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

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Abstract

Research has shown that during the hospital stay, family caregivers of patients with traumatic brain injury (TBI) perceive one their roles is to protect the patient; however, research on this topic is limited. The purpose of this article is to describe family caregivers’ experience of protecting patients with TBI during the hospital stay. Grounded theory was used to conduct twenty-four interviews with 16 family caregivers. Findings showed family caregivers worked to protect the patient’s physical and emotional safety, using some of the following strategies: 1) influencing the selection of staff, 2) breaking the patient’s bad habits, 3) anticipating how to orchestrate the home environment; 4) connecting on an emotional level, and 5) managing visitors. The findings have practice implications for educating interdisciplinary healthcare providers about the experience of family caregivers and for developing an adversarial alliance between healthcare providers and family caregivers during the hospital stay to improve support provided to them during this time.

Keywords

brain injury; patients; families; grounded theory

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).

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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 ways of supporting the patient include providing emotional support (e.g., managing emotions and adjusting to changes) and financial support (e.g., involvement in financial decisions, loaning or giving money) (Rotondi AJ et al., 2007). The above-listed support and involvement strategies suggest that family members take on the role of an in-hospital caregiver during the patient's hospital stay (Family Caregiver Alliance, 2009; Sapountzi-Krepia et al., 2008).

Family Caregivers' Perception of Their Role

In addition to supporting the patient and being an in-hospital caregiver during the hospital stay, research has also shown that some family caregivers perceive their role to be multifaceted, including being vigilant of the patient. 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. Family caregivers may be vigilant and monitor the patient's care to ensure the patient is kept safe (Brain Injury Association of America, 2015a; Keenan & Joseph, 2010).

However, limited research on vigilance in family caregivers of patients with moderate-to-severe TBI exists. To better understand vigilance of family caregivers with hospitalized patients, research on this topic, conducted on patients with and without TBI, is summarized below. Family caregivers reported wanting to be physically present at the hospital to protect the patient (Carr, 2014; Carr & Fogarty, 1999), keeping "bedside vigil" by being physically present at the patients beside to watch over the patient (Duff, 2002). Yet, information on what family caregivers were attempting to protect the patient from and reasons for watching over the patient were not specified. In other studies, family caregivers 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), attempting to ensure the patient received the best care possible (Lam & Beaulieu, 2004).

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 family caregivers' perspective of caregiving during the hospital stay specifically focusing on: 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. These gaps in research limit healthcare providers' and researchers' knowledge of: 1) the role and experience of family caregivers of patients with TBI during the hospital stay; 2) the protection work strategies enacted by family caregivers and how this may affect their wellbeing; 3) areas where family

caregivers may need more support; and 4) additional opportunities for collaboration between healthcare providers and family caregivers to improve their therapeutic relationship. To this end, the purpose of this article was to describe family caregivers' experience of protecting patients with moderate-to-severe TBI during the hospital stay.

Methods

Grounded theory is based on symbolic interactionism, which allows for an in-depth understanding of a basic social process (Blumer, 1969; Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2015), which in this case explicates the experience of protecting patients with TBI during the hospital stay. Grounded theory also allows the researcher to explore the participants' understanding of a situation and their subsequent actions and responses to the situation, as well as how certain conditions may influence their understanding and actions (Blumer, 1969; Handberg et al., 2015; Strauss & Corbin, 1998). The findings reported in this article are part of a larger grounded theory study focusing on the experience of the hospital stay for patients with moderate-to-severe TBI and their family caregivers.

After receiving approval from the participating institutional review boards, family caregivers were recruited from three facilities in a Midwestern state. Purposive sampling was used to target family caregivers with specific criteria (Charmaz, 2014). 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) was undergoing inpatient rehabilitation; 4) had a Glasgow Coma Score between 3 and 12 upon admission to inpatient rehabilitation; and 5) 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 assisted with recruitment by approaching family caregivers to inform them about the study and to determine interest in participation. Next, Dr. Oyesanya 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. Prior to recruitment, no members of the research team, including the nurse manager and authors had clinical contact with the patient or family caregiver (Chan, Teram, & Shaw, 2017).

Study Participants

The sample included 16 family caregivers associated with 13 patients with moderate-to-severe TBI (see Table 1). Family caregivers were all white, and majorities were women and anticipated primary family caregivers after discharge. Of the 16 participants, 13 identified as family caregivers and 3 identified as other family members. The average age of family caregivers was 55 years old. Biological relationships between patients and family caregivers included mostly parents and spouses. All biological relationships between patients and other family members were characterized as "other" (i.e., grandparent, sibling, cousin). Patients

were all white and were mostly male. The most common cause of injury was a fall. The average age of patients was 47 years old. Patients' average length of hospital stay at the time of the first interview with the family caregiver (from initial ICU admission to time of first interview during inpatient rehabilitation) was 26 days. Finally, patients' average length of stay at the inpatient rehabilitation facility (from admission to inpatient rehabilitation to hospital discharge) was 17 days.

Data Collection

Data were collected between February 2015 and July 2016. Twenty-four interviews were conducted via one to two interviews per participant. The first eight participants were interviewed twice. Second interviews were used to ask more questions, adding depth to the conceptual model. Interviews averaged 68 minutes.

Dr. Oyesanya 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. Family caregivers were interviewed in a private location of their choosing. No interviews were conducted with patients and family caregivers in the same room (Kosny, MacEachen, Lifshen, & Smith, 2014). All interviews were audio recorded and transcribed verbatim.

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 family caregivers could lead us in a direction that was important to them. Topics of discussion initiated by family 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 had visitors, their experience of visitors, and visitors' influence on patients.

Data Analysis

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 the authors; and 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, family caregivers immediately began discussing protecting the patient during the hospital stay without prompting. As grounded theory directs the researcher to follow participants' perspectives (Strauss & Corbin, 1998), we revised interview questions based on the participants' direction to gain an 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 family caregiver shared,

“Keeping her safe is most important... I’m trying to be the safety net... You have to protect them from certain things” [Family caregiver]. The quote from this family caregiver indicated her concern about protecting the patient’s safety. Dr. Oyesanya asked a subsequent interview question (below) to follow the direction indicated by the family caregiver and gain more in-depth knowledge about his/her 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?” [Dr. Oyesanya’s interview question]

This question allowed the family caregiver to elaborate on his/her concerns about the patient’s safety, encouraging him/her to describe specific events or instances where actions were directed toward protecting the patient’s safety. The specific event examples shared by the family 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 family caregivers’ experiences, focusing on 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 (Bowers, 1990; Charmaz, 2014), used to examine, compare, conceptualize, and categorize the data (Corbin & Strauss, 2008). For example, a family 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.” [Family caregiver]

This was coded as: 1) physical presence, 2) keeping her safe, and 3) fear about re-injury. Specific happenings were labeled and grouped based on similarities, also known as categories (Strauss, 1987). Authors determined properties, which are detailed characteristics that pertain to a specific category (Strauss & Corbin, 1998). Properties were determined during coding and encompassed detailed features of the category (Strauss & Corbin, 1998). This led to identification of salient dimensions of family caregivers’ experience (Bowers, 1990). In constant comparative analysis, dimensions identified during coding were used to compare the perspectives of family caregivers, where the sample was compared between units (events and participants) and as a whole (Strauss & Corbin, 1998). 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 family caregivers’ experiences (Corbin & Strauss, 2008). For example, a

condition influencing family 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" (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 described 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, authors used memo writing to record stages of data analysis and aid in: (a) generating information for data collection, including recording interrelations among dimensions, (b) reducing introduction of preconceived notions into developing the conceptual model, and (c) assistance with development of the conceptual model, which will be used in guiding future theory development (Charmaz, 2014; Strauss & Corbin, 1998). Memos were written by authors after each interview and each data analysis meeting. Information recorded in memos included: authors' relevant thoughts about the data, emerging categories, relationships between categories, ideas for theoretical sampling, and changes to the conceptual model with specific rationale for each change. Authors referred back to memos as needed throughout the data collection/analysis process and during manuscript preparation. Fourth, we achieved resonance by developing a conceptual model that was representative of our participants' experience through member checking (Charmaz, 2014). Dr. Oyesanya used member checking during data collection and analysis to determine whether participants' experiences were accurately described by showing them pieces of the conceptual model and asking them 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 data analysis was *family work*, detailing the nature of family caregivers' involvement during the hospital stay as in-hospital caregivers (see Figure 1). The purpose of family work was to protect the patient's physical and emotional safety. Family caregivers worked to protect the patient's physical safety to prevent re-injury, fatigue, or overstimulation. 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, implementing both observable and mental strategies. Some family caregivers perceived their presence would help mitigate any impending threats to the patient's safety. The strategies listed below varied based on family

caregiver's perception of threat to the patient's safety. When strategies were enacted, different family caregivers used the listed strategies in similar ways. While spending time with the patient during the hospital stay, the majority of family caregivers were alone with the patient with few, intermittent, and brief visits from other family members or friends. Some family caregivers enlisted the help of others to protect the patient while others attempted to protect the patient on their own.

Protecting the patient's physical safety

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

Influencing the selection of staff.—Throughout the hospital stay, many family caregivers wanted to be physically close to the patient, desiring to be present when the patient woke up from the initial trauma. Initially, family 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 family caregivers began casually observing the patient's care, including observing how the patient responded to staff. By doing so, family caregivers began to have concerns about the patient's care, specifically noticing perceived or potential threats to the patient's physical safety, including questions about staff expertise, recognizing that some staff did things the right way while others did not.

"I was in the room when I saw her holding her [the nursing assistant] 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." [Family caregiver]

Family caregivers' concerns about care caused them to begin deliberately monitoring the quality of the patient's care. When monitoring the care, family caregivers observed evidence of inadequate care. This included perceptions that a staff member seemed inattentive, used an ineffective technique, or appeared to be inexperienced. Family 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." [Family caregiver]

When some family 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.” [Family caregiver]

The perception that the patient’s physical safety was in danger due to staff’s performance led family caregivers to increase the time they spent at the hospital.

Breaking the patient’s bad habits.—Some family 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, family caregivers took the hospitalization as an opportunity to make significant life changes. To prevent the bad habit from causing future injury, family caregivers of older adult patients often spoke to patients about their concerns. During inpatient rehabilitation, when the patient was more cognizant, family caregivers talked to the patient about past or ongoing problems, encouraging the patient to “start fresh.” “I told him don’t drink as often, you’re going to hurt yourself. You’re hurting our family” [Family caregiver].

In contrast, family 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 were a negative influence in the past, it was kind of hard to initially let them come.” [Family caregiver]

Anticipating how to orchestrate the home environment.—Family caregivers also planned how they would orchestrate the patient’s home environment to prevent future harm in anticipation of the possible future needs of the patient. This was typically a mental strategy that occurred at a distance and did not require the family caregiver to be at the hospital for strategic planning to occur. Some family 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. Family 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 family caregiver stated that once the patient returned home, she would ask him “to stay within hollering distance” in case anything happened [Family caregiver]. Family 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.” [Family caregiver]

Other family caregivers stated they would monitor the patient’s interactions with others and make sure to re-direct 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.” [Family caregiver]

Still other family 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.” [Family caregiver]

Protecting the patient’s emotional safety

When protecting the patient’s emotional safety, family caregivers attempted to control the patient’s hospital environment to stabilize the patient’s emotional state by connecting on an emotional level.

Connecting on an emotional level.—Family 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, which were observable strategies. When reassuring the patient verbally, the family caregiver attempted to talk the patient through the ongoing situation by using personal information about the patient and visual imagery 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 family 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!’ [Family caregiver]

Throughout the hospital stay, when reassuring the patient physically, family 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” [Family caregiver]. Some family 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." [Family caregiver]

Family caregivers also worked to protect the patient's emotional safety by managing their own emotions in front of the patient for fear that their display of negative emotions would negatively influence the patient's emotional state. "You got to pick your moments to cry" [Family caregiver]. Many family 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" [Family caregiver].

Protecting the patient's physical and emotional safety

To protect the patient's physical and emotional safety, family caregivers attempted to control the environment by managing visitors, which mostly included observable strategies. Family caregivers reported the perception that visitors were a threat to the patient's physical safety because visitors could be major source of overstimulation if they kept the patient from resting during the hospital stay. Family caregivers also reported the perception that visitors were a threat to the patient's emotional safety because some visitors could be a bad influence on the patient and influence their emotional state. Thus, family caregivers attempted to manage visitors throughout the hospital stay to protect the patient.

Managing visitors.—Family caregivers used multiple strategies to manage visitors, though some strategies were successful and others were not. Throughout the hospital stay, family caregivers managed the number, frequency, duration, and timing of visits. Family 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, especially if visitors wanted to come as a group.

"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.'" [Family caregiver]

It was common for family caregivers to enlist another person (e.g., other family members or friends) to assist them if they became overwhelmed. Regardless of the method used to manage visitors, some family caregivers attempted to assign visitors specific times to visit to prevent too many people from showing up at once, perceiving that too many visitors would overstimulate the patient and threaten his/her physical safety. 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" [Family caregiver].

After visitors arrived, some family caregivers reminded visitors to limit their stay. However, visitors often stayed longer than the family caregiver desired, as visitor thought the patient looked 'just fine.' Some family 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, particularly feeling that longer visits would impact the patient physically (e.g., cause fatigue).

"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." [Family caregiver]

Managing safe and dangerous visitors.—Family caregivers did not allow any and all visitors into the patient's hospital room, especially while the patient was receiving critical care. Family caregivers identified visitors who might pose threats to the patient's safety, but often did not explicitly mention this distinction to others. 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 physical or emotional harm, thus these visitors were welcomed. Dangerous visitors were people claiming to be friends of the patient who were unknown to the family caregiver or people who may give the patient unpleasant information, which might evoke an emotional crisis for the patient. Dangerous visitors were unwelcome during the hospital stay.

To protect the patient's integrity, family caregivers first assessed the motivation of the visitors to protect the patient's emotional safety. In particular, family 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 family caregivers perceived blocking visits from specific visitors would prevent the patient from future harm.

"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." [Family caregiver]

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" [Family caregiver]. People who the family caregiver perceived to have been involved with the patient's injury were often not allowed to visit because some family 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" [Family caregiver].

As the patient became more cognizant, he/she asked questions about their accident. Most family caregivers wanted to wait for the right time and place to tell the patient what happened to them as they perceived the traumatic story might evoke an emotional crisis for the patient, threatening the patient's emotional safety. To prevent this from happening, some family caregivers explicitly 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 family 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.'" [Family caregiver]

Some family caregivers only allowed safe 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" [Family caregiver]. Family caregivers also reported the intent to use many of these same strategies to protect the patient's emotional safety after discharge.

Lack of staff involvement.—Some family caregivers reported minimal assistance from staff to manage visitors throughout the hospital stay. Lack of staff involvement was a condition that influenced how family caregivers managed visitors, particularly visitors who were deemed dangerous (influence of condition is indicated with a dashed line in Figure 1). Family caregivers had the perception that they were receiving limited assistance from staff to manage dangerous visitors, causing family caregivers to grow frustrated with having to ask these visitors to leave on their own. This frustration was often projected onto dangerous 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. [Family caregiver]

Discussion

These findings describe the nature of family caregivers' involvement during the hospital stay as in-hospital caregivers, specifically detailing strategies used to protect the patient's physical and emotional safety. Strategies for protecting the patient's physical safety included influencing the selection of staff, breaking the patient's bad habits, and anticipating how to orchestrate the home environment. The strategy used for protecting the patient's emotional safety was connecting on an emotional level. To protect the patient's physical and emotional safety, family caregivers managed visitors.

Various concepts previously described in the literature were included in these findings, including family work, in-hospital caregiving, protective caregiving mechanism, and invisible caregiving. Limited mentions of family work occur in the literature, but when discussed, family work describes the effort of family caregivers to assist patients in health care settings (Bischofberger & Spirig, 2004; Vandall-Walker & Clark, 2011). The concept of in-hospital family caregiving seen in these findings is also present in the literature (Sapountzi-Krepia et al., 2008; Stavrou, Ploumis, Zyga, & Kotrotsiou, 2014). Like this study, 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 enacting protective caregiving mechanisms by spending long hours at the hospital, similar to what has been documented in the literature (Carr, 2014; Carr & Fogarty, 1999; Lam & Beaulieu, 2004). Like this study, research has shown that family 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 "invisibility" of the work of family caregivers to protect the patient has also been documented in the literature, including work of family caregivers of patients with cognitive impairments (Bowers, 1987; Choi & Kang, 2016; Hasselkus, 1988; Wilson, 1989). Although staff involved in patients' care were not interviewed, the reports of the perception of minimal assistance from staff may imply that staff may be: 1) unaware of the work family caregivers are doing, 2) aware of the work family caregivers are doing and think positively of it, 3) aware of the work family caregivers are doing but unable to assist due to restraints caused by time and prioritizing other nursing care responsibilities.

These findings also parallel previous research on the role of family caregivers in caring for relatives, specifically aging parents both at home (Bowers, 1987) and in institutions (Bowers, 1988), including descriptions of the complexity of family caregivers' role and strategies used to protect their relative and help them maintain control of the environment while institutionalized (Bowers, 1988). For instance, our family caregivers engaged in protective caregiving mechanisms, including mental and observable strategies to protect their relative like previous studies (Bowers, 1987). Family caregivers had concerns about staff's expertise and monitored the quality of care by gathering evidence directly and indirectly and assessing outcomes to evaluate the care the patient received (Bowers, 1988). In our strategy "anticipating how to orchestrate the home environment," family caregivers attempted to prepare for management of possible needs of the patient, similar to anticipatory care strategies seen in another study (Bowers, 1987). Supervisory care strategies such as checking up, making sure, and setting up that have been previously documented (Bowers, 1987) were also factors that were present in our strategies of "managing visitors," "influencing the selection of staff," "breaking the patient's bad habits," and "connecting on an emotional level." Finally, the discrepancy between family and staff attribution of responsibility, evidenced by family caregivers' perception of lack of staff involvement in managing visitors, has also been described (Bowers, 1988).

Finally, multiple areas may have influenced the protective strategies enacted by the family caregivers of patients with TBI. First, the severity of the patient's cognitive impairment may largely influence enactment of protective strategies as patients are rendered vulnerable due to consequences of the TBI including unconsciousness, amnesia, and lack of awareness (Povlishock & Katz, 2005). These impairments may prevent the patient from making decisions (Mukherjee & McDonough, 2006) or being able to defend themselves if a threat to their safety arises. Family caregivers may feel it is their duty to protect the patient in their vulnerable state. Second, family caregivers' had the perception that the mental strategies they were using to protect the patient were invisible to staff. Although these findings were not explicitly stated in our results, invisibility of family caregivers' protection efforts is prevalent in the literature and may be due to : 1) healthcare providers' sole focus on the care of patient (Levack et al., 2009); 2) attempts to protect the patient inconspicuously as to not interrupt healthcare providers' work (Rivera & Karsh, 2010); or 3) attempts to maintain the pre-injury relationship with their relative (e.g., parent-child relationship) and avoid role reversal by preventing the patient from becoming aware of the work they are doing (Bowers, 1987). Third, family caregivers may also have perceived their work was invisible because use of family systems theory (Rosenblatt, 1994) to guide engagement of family caregivers in the care of patients with TBI is continuously emerging, as previous research documents family involvement has not always been addressed in care of these patients (LarØi, 2003). Understanding more about what has influenced or may influence family caregivers' protection of patients with TBI may provide insight into their protection strategies.

Implications for Practice

These findings allow healthcare providers to understand the hospital experience for family caregivers of patients with TBI and to potentially harness family caregivers as an asset to the care of patients with moderate-to-severe TBI. The findings are relevant to the effectiveness of healthcare providers' interventions based on the provider's ability to assess the family caregiver's involvement in care of patients with TBI during the hospital stay. Healthcare providers must be able to distinguish which family caregiving strategies are being used to prevent family caregivers from being labeled as uncooperative, controlling, or disruptive. Careful assessment from healthcare providers on the occurrence of these protective caregiving strategies will allow healthcare providers to enact adversarial alliance strategies (Family Caregiver Alliance, 2009; McLaughlin & Carey, 1993)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; Norcross, 2010). An adversarial alliance is defined as an attempt to develop a collaborative partnership out of an intermittently conflict-laden relationship between family caregivers and healthcare providers (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) staff having appropriate responses to families who are highly stressed, such as using special outreach efforts; 4) self-awareness; 5) empowerment

of the person and family; and 6) viewing the family as a unit of care (Family Caregiver Alliance, 2009; Lor et al., 2016; McLaughlin & Carey, 1993).

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 (Wright & Leahey, 2012) and the Family Systems Theory (Rosenblatt, 1994) 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' experiences during the hospital stay. Additional understanding of how family systems models and theories influence care of patients with TBI and the 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 of other groups, these findings still provide depth to family 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 family 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 family caregivers had prior experience with caregiving, which may have influenced the strategies they used. Nonetheless, these findings provide new knowledge on family caregivers' experience during the hospital stay and can be used to direct future research.

Future Research

Researchers may wish to compare the experience of family caregivers of patients with TBI to family caregivers of patients with other conditions to determine differences in protective caregiving strategies or to determine barriers to protecting the patient's safety. As our study did not ask family caregivers if they had caregiving experience, additional research is needed to determine if the strategies used by family 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), Rancho 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. Research may also wish to explore whether protective strategies present during the hospital stay persist beyond hospital discharge. Finally, future researchers

may wish to investigate health care providers' experience of family caregivers or 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. Family caregivers reported protecting the patient's physical and emotional safety and put considerable effort into doing so, using strategies that varied based on their perception of threats to the patient's safety. Questions arose about family caregivers' perceptions of staff involvement in protecting the patient. These findings support the need for staff awareness of this phenomenon and development of an adversarial alliance between family caregivers and healthcare providers to assist with making care more family-centered and to support family caregivers' needs during the hospital stay.

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Figure 1.
Conceptual Model: Family Work

Table 1.

Sample Characteristics

Demographic variables	Family Caregivers (n=16)	Demographic variables	Patients (n=13)
Age, mean years	55	Age, mean years	47
Sex		Sex	
Male	2	Male	11
Female	14	Female	2
Race		Race	
White	16	White	13
Biological relationships, primary family caregivers		Cause of injury	
Parents	5	Fall	8
Spouses	7	Motor vehicle accident	3
Other (i.e., child)	1	Other (i.e., sports related injury and gunshot wound)	2
Biological Relationships, other family members		Length of hospital stay at time of first interview with family caregiver, mean days	26
Other (i.e., grandparent, sibling, cousin)	3	Length of stay at inpatient rehab facility, mean days	17