooms are small. We’re not accepting visitors right
now””[Caregiver #3]. Those less familiar with social media used email or phone trees, contacting one or two people and having them pass the word on.

“We kind of had a phone tree. So, like I was assigned central contact and then I would pass it on to my dad. Then my dad would call my ex-husband and they’d kind of disperse information on to the rest of the family.” [Caregiver #6]

There was a large volume of individual people contacting family caregivers via phone calls and text messages to determine when would be a good time to visit the patients. Family caregivers who did not feel overwhelmed responded to each call and text by sharing pertinent information about visiting. Those who felt overwhelmed chose not to respond or chose to direct welcome visitors to Facebook for more information. “My phone rang up so much that it actually shook itself off the table because it did not stop going off from all the calls and text messages. So, I started directing people to Facebook.” [Caregiver #7]

To manage potentially problematic people who were a possible threat to the patient’s safety, caregivers had conversations with them before they arrived and asked them not to overwhelm the patient or give them unpleasant information.

After welcome visitors arrive to the hospital. Once welcome visitors arrived, family caregivers who were assertive asked them to limit the duration of their visit. When some caregivers felt the visit was long enough or felt the patient was becoming over-stimulated or fatigued, they asked the visitor to leave.

“And then if they didn't leave, I'd say, well, I think my husband looks like he's getting a little tired so we're going to go into the room and have him lie down. And so that was their cue to leave.” [Caregiver #8]
**Consequences of Welcome Visitors**

Family caregivers often had success in managing welcome visitors. Family caregivers reported that the presence of these visitors often brought the patient back to reality.

“Yeah, he's had visitors, and I think it was real good. In fact, once he became aware of his surroundings again, I think that's when it would have been the most important because that was bringing him back to reality” [Caregiver #6].

However, managing welcome visitors was fatiguing. “It was exhausting for me because I basically had to play hostess for hours on end, and it was very difficult” [Caregiver #9].

**How Managing Welcome Visitors Changed over Time**

Managing welcome visitors changed over time and the phase of the patient’s recovery was also used in determining who was welcome at the following times: 1) early in recovery; and 2) later in recovery. Early in recovery, usually during critical care, family caregivers limited visitors to close family members and friends. “When he was first admitted, my husband and I asked that they just be immediate family coming to visit” [Caregiver #12].

Later in the patient’s recovery, often during inpatient rehabilitation, some caregivers were less restrictive and allowed an increase in the frequency and duration of welcome visits.

“When he was in ICU, we never went more than two at a time. We would visit and just stay short amounts of time. As he got better, especially on rehab, the more he started to interact with us and the more awake times he had, that made a difference as to how long we would stay.” [Caregiver #11]

However, regardless of phase of recovery, unwelcome visitors were prevented from visiting.
Unwelcome Visitors

Unwelcome visitors were considered dangerous people. Unwelcome visitors were defined as people caregivers perceived to pose a threat to the patient’s physical or emotional safety, people who would take away the caregiver’s energy, or both. Unwelcome included people the caregiver: 1) no longer wanted the patient to have a relationship with due to past and potentially future negative influence; 2) perceived would overstimulate the patient; 3) thought would tell the patient unpleasant information; 4) presumed would take away energy from the family caregiver by being a nuisance or being overly emotional. Unwelcome visitors were also people who arrived unannounced.

In addition to the above-listed considerations, to determine who was unwelcome, family caregivers often assessed the visitors’ relationship to the patient, focusing on the visitor’s level of closeness to the patient. Those who family caregivers perceived to not be close to the patient (e.g., those claiming to be friends of the patient who were unknown to the caregiver) were unwelcome. To prevent any threats to the patient’s physical and emotional safety, some family caregivers made a valiant effort to block unwelcome visitors from seeing the patient.

Three Approaches to Managing Unwelcome Visitors

Family caregivers managed unwelcome visitors using three main approaches: 1) managing unwelcome visitors alone; 2) managing unwelcome visitors with others; and 3) managing unwelcome visitors by collaborating with staff (see Figure 1). Family caregivers used various combinations of all three approaches. Caregivers managed visitors as a group, and individually before and after they arrived to the hospital.

Approach #1: Managing Unwelcome Visitors Alone
Multiple family caregivers reported using approach #1, managing unwelcome visitors alone, before and after visitors arrived to the hospital.

*Before unwelcome visitors arrive to the hospital.* Some family caregivers who managed unwelcome visitors alone also attempted to do so using Facebook. When a person unknown to the caregiver inquired about visiting on Facebook, the caregiver assessed the nature of the potential visitor’s relationship to the patient and his or her motivation for wanting to visit.

“I told all of her friends that I already had on my Facebook friends list, ‘Tell others if they want to visit, send me a Facebook message, say who you are, say why you want the information, and I will add you. Just so long as you can tell me who told you to talk to me and why you want to visit.’” [Caregiver #4]

People perceived to be a definite threat to the patient’s emotional safety were kept at a distance. Caregivers talked with these people directly and told them not to come, gave them permission to be away, and gave them work to do to keep them away.

“As far as he goes, it would have been difficult if he had dropped out of school and been sitting at her bedside this whole time. Honestly, I would have been trying to take care of him too, had he been here. I told him that his sister would want him to stay in school and to keep his grades up for her, and that way he didn’t come.” [Caregiver #1]

*After unwelcome visitors arrive to the hospital.* Unwelcome visitors who arrived unannounced were often blocked from seeing the patient because caregivers perceived unannounced visitors as dangerous, potentially threatening to the patient’s safety.
“When [unwelcome] visitors showed up, I thanked them for coming and then asked them to leave. I was always very gracious, but I was very direct that my son was not up for visitors right now. I also asked them to call before coming in the future.” [Caregiver #12]

Family caregivers who used Facebook to manage visitors often had to deal with visitors who did not use Facebook and arrived unannounced. Caregivers’ reactions to these visitors varied. Some caregivers perceived these visitors had limited or no influence on the patient’s safety and allowed them to see the patient. Caregivers who perceived these visitors to have a negative influence on the patient’s safety prevented them from seeing the patient and asked them to leave. Others expressed concerns about unwelcome visitors having a negative influence on the patient, but only hoped that these people would not continue to visit.

“If he was involved with any friends that were a negative influence in the past, it was kind of hard to let them come. Then I realized I'm just hoping that he's going to get past any of those thoughts of going backwards and just keep going forward.” [Caregiver #5]

Overall, the strategies caregivers implemented when managing visitors alone were not always successful. Success was determined by the ability to keep unwelcome visitors from coming to the hospital. When one strategy was not successful (such as using social media to communicate with visitors), family caregivers tried other strategies (such as asking unwelcome visitors to leave). Inability to manage unwelcome visitors caused caregivers feelings of stress, anxiety, and being overwhelmed. Caregivers reported limited involvement of staff in assisting them with managing unwelcome visitors, which led to frustration. “I was a little angry that they [staff] were letting other people aside from family just hanging, standing right next to the door of her room” [Caregiver #3]. Because of this, caregivers increased the time they spent at the hospital, or implemented other approaches, such as managing unwelcome visitors with others.
Approach #2: Managing Unwelcome Visitors with Others

Some family caregivers reported managing unwelcome visitors with others, requesting assistance from family members or friends they trusted. Managing visitors with others often involved delegating at least some ‘managing unwelcome visitors’ tasks when the family caregiver was absent, when they were uncomfortable doing so, or when they felt overwhelmed.

**Before unwelcome visitors arrive to the hospital.** Some family caregivers asked family members or friends to help update their Facebook when they became overwhelmed. Similar to strategies use to manage welcome visitors, caregivers who were unfamiliar with Facebook had family members or friends communicate with unwelcome visitors using a phone or email tree.

“My cousin sent out mass emails to friends, family, and church group so people knew not to come. That extra person to help you relay other things to everybody else is super helpful because I can't do 50 emails or texts and phone calls per day.” [Caregiver #12]

**After unwelcome visitors arrived to the hospital.** When unwelcome visitors arrived at the hospital, family caregivers often had their family members and friends ask them to leave.

“He went to admissions and found out where she was. I found him sitting in front of her door. I ended up letting my friend deal with it. She looked at his face and said, “Now is not the time to be here.” And she turned him around and walked him out.” [Caregiver #3]

Family caregivers who managed unwelcome visitors with others were comfortable not being at the hospital constantly, as they could rely on others to help in their absence. “We're trying to stay, at least one of us, with him 24 hours. My husband does the nights and I do the days, because I'm not good at staying awake for long periods of time [chuckles]” [Caregiver #13].

Consequences of Managing Unwelcome Visitors Using Approach #1 and #2
Caregivers put a significant amount of energy and time into managing unwelcome visitors, which could have focused on the patient. These family caregivers also had lost productivity because they were constantly at the hospital instead of tending to other outside responsibilities. Family caregivers also reported feelings of stress, anxiety, frustration, and hypervigilance when managing unwelcome visitors without staff involvement. Lack of staff involvement caused family caregivers to feel exhausted and to distrust staff.

**Approach #3: Managing Unwelcome Visitors by Collaborating with Staff**

Only four of caregivers reported managing unwelcome visitors by collaborating with staff. Of these people, three had success in managing unwelcome visitors. There were also variations in who initiated the first conversation about visitors (initiated by staff or caregiver).

**Before unwelcome visitors arrived to the hospital.** One caregiver reported initiating a conversation about visitors with staff immediately after the patient was admitted. This caregiver was unsure if the patient’s injury was intentional and perceived a severe threat to the patient’s safety. The caregiver asked staff to prevent anyone from receiving information about the patient and staff agreed to do so using a specific strategy: making the patient confidential. Staff had the caregiver sign a form that listed the patient’s room location as confidential in the patient registry. This strategy was successful and no unwelcome visitors came or were allowed to see the patient.

“At first I just wasn’t allowing anybody to come. I went to talk to the staff and had them put her as confidential because we didn’t know if somebody pushed her. Even her friends wanted come and see her in the hospital, but I wasn’t allowing anyone.” [Caregiver #1]

In a situation where a caregiver was unable to successfully manage unwelcome visitors alone and with others, the caregiver enlisted the help of staff by approaching staff about the ongoing issue. Staff suggested implementing a list of approved visitors. The caregiver gave staff the list and asked for
it to be enforced at all times. This strategy was not successful as the list of approved visitors was rarely enforced and unwelcome visitors were allowed access to the patient.

“I wish that was handled different and even when we gave them a family list, there were people coming still getting in to see her I thought had no business being there. They’re obviously busy and it’s too much to ask they help in keeping people out” [Caregiver #3]

In two other situations, staff approached two, separate family caregivers immediately after the patient was admitted to intensive care to discuss visitors, determining whether any visitors would be coming and assessing the caregiver’s concerns about visitors. After these caregivers shared concerns about visitors, staff implemented strategies to prevent unwelcome visitors and communicated openly about their efforts. Staff asked the caregivers to provide a list of approved visitors, and the caregivers perceived staff would enforce this list in their absence.

“We gave them a list of approved visitors, it was my daughters, their spouses, and myself…No one really went against it, but the nurses did say, if somebody that wasn’t on the list came, they would tell them the patient isn’t taking visitors.” [Caregiver #11]

Next, if any person was persistent in getting information about the patient over the phone, staff told the caregiver and suggested making the patient confidential.

“He did call and was extremely persistent about getting information. The nurse I talked to recommended that I sign this confidential form. She said without that form, he could call back, get my husband’s room number, and come walking up there.” [Caregiver #11]

After unwelcome visitors arrived to the hospital. If a visitor came to see the patient, another strategy agreed upon was asking the caregiver whether each visitor should be allowed to see the patient. However, this strategy required the caregiver or another trusted person to be there at all times
to determine who was welcome. “We had the staff ask us before they let anybody back there. The staff were instructed to ask us when each person arrived.” [Caregiver #13]. Finally, if the caregiver had provided staff with a list of approved visitors, staff enforced this list, even in the caregiver’s absence.

**Consequences of Managing Unwelcome Visitors Using Approach #3**

Because of the actions of staff, almost all of these caregivers perceived staff to be willing to assist in managing unwelcome visitors, particularly when staff implemented all agreed upon strategies. The caregivers with this experience felt comfortable leaving the hospital to fulfill outside responsibilities, as they trusted that staff would manage visitors in their absence.

“I was very comfortable and that helped because I could not be there during the day. I knew he was in good hands. If somebody would have gotten past to visit that should not be there, I know the staff would’ve have asked them to leave.” [Caregiver #11]

**Discussion**

The purpose of this study was to investigate family caregivers’ experiences with visitors while patients with moderate-to-severe TBI are hospitalized. Results show caregivers managed all visitors longitudinally during the hospital stay and put considerable effort into doing so. Caregivers filtered welcome and unwelcome visitors and managed the number, frequency, duration, and timing of visits. Caregivers reported limited success in managing unwelcome visitors and perceived staff were both unaware of their efforts and uninvolved in the process.

Research on hospital visitation policies during the hospital stay show that there are generic visitation policies during critical care, with restrictions that only limit the frequency and duration of visitors stays (Ciufo et al., 2011) as opposed to the visitor’s characteristics and their perceived influence on the patient. No research or clinical guidelines could be found to direct healthcare
providers on assisting caregivers with unwelcome visitors throughout the hospital stay. The generic nature of hospital visitation policies and clinical guidelines imply that there is a “one size fits all” visiting policy. This study shows that families are a lot more discriminating.

Family caregivers’ use of protective caregiving strategies (Carr, 2014; Carr & Fogarty, 1999) and attempts to conserve their own energy (Vandall-Walker & Clark, 2011) during the hospital stay have been documented in the literature. However, current literature does not specify what the family is trying to protect the patient from or strategies they use to do this, which is demonstrated in this study. In addition, the literature suggests that family caregivers conserved energy using self-care strategies, such as resting at the patient’s bedside and decreasing the length and frequency of their own visits (Vandall-Walker & Clark, 2011). This study adds to the literature on strategies family caregivers use to conserve energy during the hospital stay.

When comparing the literature on nurses’ perceptions of visitors to the findings of this study focusing on families’ perceptions, it is clear that nurses’ and families’ perceptions differ. Based on literature and the current study, there appears to be overlap between nurses and family caregivers perceptions only concerning patient overstimulation (Farrell et al., 2005). Caregivers in this study also perceived that the work they were doing was invisible to nurses. Consistent with research on invisible family caregiving (Abrahamson, Suitor, & Pillemer, 2009; B. J. Bowers, 1987), this study shows how that process takes place, even in hospital settings.

**Implications for Practice**

These findings emphasize the need for staff to assist caregivers to manage visitors. First, although this sample only included caregivers of patients with moderate-to-severe TBI, these findings have wide reaching implications for caregivers of patients hospitalized for various health conditions. Second, these findings can increase staff awareness that managing visitors is a difficult process for
caregivers during the hospital, particularly emphasizing the consequences of discrepancies in nurses’
and families’ perceptions about visitors. If nurses are only concerned that visitors will interfere with
their work and pose an infection risk to the patient, they will likely miss family caregivers’ concerns,
leading unmet expectations and frustration.

Third, these findings not only raise questions for who should be responsible for managing
unwelcome visitors, but have implications for system level change to increase staff involvement in
managing visitors. From a hospital administration standpoint, changing policies to state the institution
should be held accountable to assist families to manage visitors may pose a liability; however it is still
important to discuss ways staff can informally assist families. Recommendations for informal
management of unwelcome visitors at the hospital level include system change and administrative
support to change visiting policies to address families’ concerns by: 1) requiring each family to submit
a list of approved visitors that is enforced by staff, 2) having all visitors check in at the nurses’ station,
and 3) giving the caregiver visitors’ badges to hand out to approved visitors and having staff ask
people without badges to leave.

Fourth, it is important that staff are adequately trained and educated on how to assist caregivers
in this process. Recommendations for staff education and training include educating and training staff
to: 1) talk with the family immediately after hospital admission and throughout the hospital stay to
determine their needs about visitors and to notify them of limits that can be placed on visitors (e.g., a
list of approved visitors); 2) be consistent with implementing caregivers’ requests about managing
visitors (i.e., sharing requests at interdisciplinary team meetings and during hand-off); 3) educate
family members on how to manage visitors, such as putting the blame on staff (e.g., “I’m sorry, my
husband’s nurse said he is not ready for visitors yet”) or enlisting a trusted person indirectly involved
with patient’s care as gatekeeper (e.g., patient’s aunt); and 4) tailor strategies for each family, as
“things that are helpful to one family may not be helpful or even useful to another family” (Slota et al., 2003, p. S365).

Limitations

First, this sample contains many caregivers who had difficulty managing visitors, limiting knowledge about the strategies used by caregivers who had success in managing visitors. However, as the majority of our sample had this experience, these findings may be representative of the typical experience for managing visitors. Second, all caregivers in this sample were white, limiting application to caregivers from diverse backgrounds. However, these findings provide a foundation for future research. Finally, the cause of each patient’s injury was not taken into consideration, which may have altered strategies used. Regardless, without considering this factor, strategies used were consistent throughout our sample.

Future Research

The findings of this study describe the theoretical possibilities of managing visitors. More research is needed to determine the range, frequency, and distribution of caregivers specific to managing visitors. As family caregivers seemed to have the most success managing visitors by collaborating with staff, researchers could further investigate this approach to managing visitors, including investigating staff’s perceptions in managing visitors to better understand their perceived roles in this process. Finally, future researchers could investigate how managing visitors may vary for family caregivers from diverse backgrounds.

Conclusion

Family caregivers of patients with moderate-to-severe TBI play a large role in supporting the patient during the hospital stay, including managing visitors to protect the patient’s physical and
emotional safety and conserve their own energy. Many caregivers perceived staff to be unaware of their efforts and uninvolved in this process. These findings provide evidence that management of visitors is an area where caregivers need more assistance from hospital staff.
References


