ASSESSING THE QUALITY OF EDUCATION AND INFORMATION DELIVERY

TO FAMILY MEMBERS OF PATIENTS WITH MODERATE TO SEVERE

TRAUMATIC BRAIN INJURY

by

Bonnie Jane Hoewing

A DNP Project Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

DOCTOR OF NURSING PRACTICE

In the Graduate College

THE UNIVERSITY OF ARIZONA

2 0 1 7

THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

As members of the DNP Project Committee, we certify that we have read the DNP Project prepared by Bonnie Jane Hoewing, entitled "Assessing the Quality of Education and Information Delivery to Family Members of Patients with Moderate to Severe Traumatic Brain Injury" and recommend that it be accepted as fulfilling the DNP Project requirement for the Degree of Doctor of Nursing Practice.

_____ Date: April 10, 2017
Matthew Gallek, PhD, RN, CNRN

_____ Date: April 10, 2017
Sharon Hom, PhD, MS, RN

_____ Date: April 10, 2017
Jane M. Carrington, PhD, RN

Final approval and acceptance of this DNP Project is contingent upon the candidate's submission of the final copies of the DNP Project to the Graduate College.

I hereby certify that I have read this DNP Project prepared under my direction and recommend that it be accepted as fulfilling the DNP Project requirement.

_____ Date: April 10, 2017
DNP Project Director: Matthew Gallek, PhD, RN, CNRN

STATEMENT BY AUTHOR

This DNP Project has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this DNP Project are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the head of the major department or the Dean of the Graduate College when in his or her judgment the proposed use of the material is in the interests of scholarship. In all other instances, however, permission must be obtained from the author.

SIGNED: __Bonnie Jane Hoewing_____

TABLE OF CONTENTS

TABLE OF CONTENTS - *Continued*

TABLE OF CONTENTS - *Continued*

LIST OF FIGURES

LIST OF TABLES

ABSTRACT

Background: Traumatic brain injury (TBI) is devastating to patients and their family members who are left trying to understand and cope with this diagnosis. This is especially true for family members of patients with TBI who are treated in the intensive care unit (ICU), which presents additional challenges. Family members are often present at the bedside and desire information about the patient and diagnosis. However, this can be a stressful event for family members as they attempt to understand the complexities of TBI. This DNP project analyzed the quality of education and information delivery from ICU staff members to family members of patients with moderate to severe TBI and used the findings to create a standardized education program for future implementation.

Methods: A mixed-model, descriptive design with both qualitative and quantitative components was used to conduct a needs assessment at an urban, Level II trauma center within the ICU. Patients with moderate to severe TBI, as measured as Glasgow Coma Scale of 12 or less, were selected. From these patients, family members and close friends who were 18 years of age and older were asked to complete surveys and interviews about their experiences with education and information delivery in the ICU. ICU staff nurses also completed surveys about their opinions of delivering education and information to family members.

Results: Over a time period of 5 months, 6 patients who met criteria were selected, and 5 family members completed surveys and interviews. Of the 56 staff nurses who received surveys, 17 participated in the surveys. Based on quantitative data, family members did not demonstrate a need for improvement in the method of education and information delivery, but provided a rich description of many needed improvements through qualitative responses. On the other hand, staff

nurses reported dissatisfaction in current method of education and information delivery in all aspects except for one.

Conclusion: Based on the results, the TBI Family Education Model was developed as an education tool that can be implemented in the future to standardize education and information delivery to family members of patients with moderate to severe TBI.

INTRODUCTION

Traumatic brain injury (TBI) results from a penetrating or non-penetrating sudden force to the head, which leads to a decrease in brain function (Centers for Disease Control and Prevention [CDC], 2015). TBI was associated with 2.5 million hospital/emergency department visits or deaths in the United States in 2010, and the incidence continues to rise (C, 2015). Common causes of TBI include motor-vehicle crashes, falls, sports injuries, and assaults (Brain Trauma Foundation, n.d.). Although around 52,000 people die each year from TBI, a total of 5.3 million Americans currently suffer disability caused by TBI (Brain Trauma Foundation, n.d.).

Background

The severity of TBI ranges from mild to severe, and is often graded using the Glasgow Coma Scale (GCS), in which a score of 3 to 8 is considered severe, 9 to 12 moderate, and 13 or greater being mild (Mena et al., 2011; Teasdale & Jennett, 1974). Moderate to severe TBI often requires treatment and/or monitoring in an intensive care unit (ICU). Managing the most severe injuries may include interventions such as

- mechanical ventilation via endotracheal tube or tracheostomy;

- hemodynamic monitoring;

- sedation and possibly induction of barbiturate coma;

- intravenous fluids and medications;

- invasive monitoring of intracranial pressure;

- surgical interventions such as decompressive craniectomy;

- eye and skin care;

- bowel management;

- nutrition and hydration;

- diagnostic tests such as radiographic imaging and blood draws;

- and a variety of nursing tasks performed frequently throughout day and night
  (Haddad & Arabi, 2012).

These interventions are complex and are overwhelming to the layperson unfamiliar with the hospital setting or type of injury. Thus, this is a stressful and uncertain time for family members of TBI patients, who often remain close by at the bedside and are sometimes relied upon to make important decisions for care as well as provide continuous support. Such a sudden and tragic event as dealing with a family member being diagnosed with severe TBI has been shown to be related to symptoms of post-traumatic stress, such as hyperarousal and avoidance behavior (Pielmaier, Walder, Rebetez, & Maercker, 2011). Turner-Cobb, Ramchandani, Began, and Padkin (2016) agree that family members of patients in the ICU suffer these post-traumatic stress symptoms, in addition to anxiety and depression. Research has suggested that family members need information, communication, and support, which is important not only in being able to understand the situation but also to be involved in care and decision-making (Bond, Draeger, Mandleco, & Donnelly, 2003; Davidson et al., 2007). Bond et al. (2003) further mention the vulnerability and distress of family members during this time, often with many unmet needs, such as the need for information and knowing.

Local Problem

Although limited research exists on the topic of TBI family education, the literature strongly supports the need for family members of critically ill patients to receive clear and consistent information (Bailey, Sabbagh, Loiselle, Boileau, & McVey, 2010; Coco, Tossavainen,

Jaaskelainen, & Turunen, 2011; Shelton, Moore, Socaris, Gao, & Dowling, 2010). Though patients and family members require teaching throughout the course of illness or injury, the initial days after admission to the ICU provide key moments where support and education are needed most. For example, Norup, Welling, Qvist, Siert, & Mortensen (2012) measured symptoms of anxiety and depression in family members of patients with severe TBI admitted to ICU, and found that these emotions negatively affected the family member's quality-of-life. Uncertainty also may prevail among family members in the acute phase of TBI, and relatives may feel uninformed—needing specific and clear information delivered consistently from the healthcare team (Keenan & Joseph, 2010).

Additionally, Pielmaier et al., (2011) revealed that family members of patients with severe TBI experience significant post-traumatic stress in the first month following injury. A review by Linnarsson, Bubini, and Perseius (2010) found that family members of critically-ill patients also experience "a sense of chaos and uncertainty" (p. 3104) as well as poor comprehension of information due to emotional distress. This demonstrates the need to assess if the current methods of education and information delivery in the ICU to family members of patients with TBI are sufficient to reduce or prevent the stress response exhibited by family members in this situation.

Little is known about the quality, cohesiveness, and effectiveness of education provided by physicians, nurses and advanced practice nurses (APNs). Few studies have sought to understand family satisfaction and comprehension of education about TBI, necessary care, and outcomes, especially within the ICU setting. For example, Bailey et al. (2010) discuss informational support to families in the ICU, but it is not specific to patients with TBI.

Furthermore, McLaughlin, Glang, Beaver, Gau, and Keen (2013) as well as Sinnakaruppan, Downey, and Morrison (2005) studied family education and training to patients with TBI, but in the community and not the hospital setting. It is therefore unclear if nurses and APNs provide adequate education and information to family members. However, this education is fundamental in decreasing negative emotional consequences and improving understanding in the acute phase of injury.

In 2014, there were 83 patients admitted with a diagnosis of non-penetrating, moderate to severe TBI (defined as GCS <12) to the ICU at Saint Alphonsus Regional Medical Center, a division of Trinity Health and a Level II trauma center in Boise, Idaho. However, TBI education resources for families of these patients are non-existent. The lack of a formal education process for family members of patients with moderate to severe TBI may result in inconsistency of information, which consequently may lead to inadequate knowledge, increased family stress, and decreased patient and family satisfaction.

Nurses play pivotal roles in the information pathway, often spending a great amount of time with patient relatives (Verhaeghe, VanZuuren, Defloor, Duijnstee, & Grypdonck, 2007). Therefore, nurses and advanced practice nurses (APNs)—key advocates for patients and their family members—should be skilled in delivering, disseminating, and clarifying important education and information to patient relatives throughout the process. Other key stakeholders include trauma physicians, neurosurgeons, intensivists, physician assistants, nurse managers, and the director of critical care at this organization.

Intended Improvement

  Purpose. The purpose of this DNP quality improvement project is to assess the quality of education and information delivery by healthcare staff to family members of patients with TBI in an urban, Northwest United States setting. Based on the findings of this quality improvement project, recommendations for standardizing TBI family education will be given.

  Project Aims.

1. Aim 1: To perform a unit-based needs assessment of quality of education and information delivery given by nurses and providers to family members of patients with moderate to severe TBI

  a. Education is defined as: knowledge of the basics of TBI and ICU admission that family members need to understand such as type of injury, equipment used, and the environment of the ICU

  b. Information is defined as: communication regarding concepts such as prognosis information, results of diagnostics, and unit procedures

2. Aim 2: Analyze survey results to determine themes and topics to be included in TBI family education for the ICU

3. Aim 3: Use survey results to develop and recommend a standardized education program to be delivered to family members of patients with moderate to severe TBI, with the inclusion of a TBI education checklist to be used with each patient; include a plan for unit-based implementation

  Reason for Change. Frustration is often voiced between nurses and family members alike regarding the varied education topics and styles, as well as the lack of cohesiveness between

members of the healthcare team when it comes to delivering information. Family members sometimes report learning about TBI from their own Internet searches, friends who have experience with TBI, and even other family members they come in contact within the waiting room. This method of self-teaching may add to physiologic and psychological stress for family members, as they are not only burdened by the need to support their loved ones, but also to independently search out information and understanding of the diagnosis. This calls for the need to equip and empower nurses and other healthcare team members to confidently provide family members with the education they need to support their injured relative in the difficult acute phase following TBI.

Project Questions

1. What is the current method of education and information delivery from ICU staff to family members and surrogates of patients with moderate to severe TBI?

2. Is there a need for standardization of the current method of education given to family members of patients with moderate to severe TBI by nurses and providers in the ICU?

3. What do family members believe are the most important topics or concepts to focus on in initial TBI education?

THEORETICAL FRAMEWORK

Model of Perceived Uncertainty in Illness

Merle Mishel's Model of Perceived Uncertainty in Illness (Mishel, 1988) will be used to guide the development of this project. TBI is often associated with feelings of uncertainty and resultant family stress, and this effect can be more pronounced in the ICU setting (Mishel, 1988; Piyakong 2014; Verhaegh, Defloor, & Grypdonck, 2005). Mishel (1988) focuses on the concept of uncertainty, describing it as "the inability to determine the meaning of illness-related events" (p. 225).

Family members of patients with TBI may experience uncertainty early in the course of illness, resulting from not knowing what is happening to their loved one, or what the outcome will be, which may be worsened by the misunderstanding or poor comprehension of medical jargon used by staff. Family members may perceive uncertainty as a danger or an opportunity to develop meaning from the circumstances (Mishel, 1988). Ultimately, depending on how the uncertainty is met, adaptation can occur through coping strategies (Mishel, 1988).
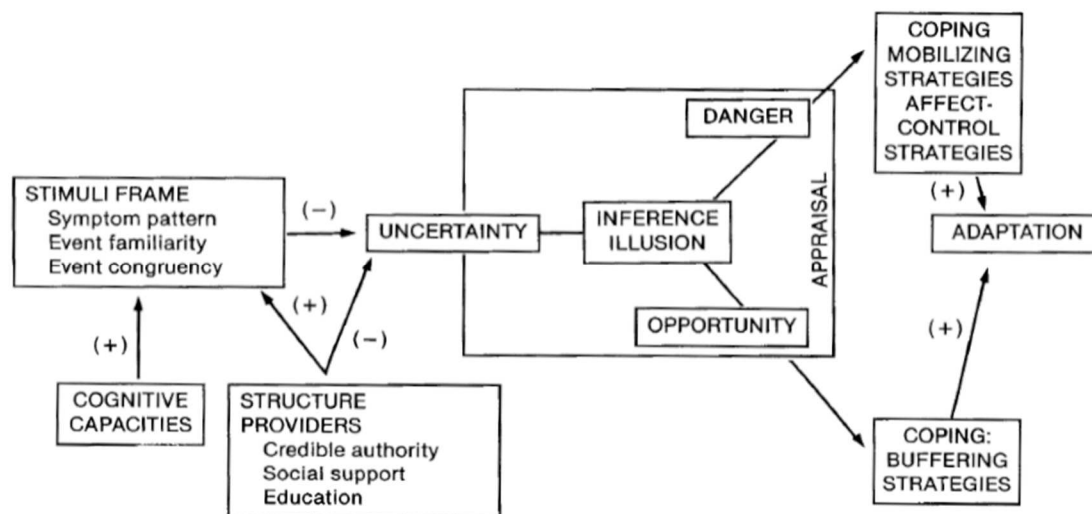
FIGURE 1. Mishel's Model of Perceived Uncertainty in Illness (Mishel, 1988). *Used with*

permission. (Copyright © 2007, John Wiley and Sons)

Figure 1 shows the process of uncertainty leading to adaptation through Mishel's

Perceived Uncertainty in Illness theory (1988), which will be used to guide this project

development. The elements of Mishel's Stimuli Frame that affect uncertainty include symptom

patterns, event familiarity, and event congruency, which are concepts perceived by the individual

(Mishel, 1988). In this project, family members encounter tenets of the Stimuli Frame when they

see the patient exhibiting behaviors or events arising from the injury (such as agitation, fever, or

neurological changes), and process these occurrences as pre-existing or new, familiar or

unfamiliar, expected or unexpected. These concepts will be included in the survey and interview

questions, exploring what events or behaviors exhibited by the patient were perceived as

unfamiliar, unexpected, or new.

Structure Providers (nurses and providers) affect the Stimuli Frame by delivering

education and information in order to decrease uncertainty and provide meaning to unfamiliar

events and circumstances faced by family members. Because family members usually do not have experience dealing with TBI, they require the help of these Structure Providers to assist with establishing meaning and understanding to these events. Mishel (1988) points out that individuals with more education are able to deal with uncertainty more quickly than those with less education, which emphasizes the importance of the relationship between family members and Structure Providers who deliver this education. Linnarsson et al. (2010) found that family members of critically-ill patients need a supportive, communicative relationship with caregiver staff to develop trust as well as create understanding.

Another factor affecting the Stimuli Frame is the cognitive capacity of the individual (Mishel, 1988). Cognitive capacity, or the ability to process information (Mishel, 1988), may be affected by family members' emotional stress, sleep deprivation, discomfort, or distractions, which may be present within the ICU setting. These elements must be appropriately addressed in order for optimal education to occur. Thus, survey/interview questions will also explore what physical factors affected the ability to learn and process information.

As this quality improvement project will focus primarily on the education and information delivered by the healthcare team as modifier of uncertainty, it is necessary to explore how the concept of uncertainty affects coping and adaptation. Because uncertainty can be an opportunity for positive learning or negative coping (Mishel, 1988), it is essential that the healthcare team appropriately address unfamiliar circumstances in order to promote appropriate coping strategies that lead to positive adaptation guided by hope rather than stress.

Understanding this process will guide the development of a survey and interview questions that center around these principles. Along with gaining an understanding of how

family members experienced uncertainty during the ICU stay, it is also important to note how the

healthcare staff (the Structure Providers) currently provide education and information to family

members. Based on the results, key concepts found during surveys and interviews that are

strongly associated with concepts such as uncertainty and coping will then be used to provide

recommendations for a future education program to be used in this context.

Planning implementation of the standardized education program to be used by the

healthcare team aligns with Mishel's (1988) belief that providing familiarity with illness assists

individuals in recognizing and appraising the unfamiliar stimuli, which is a process that

ultimately affects coping and adaptation. Improving the quality of education given to family

members of patients with moderate to severe TBI will theoretically facilitate the process of

stimuli appraisal and allow meaning and understanding to be applied to the situation more

effectively than before the intervention.

Concept Definitions

Traumatic Brain Injury. As previously stated, TBI refers to a cognitive or neurologic

alteration after a blow to the head (Watanabe & Marino, 2014). For the purposes of this project,

patients with non-penetrating head injuries with a moderate to severe TBI as defined as a

Glasgow Coma Scale (GCS) 3-12 will be considered. Because patients with moderate to severe

TBI may require substantial interventions in comparison to those with only mild TBI, this project

will specifically target these patients whose family members are apt to suffer higher levels of

uncertainty and thus be at risk for ineffective adaptation.

Family Stress. Though generally classified as positive or negative, stress is often

multifactorial. In the ICU setting, stress may be an unpleasant emotion associated with anxiety,

depression, and fear caused by "the accumulation of unmet family needs" (Lange, 2001, p. 2025). Stress, whether actual or perceived, can further be defined as a threatening stimulus, (Verhaeghe et al., 2005). In this project, the family stressor will be considered the event of TBI and need for hospitalization. Using the Mishel's Model of Perceived Uncertainty in Illness in this project to address the need for education in family members of patients with moderate to severe TBI will draw attention to the structural variations in information delivery that contribute to family stress.

Coping. Coping can be seen as the mechanism that family members employ in order to address and reduce the response to the stressor (Verhaeghe et al., 2005). The aims of this project focus indirectly around improving family coping in the acute setting of ICU admission, as satisfaction with education and information delivery will be measured through surveys and interviews. The quality of information to family members in the ICU has been shown to affect coping (Bailey et al., 2010; Keenan & Joseph, 2010), and survey results will be used to create standardized education and information delivery recommendations which will seek improved family member coping and satisfaction.

Uncertainty. Mishel, Padilla, Grant, and Sorenson (1991) describe that uncertainty stems from difficulty associating the various facets of illness with a familiar meaning. In this project, it is theorized that knowledge deficits regarding TBI in patient family members lead to uncertainty, which becomes a stressor in the initial hospitalization period after injury.

Adaptation. In this context, adaptation takes into account the concepts of family stress caused by uncertainty as well as the way in which coping occurs. According to Keenan and Joseph (2010), family members must adapt to changes within the ICU environment and to the

injury of their loved one—a process which can be supported by interaction with staff. Positive

adaptation may be promoted by guided education and information about the injury and other

factors related to the ICU, which will in turn lead to decreased uncertainty

Synthesis of Evidence

The need for family members of patients admitted to ICU—including patients with

moderate to severe TBI—to receive information has been demonstrated through both

quantitative and qualitative studies (Keenan & Joseph, 2010; Shelton et al., 2010), as well a

systematic review (Coco et al., 2011). A literature review was conducted to assess the

availability of programs, educational methods, and needs assessments regarding education and

information delivery to family members of patients with moderate to severe TBI.

Articles were located using the PubMed and Cumulative Index to Nursing and Allied

Health Literature databases. Studies were included from the past 10 years, and were limited to

English publications. Search keywords consisted of "family education;" "family support;"

"intensive care unit;" "traumatic brain injury," "need for information" and others. The research

articles found were then appraised (see Table 11, Appendix A) and concepts derived from the

literature are presented.

Family Involvement and the Need for Information. Patients with moderate to severe

TBI often rely on family members as surrogate decision makers to help direct goals of care and

to support them from initial injury through recovery and beyond. Yet, this situation is generally

a high stress, confusing, and rapidly changing whirlwind that can be challenging for relatives to

understand and cope with. Many agree that if family members are not able to appropriately

process the variety of information delivered from a number of health care professionals—due to

inconsistency, inattention by staff members, ambiguity, or medical jargon—the result may be anxiety, frustration, confusion, and dissatisfaction (Chien, Chiu, Lam, & Ip, 2006; Lefebvre, Pelchat, Swaine, Gelinas, & Levert 2005; Moore et al., 2012; & Verhaeghe, vanZuuren, Defloor, Duijnstee, & Grypdonck, 2007).

A primary theme in many studies is the overarching need of family members of critically ill patients, including patients with TBI, to receive accurate, specific, understandable, and consistent information from healthcare providers (Bailey, Sabbagh, Loiselle, Boileau, & McVey, 2010; Chien et al., 2006; Keenan & Joseph, 2010, Lefebvre et al., 2005; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007; & Verhaeghe et al., 2007). Verhaeghe et al. (2007) describe how information is "intertwined" with hope, and that adequate information is necessary in order to family members to realistically progress through stages of hope.

Improving and Optimizing Information Delivery. Several studies support the notion that improving delivery of information to patients and their family members leads to increased satisfaction and the improved ability to cope with change (Bailey et al., 2010; Keenan & Joseph, 2010; Shelton et al., 2010). In addition, Rotondi et al. (2007) found that patients with TBI and their family members identify the want to improve the recognition of needs, the delivery of understandable information, and other supportive strategies. Education topics found to be of primary interest and requested by family members include information about prognosis, injuries, treatment, long-term consequences, and transferring between units (Bailey et al., 2010, Lefebvre et al., 2005; & Rotondi et al., 2007).

The literature overall supports the notion that information is important in establishing hope and understanding, but clarification is needed to determine when education is best

delivered, as the need and type information changes over time as patients progress through and beyond the acute phase of injury (Keenan & Joseph, 2010; Rotondi et al., 2007; Verhaeghe et al., 2007). Chien et al. (2006) suggest that providing educational information during the first few days of ICU admission is essential to decreasing anxiety and other negative emotions. Therefore, a needs assessment will focus on what factors positively and negatively affect education and information delivery, including timing and topics to be discussed.

Opportunities for Education. Family education can occur in many contexts. Face-to-face communication, written documents, casual conversation, web-based programs, and formal workshops are all examples of delivering important education and information to individuals and families. Professionals delivering high-quality education may include physicians, nurses, APNs, and other members of the healthcare team. Larson et al. (2005) report results from a nurse-led program for stroke patients and found increased well-being and quality of life in participants after multiple education sessions. McLaughlin et al. (2013) describe a web-based approach to family education, and demonstrated knowledge increases in several areas. Sinnakaruppan, et al., (2005) studied a community-based approach to education after head injury and found that there were non-statically significant improvements in caregiver distress, such as anxiety and depression, but suggest that more research is needed to generalize these findings.

Though many venues and methods are available for delivering family education, their effectiveness varies. Thus, it is not known how family members will perceive the quality of informational support in each individual circumstance. This calls for a needs assessment within the specific context of this ICU to determine the overall satisfaction with the current methods of education and information delivery.

Strengths and Weaknesses of the Literature. The availability of both quantitative and qualitative research on this topic provides supporting evidence regarding meaningful descriptions of what family members experience throughout the process of TBI recovery. For example, Chien et al. (2006) quantitatively studied an educational intervention to family members in the ICU in a quasi-experimental design, which resulted in higher family satisfaction and decreased anxiety. Qualitative research also supported the notion of the need for family members to receive informational support after TBI, including research by Keenan and Joseph (2010), Lefebvre et al., (2005) and Rotondi et al., (2007). Furthermore, the availability of studies from multiple countries and settings add to the cultural and geographical diversity of information on the topic. The congruency of results and themes supporting the need for quality education and information and the effects of uncertainty and family satisfaction within the ICU strengthens the call to assess the current quality of informational support being delivered in the setting of this DNP project. This supports not only the need to answer the project question, but also the appropriateness of the theoretical framework being used in this project.

Some studies demonstrated weaknesses including small sample size (Bailey et al., 2010), lack of assessment of external factors contributing to family stress (Bond et al., 2003), or limited generalizability due to a short study period and limited demographic variability (Sinnakaruppan et al., 2005). Also, though certain studies showed an increased in family satisfaction scores within the hospital after an educational or informational intervention (Bailey et al., 2010, Chien et al., 2006, & Shelton et al., 2010), there is disagreement whether the same effect is true for satisfaction with life or other psychosocial variables outside of the hospital setting (Sinnakaruppan et al., 2005; Larson et al., 2005; McLaughlin et al., 2013). Thus, a needs

assessment designed to answer the specific project question being posed must be focused on clear-cut factors such as focusing on the time period immediately following initial TBI within the ICU setting and seek to understand more clearly what individual themes or concepts family members wish to better understand when receiving education and information.

Gaps in the Literature. Though research is available on the needs of family members in general in a hospital or rehabilitation setting (Bailey et al., 2009; Chien et al., 2005; Moore et al., 2012; Shelton et al., 2010), few recent studies were found specifically discussing family members of individuals with TBI in the ICU context (Bond et al., 2003; Keenan & Joseph, 2010; Lefebvre et al., 2004; Verhaeghe et al., 2007). There is therefore a need for more current research regarding this topic, as well as literature that recommends ICU-based education programs for TBI. Few articles were available that were published in the last 5 years that addressed the aims of this DNP project, so older studies were included, as well as studies that did not address TBI specifically but spoke to the theme of family information in critical illness.

METHODS

Design

This DNP quality improvement project will consist of a needs assessment to determine if there is a need for improvement in education and information delivery by ICU staff to family members of patients with moderate to severe TBI. A mixed model, descriptive design will be used to gather and evaluate information, as the survey will include both qualitative and quantitative questions. Patient and participant demographic data will be quantitatively analyzed to determine characteristics of participants, and qualitative interviews will be conducted in addition to the surveys. Based on the findings of the needs assessment, recommendations will be given regarding the current state of education and information delivery in this setting.

Setting and Participants

This DNP project addresses two participant groups: ICU staff members, and family members/surrogates of patients with moderate to severe TBI. ICU staff members will be recruited from a 21-bed mixed ICU serving medical, surgical, trauma, and neurosurgery patients. This ICU is seated within Saint Alphonsus Regional Medical Center, a Level II Trauma Center that is part of a four-hospital Catholic faith-based system.

Family member participants will be selected and interviewed after discharge of their family member from the ICU, preferably while they are still in the inpatient neurosciences unit or the inpatient rehabilitation center at Saint Alphonsus Regional Medical Center, which serve patients recovering from brain and spinal cord injuries, neurosurgery, stroke, and trauma. If the patient has been discharged from the hospital, then attempts will be made at distributing surveys and conducting interviews post-discharge.

The key informants for the project are the survey and interview participants, who will provide the needed knowledge and insight to answer the project question (Polit & Beck, 2012). Participants will be selected based on the following characteristics:

- Family members/surrogate group inclusion criteria:
  - Must be ages 18 and older, English-speaking, and may include immediate family members, close friends, or any other individual who is closely associated with the patient and spends significant time (greater than 2 hours per day, 3 or more days a week) at the bedside of the patient, such as unmarried significant others
  - TBI patients from whom family members/surrogates will be selected must meet the following inclusion criteria:
    - Moderate to severe TBI, defined as Glasgow Coma Scale (GCS) 12 or less at the scene of incident or at ICU admission
    - Admitted to ICU for 3 days or longer
    - Injury was non-penetrating
- ICU staff member group
  - ICU nurses
  - Physicians
    - Recruit trauma surgeons, neurosurgeons, and consultant intensivists
  - Nurse Practitioners

- May include nurse practitioners with intensivist service, as there are no nurse practitioners who regularly see ICU patients on the trauma or neurosurgery service

- Target number for key informants for each phase of the assessment:
    - For surveys: will be distributed to all ICU nurses on staff (approximately 85) as well as 5-10 providers (physicians/nurse practitioners); and target multiple family members/surrogates of at least 5 patients who meet criteria
    - For interviews: 10 family member/surrogates

Methods of Evaluation and Tools

Surveys will be distributed to all eligible staff in the ICU. ICU staff members who meet criteria based on job title may voluntarily complete the survey. Family member/surrogate participants will be chosen based on specific eligibility criteria of the patient, as determined by data in the electronic health record and listed in the trauma database. Patient data will be obtained and recorded from the medical record and trauma database with the assistance of the trauma program coordinator and will include GCS on ICU admission and/or at the scene of incident, length of ICU stay, and type/mechanism of injury. After eligible patients are identified based on the inclusion criteria specific to the patient, associated family members/surrogates will then be broadly selected from the pool of patients to participate based on the family member/surrogate inclusion criteria listed previously. Data will be de-identified to maintain patient confidentiality.

Surveys. Data collection will begin with an electronic survey based on the Critical Care Family Needs Inventory (CCFNI) (Leske, 1991) (See Appendices B and C). The CCFNI has

been used in many studies regarding family satisfaction in the intensive care unit based on the concepts of information, support, comfort, assurance, and proximity (Bailey et al., 2010; Maxwell, Stuenkel, & Saylor, 2007). Using questions developed from the information section of the CCFNI with permission of the author, two surveys will be created, one for the ICU staff group and one for the family member/surrogate group. Each survey will include both quantitative questions that will rate satisfaction with education and information delivery on a 1-4 Likert scale as well as demographic data, mixed with open-ended questions where participants will be able to qualitatively describe answers.

Survey questions will be placed into the Qualtrics website (http://www.qualtrics.com/) to create an electronic survey, which will help protect the anonymity of the respondents. Surveys will then be distributed to each participant group along with a letter explaining the purpose of the survey (see Appendices D and E). The ICU staff group will be emailed the survey letter and link, and they will have 14 days to complete the survey, with a reminder email to be sent 10 days after survey distribution. The family member/surrogate group will be hand-delivered a printed survey letter by the researcher with the link to the electronic survey to be completed online and will be encouraged to complete the survey prior to the patient being discharged from the hospital, if possible. This will ensure that family member/surrogate participants have access to the Internet through the hospital library to complete the surveys while the patient is hospitalized in the neurosciences or rehabilitation unit.

Interviews. Family members or surrogates will be asked at the time of the distribution of the survey letters to attend a voluntary interview after the surveys are distributed. This will consist of a semi-structured, recorded interview with the researcher to discuss the survey

components. Interviews will include open-ended, guided questions based on the survey topics, and will be either one on one or in a focus group setting within a family, based on the preference of the participants. Interviews will then be transcribed verbatim.

Ethical Considerations

Respect for Persons. Both the electronic and printed letters with the survey link will begin to be distributed after receiving Institutional Review Board approval and providing appropriate consent information to participants, with the understanding that completion of the survey implies consent. However, the participants being interviewed will sign an informed consent form. This consent form will ensure respect for persons and autonomy by clearly stating that participation is voluntary and the responses anonymous. After analysis, data will be de-identified in order to also ensure privacy of the patients from which family members are associated with, as well as family member/participant demographic and qualitative data. Because it is possible that vulnerability may result from patient family members feeling that the care of their loved one may be compromised by refusal to participate in the survey, they will be reassured that the project is independent of any current caregivers of the patient, and that this will not be affected.

Beneficence. As a descriptive design using both qualitative and quantitative data, the objective of a needs assessment will be safely accomplished without the risks associated with a study involving an intervention or test group. There are still some small risks, however. For example, in qualitative research, the role of researcher or clinician may be confused (Orb, Eisenhauer, & Wynaden, 2000). For this reason, the researcher's role will be clear and be

differentiated from that of a caregiver. Other risks may include causing family members to think about and discuss sensitive or painful thoughts about their loved one becoming injured.

   Justice. The population that will benefit most from the project are future family members of patients with TBI.Though the current survey participants likely will not benefit from the results, they will be helping to improve the current process for others who will be in a similar position in the future. Because the population is specific to TBI patient family members and does not specify a certain population otherwise (such as just women, or just the elderly, etc), it is a fair selection. The inclusion/exclusion criteria are broad and related to the type of injury of the patient, and they will appropriately include a wide group of eligible participants.

Data Analysis

   After surveys are completed, data will be extracted from the Qualtrics website based on the responses. Quantitative responses will be entered into a database for descriptive statistical analysis of the participant demographics as well as answers to the main survey questions. Descriptive statistics will also be used to analyze the patient-specific data, which will be extracted from the medical record and trauma database, including GCS on ICU admission, length of ICU stay, and type of injury. A statistics database will be used to calculate range, mean, and standard deviation of the quantitative responses.

   First, quantitative data will be analyzed to determine overall satisfaction with education and information delivery. With response options ranging from a value of 1 representing "not satisfied"; 2 representing "somewhat satisfied"; 3 representing "mostly satisfied", to a value of 4 representing "very satisfied" respondents will choose their answers to each closed-ended question. The responses of all completed surveys will be averaged, and an overall score of 2.5 or

less on a majority of questions on either the staff or family member survey will indicate the need for improvement in education and information delivery.

Next, qualitative responses will be analyzed for themes within the answers using content analysis. Open-ended questions to the surveys and interviews will be categorized by theme and summarized. Thematic analysis will be used to look for similarities in survey responses (Polit & Beck, 2012). Once themes and patterns have arisen from the data, they will be analyzed by context and further described using matrices or tables to categorize the content by participant (Polit & Beck, 2012).

Once interpreted and organized into concepts, the categories of themes discovered in qualitative content analysis will be compared with the quantitative data in a mixed-methods analysis. This will involve combining the quantitative and qualitative data into meta-matrices that include the answers to the closed-ended questions, as well as the major concepts pointed out in the open-ended questions into a table of results (Polit & Beck, 2012). These matrices will then be summarized into constructs found from comparing the quantitative and qualitative responses.

Opportunities for Future Implementation

The survey and interview findings will be used to make recommendations for a standardized method for education and information delivery. This will include the development of an education and information communication checklist that can be used in the future to guide education for family members, applying the most pertinent and sought-after topics as described by the results of this project. These results, including the needs assessment and proposed checklist, could serve as part of a larger quality improvement project where future implementation would be recommended in order to standardize the methods of education and

information delivery to family members of patients with moderate to severe TBI in this urban hospital setting.

After completion of this portion of the project, the plan-do-study-act (PDSA) cycle (W. Edwards Deming Institute, 2015) could be used to implement the checklist and new education program on the unit. This cycle uses a series of steps to implement changes on a smaller scale and includes setting goals and measurements and testing and implementing changes, among other processes to lead to organizational improvement (Institute for Healthcare Improvement, 2015). The model design allows for selection and implementation of a newly adapted education program with a target date for implementation, and would transition through small-scale introduction to unit-wide practice change.

The use of a logic model would also be included in the plan for implementation. Logic models are visual representations of the series of steps included in a plan for change (W. K. Kellogg Foundation, 2004). The logic model for this project would include a depiction of the needed inputs of resources such as staff members and educational materials in combination with the outputs of training sessions and the education checklists to meet proposed short-term and long-term outcomes of improved education and information delivery and the potential for improved satisfaction and quality of care.

RESULTS

Here I present the results of this quality improvement project that sought to assess the quality of education and information delivery to family members of patients with moderate to severe TBI, guided by the project aims.

The data collection process was carried out over a period of approximately five months, from August, 2016 to December, 2016, in which respondents participated in the two main phases of the evaluation. Of the 56 surveys distributed to nurses, 17 (30%) completed the survey. No providers responded to the surveys. Surveys were distributed to multiple family members chosen by convenience sampling of 6 patients who met inclusion criteria, and 5 surveys and 5 interviews were completed.

Staff surveys were emailed to the nurse assistant manager for distribution to the staff nurses via an emailed letter containing the survey link. An email was also sent to the trauma coordinator and another physician for distribution to other physicians but due to poor response, the surveys were focused instead on the nursing staff input.

The trauma coordinator searched the trauma database each month for qualifying patients based on the inclusion criteria for the survey. For patients who were still in the hospital, the DNP student then hand-delivered surveys to the family members of those patients if they were present, or left them with the bedside nurse to give to the family members. For ease of data collection and/or time limitations, some family members chose to complete the survey verbally with the principle investigator who then completed the data entry into the Qualtrics website, and also completed the interview at the same time. This process was repeated several times until the target number of patients was reached. Due to difficulty with availability of family members at the

bedside, some family members were reached by phone to complete the survey and interview over the phone. Surveys were also conducted after ICU discharge in the neuroscience unit, but additionally, there were some family members of patients with a prolonged ICU length of stay who agreed to participate in the survey while still in the ICU.

Interviews with family members were transcribed and analyzed by theme of responses by the DNP student. The themes were used to compare with survey answers. Patient demographic information was de-identified and extracted from the medical record and trauma database. Survey responses were downloaded from the Qualtrics website, which also generated tables and statistical information including range, mean, and standard deviation which are summarized below.

Description of Respondents

Staff Member Group. Of the 17 staff members that participated in the survey, all were reported as staff nurses. Most (47%) endorsed spending greater than 60 minutes in family member teaching/support each day, and reported 2-3 shifts spent caring for the same patient with moderate to severe TBI. These factors are demonstrated below in Tables 1 and 2.

TABLE 1. *Time Spent per Shift in Family Member Teaching/Support*

Time in Minutes	Responses	Percentage
15-30	2	11.76
30-45	2	11.76
45-60	5	29.41
>60	8	47.06

TABLE 2. *Shifts Spent with Same Patient*

Number of Shifts	Responses	Percentage
1	0	0
2	7	41.18
3	7	41.18
4	1	5.88
5	0	0
>5	2	11.76

Family Member Group. Five family members participated in the survey and subsequently the interview. Most (60%) were described as adult children of the patient, though there was also 1 parent and 1 significant other who participated. Two of the five reported spending 3.5 to 4 hours during each ICU visit, and the other three reported spending more than 5 hours at a time. Three of the five visited 6-7 days per week. Two reported a background of having some college education, and three had an associate's degree completed.

Patient Demographics. Six patients who met criteria for moderate to severe TBI with an ICU length of stay 3 days or longer were chosen during the data collection period for family member survey distribution. Their characteristics are listed in Table 3.

TABLE 3. *Patient Characteristics*

Patient	Age	Initial GCS	LOS	Nature	Type
A	60	12	16	MCC	SDH, cerebral contusion, skull fx
B	53	5	4	MCC	SDH, SAH, skull fx
C	89	7T	4	Pedestrian vs car	SAH
D	43	7T	41	MVC	DAI, SDH, skull fx
E	52	3T	7	Bicycle vs car	ICH
F	23	12	11	MCC	SDH

Abbreviations used: GCS: Glasgow Coma Scale, LOS: Length of stay, MCC: motorcycle collision, SDH: subdural hemorrhage, SAH: subarachnoid hemorrhage, fx: fracture, DAI: diffuse axonal injury, ICH: intracranial hemorrhage, MVC: motor vehicle collision; "T" next to GCS score denotes that the patient is intubated at the time of measurement

Quantitative Survey Results

Staff Surveys. Staff nurses were asked to rate on a scale of 1 to 4 their perception of the quality of time spent with caring for patients with moderate to severe TBI and their families, through the survey shown in Appendix B. Results for each question are shown in Table 4. Responses are rated as follows: 1=never/not satisfied, 2=sometimes/somewhat satisfied, 3=usually/mostly satisfied, 4=always/very satisfied. The last column of Table 4 represents those areas in which the mean score was 2.5 or less, which indicates a need for improvement.

TABLE 4. *Staff Survey Results to Closed Ended Questions*

Question	Min Value	Max Value	Mean	Standard Deviation	Needs Improvement
Are you satisfied with the current method of delivering information and education to family members of patients with moderate to severe TBI?	1	3	2.313	0.602	Yes
How well do you feel that providers (physicians, nurse practitioners, physician assistants) adequately deliver information and education to family members of patients with moderate to severe TBI?	1	4	2.125	0.719	Yes
How satisfied are you with the method of organizing/standardizing family education so that information is delivered consistently?	1	4	1.625	0.806	Yes
How well do you feel the healthcare team delivers all needed information to family members?	1	3	2.188	0.544	Yes
How satisfied do you perceive that family members are with the current method of receiving education/information from the healthcare team?	1	3	2.062	0.680	Yes
How well do you feel that the healthcare team delivers information/education about diagnostic results and laboratory data?	2	4	2.375	0.719	Yes
How well do you feel that the healthcare team delivers information/education about the type of injury?	1	4	2.313	0.602	Yes
How well do you feel that the healthcare team delivers information/education about plans for patient transfer?	1	4	2.688	0.704	No
How well do you feel that the	1	4	2.375	0.806	Yes

healthcare team delivers information about prognosis?					
How well do you feel that the healthcare team delivers information about unit policies, procedures, and resources?	1	3	2.313	0.704	Yes

As shown, there were no areas in which staff members averaged a response of usually/mostly or always/very satisfied. Though scores in most areas ranged from 1 to 4, 90% of the responses (all but one) suggested the need for improvement with a mean of <2.5. No areas scored an average of 3 or above. One area, scored particularly low with a mean of 1.625, which described nurses' satisfaction with the method of organizing/standardizing family education so that information is delivered consistently. The highest scoring area with a mean 2.688, was the area of satisfaction with delivering information about patient transfer.

Family Member Surveys. Similarly, family members of the patients described were asked to complete a survey rating their feeling about the time their loved one spent in the ICU on a scale of 1 to 4 as shown in Appendix C. Results for each question are shown in Table 5. Responses are rated as follows: 1=never/not satisfied, 2=sometimes/somewhat satisfied, 3=usually/mostly satisfied, 4=always/very satisfied. The last column of Table 5 represents those areas in which the mean score was 2.5 or less, which indicates a need for improvement.

TABLE 5. *Family Member Results to Closed Ended Questions*

Question	Min Value	Max Value	Mean	Standard Deviation	Needs Improvement
Were you satisfied with how often you were able to talk to the doctor (or nurse practitioner/physician assistant)?	2	4	3.00	0.63	No
Were you satisfied with how often you were able to talk to the nurse?	3	4	3.80	0.40	No
Were your questions answered in a way that you could understand?	3	4	3.80	0.40	No
Do you feel that your questions were answered honestly?	3	4	3.80	0.40	No
How well did the ICU nurses explain what was going on with the patient?	3	4	3.80	0.40	No
How well were you explained to about the patient's type of injury?	3	4	3.60	0.49	No
How well were you explained to about the different tests that patient had and what the results were?	3	4	3.60	0.49	No
Were you given directions about what was ok to do and what you couldn't do while visiting the patient?	2	4	3.20	0.98	No
Were you explained to about what the prognosis would likely be, and if not were you told why?	2	4	3.00	0.89	No
Did the nurses tell you enough about the ICU that you felt comfortable while visiting?	3	4	3.80	0.40	No
Were you told about other people that you could talk to if you needed help with something, such as chaplain, social worker, case manager, or others?	1	4	3.00	1.26	No
Did the nurses explain what they were doing to the patient and why?	3	4	3.60	0.49	No
Did the doctors, nurses, and other healthcare personnel introduce	3	4	3.80	0.40	No

themselves and tell you what they would be doing for the patient?					
Did you feel that there was someone you could talk to if you needed extra help, had questions, or concerns about the care of the patient?	1	4	3.00	1.10	No
Did the doctors, nurses, and others speak in language that you could understand?	3	4	3.80	0.40	No
Were you told about plans to transfer the patient out of the ICU ahead of time, and in a way that you could understand?	2	4	3.40	0.63	No
Were you told when the patient had a change in condition?	2	4	3.40	0.80	No
Were you given an update every day by the nurses or doctors about the patient's progress?	1	4	3.20	1.17	No

In contrast to the staff member survey, the family member survey results for the closed

ended questions had a mean of greater than 2.5. In fact, no questions scored less than a mean of

3, which did not suggest any obvious areas that needed improvement. However, there were a few

areas where scores ranged from 1-4, which means that there was at least one respondent who was

unsatisfied with the area represented in the corresponding question.

Qualitative Survey Results

Family Member Answers. Transcribed interview answers were analyzed by looking for

themes and similarities within the open-ended questions. Within the interviews, nine main

categories of themes were observed. These are described in Table 6, with definitions of each

category and examples of included themes from the qualitative results.

TABLE 6. *Categories of Themes Observed in Qualitative Interviews*

Category	Definition	Example Themes
The need for basic information	Learning about patient location, unit procedures and policies, identification of persons, etc.	Knowing unit policies, procedures, and restrictions Wanting to know all that can be told Knowing what resources or support staff are available
Understanding worth	Conveying to staff the importance of the patient to the family members	Importance of family members within the family unit Patients as a special being
Reaching mutual understanding	Setting the boundaries of knowledge between staff and family members by having to explain the need for information or what information is most desired	Having to ask for what should be told Telling providers about dissatisfaction of knowledge gap Overcoming initial misunderstandings
Uncertainty and the desire for specific diagnoses and results	Wanting to know about the type of injury and what it means, as well as results of tests and imaging studies as soon as they are available	Results of diagnostic testing Degree of brain damage Prognosis Condition
Frustration with mixed messages	Lack of consistency in received information that leads to distress and confusion in family members	Having two physicians guiding care: neurosurgeon & trauma surgeon, sometimes differing information Waiting versus "giving up"
Importance of timing in receiving information	Ensuring that information is received when it matters most and avoiding delays in communication, as well as the need to know that there is not a specific timeline to individual recovery or prognosis	Knowing when milestones can or cannot be expected Hearing specific numbers, i.e. "6 months" Being told at the beginning that it will be a long process
The need for honesty and direct answers	Wanting to hear straight, truthful answers without "sugarcoating"	Truth versus "wishful thinking" What does "stable" mean?—can be good or bad The need to know the actual truth

The desire to understand the process of injury/healing	Needing help to figure out what is most common or expected in terms of progression of injury/healing, and what would be expected to be normal/abnormal in the short- and long term	Fear/uncertainty Ups and downs in recovery "Baby steps" What is normal?
The need for face to face communication and debriefing	Preference of family members to be present during physician rounding, or receive a formal update/debriefing instead of hearing information secondhand	Need for formal debriefing/family meeting Piecing together bits of information gained from each family member Not seeing the doctor

Congruencies in categories and themes in the qualitative data were found between interviewees

as manifested in the responses to interview questions. These are summarized by respondent in

Table 7.

TABLE 7. *Qualitative Categories of Themes by Interview*

Interview	Category	Exemplars in Qualitative Answers
1	1	*We weren't kept informed very well…I'd come down to see her and she wasn't here. They said she was in CT. I came back later and I said "how long has she been here?" and they said "a while" and I said "and you didn't think to tell me she was back?"* *Even if it's a basic, basic thing we want to know…I think basically they were taking care of her they just weren't letting us know what was going on and we wanted to know, to the extent that we can be told.*
2	1	*The first couple of days I didn't know where she was. I didn't know if there was a CT scan, if the brain had damage or…we didn't know. And I was not happy with that.* *I've seen the neurosurgeon. He's come in once. Looked at her, shook my hand, introduced himself and then walked out. I never knew why he came in the room.*
3	1	*I was on my phone when I was in there and [the nurse] told me I wasn't allowed to do that, which, no big deal, but I had no idea about the rules until I went back there and asked about visiting times and stuff…* *Nobody really explained that stuff to me (availability of*

		resources)…I kind of reached out and asked for a chaplain and then I had to reach out and try to figure out a social worker.
1	2	*We talked to the doctors the next day and they have been on top of it ever since. Actually, we had one of the nurse managers come out and talk to us during that time because we were a little disgruntled about the whole thing…* *It all stemmed from lack of communication that first week…once we got all that straightened out, we had no problems.* *Once the initial misunderstanding, it's been fine ever since.*
2	2	*The nurses and the other staff didn't quite know what to tell me about the CT scans and stuff like that…it just drove me crazy*
1	3	*[She's a] special person. All the nurses know her.*
2	3	*This is the most important person in our world, and to them it's a name or a number…*
3	3	*…make sure you have their next of kin on file, because…nobody knew about me until I called them.*
1	4	*In the first three days we had some kind of up and down news and didn't know which direction it was going to go. They really did tell us out of the gate that it was gonna take a long time, but…when he stood right there and said "give her 6 months"…that's what wasn't clear to us.*
2	4	*We know she had some bleeding on the brain, but they did a CT scan and I never heard the results of it…they still never said how extensive the damage was or how not.* *We're still waiting…so they finally today took the images of her arm and we haven't gotten the results back.*
3	4	*That's what I need help with but am…kind of struggling to get the answers for all of that.*
1	5	*…about extubating her and letting her go, and I think the doctor set us straight on that. If the doctors had told us that beforehand…but they didn't. They'd been telling us all along, "She's stable, just give her time."…so kind of some mixed message of "she's doing good give her time" and then kind of the other end of just "give up."*
2	5	*…we've heard that her arm was broken, then we heard that it was just possibly shadows of old breaks…the funny part is that when we were talking about that earlier they didn't even know which arm we were talking about.*

3	5	*They were talking about transferring him to a skilled facility but now they're talking about putting him in rehab…and nobody talked to me prior that that because I didn't know what he had for medical coverage…*
1	6	*If the doctors would have told us that beforehand…we didn't just get the 'just give her time part'…when she opened her eyes at 2 weeks we thought she was gonna be walking the next day.* *We know now that we don't know when we can't expect anything, and that's taken a big stress off of us and we're… not expecting it because if we expect it then we get let down.*
2	6	*I've never gotten a prognosis on where we stand on time. Now I understand that some of that takes a while, but they had told us this the day after she came in…* *It's like a waiting game; it just drove me crazy.*
1	7	*We want you to lay it out. Just tell us. We need to know. We don't care about how bad it is or how good it is, we just want it all laid out…I think he needed us to tell him that—that we're not those kind of people where you need to sugar coat it; we want it real.*
2	7	*She's getting better. We're seeing things…but we're not sure if it's our wishful thinking…I've never talked to a doctor.*
3	7	*I'm still not getting straight answers on what I should and shouldn't be doing.*
1	8	*I think we were a little bit confused about the process of some of this stuff and how it all…I think the process was confusing…so now we know…it's all baby steps; we don't know when they're gonna quit or how far they're gonna go but we're taking every one of them.*
2	8	*I know this probably, a lot of what she's doing is normal for what she's hand, what's happened for her…but the nurses and the other staff didn't quite know what to tell me about the CT scans and stuff like that.*
3	8	*I think they did a fantastic job of explaining everything to me, keeping me updated.*
1	9	*The nurses are so good about letting us know what's going on. The doctors have been coming in. We see a doctor almost every day.*
2	9	*There was about 7 of us at the time and it would have been really nice to have like a briefing. I'm used to that. I like to have that information. We were all together in the waiting room and it was a constant, "What did you hear?" "What*

		did you hear?" We were piecing together little bits of information because there was only 2 people allowed in the room at a time. So when we'd go in there, we'd get a piece of information and have to piece it all together when we get together with the rest of the group.
3	9	*...when the doctors did their rounds and I wasn't there when they did it, we had to rely on chart notes to find out what was going on...*

Staff Member Answers. Staff members were not interviewed. Rather, they had the opportunity to provide answers and feedback to the following open-ended questions at the end of the online survey:

1. What do you feel could be done better to improve information delivery from nurses to patient family members?

2. What do you see as barriers to delivering information/education to patient family members?

3. What information or communication do you feel is the hardest for patient family members to understand?

4. What information or communication do you feel is the hardest for patient family members to understand?

5. What information or communication do you feel is the most important for patient family members to understand?

These answers were analyzed and compared with the categories of themes discovered in the family member surveys. These congruencies are listed in Table 8. These represent where staff members and family members shared similar ideas in regards to needs or deficiencies of the current process of education and information delivery.

TABLE 8. *Staff Results to Open Ended Questions*

Question (from staff survey)	Verbatim Answer	Category (from family member survey)
1	*Family members often want more information than we can provide as a bedside nurse.*	9
1	*Consistent and realistic information*	7, 5
1	*Have better tools and resources to help explain processes*	8
1	*Some standard handouts might be helpful, but the biggest hurdle, I think, is having time to spend at the time the family is ready.*	6
1	*More printouts given. also, opening up the circle of communication, find out what the questions are, and clear up any misconceptions*	1, 5, 9
1	*More consistency with key words*	1, 5
1	*Not having to wait for the provider to give the results of CT scans and other diagnostic information*	4
1	*The MDs need to be present to answer questions and deliver results from diagnostic tests in a timely manner."*	6, 9
2	*Lack of understanding/education*	1
2	*Time demand on physicians - family structure/coping abilities - no organized method of when and how to approach families*	6
2	*Mixed message from multi providers*	5
2	*Many people have false preconceptions based on anecdotal accounts or TV/movies. It is also difficult to strike the right balance between hope and realism.*	7, 8
2	*Each nurse describing what is happening or what has happened differently*	5
3	*Translating the injury to everyday life - etc. the patient will need a feeding tube - thus never able to eat or drink again and needing assistance to feed by pump, etc.*	8
3	*Many times the patient "looks" ok to the family, so it is hard for the family to*	6, 7, 8

	understand how bad the brain is injured and the consequences of that injury.	
3	*Pathophysiology and outcomes*	4, 8
3	*When news is not what they wanted or expected, it can tend to shut the doors to communication.*	2
3	*Lack of consistency with follow up exams and waiting too long to have results*	4, 5, 6
3	*The seriousness of the injury. Real life is not like TV. Not everyone can return to normal post injury.*	7, 8
4	*It's a battle every day and there will be good and bad days, but the road to recovery is LONG & HARD.*	6, 7, 8
4	*The degree of injury and long term prognosis*	4
4	*What's happening and why we are doing what we are doing*	1, 8
4	*Rarely, we can say something with certainty, such as, "Medical care is futile, this is a deadly injury.", or "Your loved one will recover well from this." Mostly we can offer our best guesses only. But if we say we are sure, then we really are sure, not just guessing.*	4, 6, 7, 8
4	*The plan, what the short term goals are, and someone to be completely realistic if a patient's family is still focusing on an unrealistic goal*	7, 8
4	*The future process and exactly what the next few years will look like*	7, 8
4	*Long-term implications of injury*	8
4	*Diagnostic results and how they pertain to the plan of care and ultimately goals for patients back at home*	4, 8

As shown in Table 8, there were congruencies between most of the categories derived from family member survey answers and what the staff members felt were important pieces of family teaching. The most common category shared between staff and family member survey answers were numbers 8, 7, and 6. These are the categories of themes that family members

described as in their responses to survey questions as being significant and were also felt by staff members to be either important or challenging to present to family members during daily bedside teaching. The frequencies of categories of themes that emerged in the staff survey responses are shown in Table 9.

TABLE 9. *Frequency Table for Categories Discussed in Staff Responses*

Category	Frequency	Percentage
1	4	8.7
2	1	2.1
3	0	0
4	5	10.9
5	5	10.9
6	7	15.2
7	8	17.4
8	13	28.3
9	3	6.5

In summary, quantitative data from staff surveys showed a mean score of <2.5 (indicating the need for improvement) in all areas except for the area regarding plans for patient transport. Conversely, quantitative data from family member surveys had a mean score of >2.5 in all areas (indicating no need for improvement). For the interviews and surveys, the answers to open-ended questions by staff members seemed to mirror themes given by family members during qualitative interviews, with the most common categories of themes being 8, 7, and 6, respectively, out of a total of 9 main observed themes.

DISCUSSION

Here I present a discussion of the findings from this quality improvement project.

Demographics

Staff Members. Only nurses participated in the staff member survey. No providers responded to the survey, which is likely due to difficulty with direct communication between the researcher and the providers. Emails containing the survey letter and link were sent to the director or head of the provider groups with anticipation that communication would be forwarded to all providers within the respective service. It is uncertain if the emails were received or forwarded. The ability to hand deliver letters may have increased response, but logistically this was not possible due to factors such as limited face to face availability of the providers and scheduling difficulties. However, nearly one third of nurses responded and completed the surveys, which was likely due to closer contact and communication between the researcher and nursing staff.

Of the nurses that responded to the survey, a majority (nearly half) reported spending greater than an hour per shift in family member teaching/support. This is important because a greater amount of time spent in contact with family members likely allows for a more significant insight into the challenges and strengths of the current method of education and information delivery to patient's family members. Likewise, all nurses reported spending at least 2 shifts with the same patient, which implies more time spent with the family members of the same patients.

Patients and Family Members. There were 6 patients who were chosen based on inclusion criteria. This exceeded the target number of 5 patients. The initial plan was to survey patient's family members outside of the ICU in the other inpatient units during the patient's

recovery. However, this was challenging due to lack of availability of patient family members throughout the day, above normal length of ICU stay of some patients, patient deaths while in the ICU, and extenuating circumstances (profound grief or withdraw of life support) that made surveying/interviewing inappropriate on the day of data collection. Therefore, some patients were surveyed or interviewed over the phone. Furthermore, the survey link that was provided by Qualtrics to reach the survey website address was comprised of random, lengthy characters that were difficult to type in correctly, which may have deterred some family members from participating in the survey. Therefore, the researcher verbally conducted some of the studies at the bedside of the patient, or provided a printed copy, which was later electronically submitted by the researcher.

Most family members (60%) reported visiting nearly every day per week, and all reported spending at least 3.5 hours during each visit. As with the staff member survey, this helps to provide a greater insight into the quality of information and education received throughout the ICU stay. However, this does not represent family members who spend very little time at the bedside and are therefore less available for receiving information and education. Furthermore, all of the family members reported having at least some college education, if not a college degree, so this may limit or exclude family members who do not have any college education or perhaps who had not even completed a high school degree.

The mean age of the patients in the project was 53. Of the six patients chosen, the average length of stay was 13.8 days. Though the literature varies on ICU length of stay depending on geographical location, age group, and severity of injury, one study by the National Health Statistics Reports describes an average ICU length of stay for patient with TBI of all

severities was 1.2 days (Levant, Chari, & DeFrances, 2016). When comparing survey results to the literature, the population in this project had a significantly longer length of stay; however, this may be somewhat skewed by the outlier who was in the ICU for 41 days. A longer than usual length of stay provides more opportunity to receive education and information, but may not accurately reflect the experiences of those family members with a shorter length of stay who require delivery of information and education more succinctly. Severity of brain injury of the patients ranged from very severe (GCS 3T) to moderate (GCS 12). All of the patients in the project were injured in some way by a motor vehicle (half by motorcycle collision and the other half by automobile, including pedestrian or bicycle), which is the third leading cause of TBI nationally (CDC, 2015).

Key Findings

Staff Member Surveys. In general, staff members indicated the need for improvement in education and information delivery in all areas surveyed except one, which was in regards to delivering information about plans for patient transfer. The lowest scoring area regarded standardization and organization of education and information delivery to provide consistency. The responses to the quantitative questions of the staff member survey demonstrated that staff members are indicating a need for improvement of education and information delivery to family members. Regardless of how family members perceived the information received from staff, the staff nurses conveyed a general dissatisfaction with the current method of education and information delivery in all areas except for one (plans for patient transfer) which is shown in Table 4. This suggests the need for improvement in terms of the methods of staff nurses are equipped to deliver education and information to family members, especially in the lowest

scoring area of standardization of delivery. Not only did this help to fulfill project aim 1, which was the needs assessment, but also supports aims 2 and 3, which include the development of a TBI education model to help direct which topics need to be included in family education.

As presented in Table 4, staff nurses reported dissatisfaction in areas such as organizing/standardizing information for consistency of delivery, presenting diagnostic and laboratory results, discussing type of injury and prognosis, and others. Frustration with the current method of providing information to family members in the ICU may stem from communication difficulties between ICU nurses and family members. This phenomenon has been documented across literature. For example, Eggenberger and Sanders (2016) describe that, though nurses are an important key to providing comfort and support for family members, there are challenges including decreased nurse confidence and/or knowledge and skills that may interfere with the nurse-family relationship. A literature review by Adams, Mannix, and Harrington (2015) also point out that additional barriers such as limited time or location to talk with family members, fear of giving the wrong answer, or feeling that it isn't the job of the nurse to give certain information may hinder nurses from fully supporting family members in terms of giving information. Thus, it appears that the literature also supports the notion that there are gaps in education and information delivery from healthcare providers to family members, and that this problem is not just a local problem. The challenges presented in the literature such as decreased confidence or knowledge, fear, or time barriers are a universal difficulty, which could be addressed by an education model developed to minimize these obstacles.

Interestingly, the quantitative data seemed to align with qualitative results for the staff surveys. As shown in Table 8, there were many statements by staff nurses that were consistent

with dissatisfaction with the current method of education and information delivery. For the staff survey, it was not helpful to construct a meta matrix describing which questions/categories of themes represented the need for improvement by quantitative analysis and which qualitative answers supported this need, because all but one area described a need for improvement, which seemed to be demonstrated in nearly all of the qualitative answers as well. Some examples of congruencies of categories of themes between quantitative and qualitative answers from staff surveys are listed in Table 10. Likewise, the category that is incorporated from the family member survey is also described.

TABLE 10. *Comparison of Quantitative and Qualitative Answers from Staff Surveys*

Quantitative Question	Representing Category	Qualitative Answer
How satisfied are you with the method of organizing/standardizing family education so that information is delivered consistently?	5	*Consistent and realistic information* *More consistency with key words* *Mixed messages from multi providers* *Each nurse describing what is happening or what has happened differently*
How well do you feel that the healthcare team delivers information/education about diagnostic results and laboratory data?	4	*Not having to wait for the provider to give the results of CT scans and other diagnostic information* *...waiting too long to have results* *The degree of injury and long term prognosis diagnostic results*
How well do you feel that the healthcare team delivers information about prognosis?	8	*Have better tools and resources to help explain processes* *Pathophysiology and outcomes* *The seriousness of the*

injury…
The future process and
exactly what the next few
years will look like
Long-term implications of
injury

Family Member Surveys. On the other hand, the family member survey quantitative

results did not indicate a need for improvement in any of the areas, based on the scoring of

answers to the closed ended questions. However, when compared with the qualitative answers,

there was not an obvious congruency with the qualitative scores. For example, family members

indicated satisfaction in every area in the quantitative survey, but qualitative answers clearly

expressed sentiments of dissatisfaction in many areas with statements describing

misunderstandings, lack of briefings, being "disgruntled", and miscommunication. However,

there were also statements praising the nursing staff and providers for keeping them well-

informed.

Based on the qualitative results, it was anticipated that the quantitative answers would

demonstrate a need for improvement in at least one area, but this was not the case. It is difficult

to say whether or not the quantitative and qualitative data aligned, because it is possible that

family members were overall satisfied with education and information delivery, but rather chose

only to speak during the qualitative interviews about occasional events and concerns in which

they were unsatisfied.

Interpretation of Results

Most importantly were the nine categories of themes derived from the qualitative portion

of the family survey, which are key in developing an education model to guide future family

education. These categories arose from the open-ended questions from the family surveys, which describe the most important topics and needs for information and education as described by patient family members. These categories of themes are reiterated in Figure 2.

1. Need for Basic Information	4. Desire for Specific Diagnoses	7. Need for Honesty
2. Reaching Mutual Understanding	5. Frustration with Mixed Messages	8. Understanding the Process
3. Understanding Worth	6. Importance of Timing	9. Face to Face Communication

FIGURE 2. Categories of Themes for Family Education

These categories of themes were not only described in more than one interview, but were also mentioned by staff as being important or difficult topics for family education/information. In other words, these categories aligned between family member interviews and emerged as well again within the staff member surveys (see Tables 6-8). Additionally, many of these categories were common between the quantitative and qualitative portions of the staff surveys (see Table 10).

These categories of themes derived from the data collection process also are congruent with the literature on the subject of family needs in the ICU, for family members of patient with TBI, or both. For example, in their study on supporting families in the ICU, Bailey et al. (2010) found that providing basic information such as ICU orientation and available resources are important family needs (category 1). They also discuss the importance of preserving patient dignity and being "treated as a person" (category 3) (Bailey et al., 2010, p. 120). The need for

consistent information (category 5) as well as honesty in information delivery (category 7) are

pointed out by Bond et al. (2003) in their article on *Needs of Family Members of Patients with*

Severe Traumatic Brain Injury. Uncertainty (category 4) is a prevailing theme in Keenan and

Joseph's (2010) study on family members of severe TBI patients in ICU, which they describe in

three phases: "not knowing", "waiting", and "uncertainty", which are in the forefront of the

thoughts of patient family members during the ICU stay (p. 27). Lefebvre and Levert (2006)

depict the difficulty with predicting the process and outcome of healing after TBI, which leads to

uncertainty and may contribute to dissatisfaction (categories 4, 8). O'Malley and Lawrence

(2011) implemented an education model to for family members of patient with TBI, and found

during postimplementation surveys that it was helpful when families were able help direct their

learning by choosing the topics that they wanted to learn about, which is similar to category 2.

Additionally, Verhaeghe et al. (2007) report that family members learn to "become more active

in collecting and interpreting information" over time, which is important for them to have hope

(p. 1495). Bond et al. (2003) quote one family member's prolonged ICU experience as described

as a "roller coaster" from one extreme to the next as the patient progressed through the process,

and another family member describing the importance of timing and the need for a family

conference to prevent prolonging the patient's life unnecessarily (category 6) (p. 68). Family

meetings may also help to promote more clear, direct explanation of patient information to

family members of ICU patients, especially when multiple providers or specialists are involved

in the patient's care (Gay, Pronovost, Bassett, & Nelson, 2009).

Overall, the outcome of the needs assessment based on quantitative surveys showed that

there was a substantial need for improvement in nearly all areas of family education and

information delivery as determined by staff, but not necessarily by the family members. Perhaps this demonstrates the need for nursing staff to feel better equipped, organized, and consistent in information delivery and family education. Though not necessarily reflected by family members on the receiving end of the information, staff nurses verbalized a dissatisfaction in education and information delivery, thus signifying the need for process improvement. The qualitative data from nursing staff support this need, and recommend areas for specific gaps in current practice. This was the anticipated outcome of the needs assessment, though it is possible that the results may have been different if providers as well as staff nurses also participated in the survey as was initially planned.

On the other hand, the quantatitive family member surveys did not show a dissatisfaction in any of the areas, though qualitative data suggested need for improvement. This was not the anticipated outcome. This may reflect high quality education and information delivery by staff nurses, but it is uncertain if the results would be the same if the project was expanded to a larger sample or to family members who spent less time at the bedside.

Limitations

It is possible that the selection process affected the results. For example, patients were chosen based on inclusion criteria; however, the family members that participated in the interview process were mostly individuals who were present at the bedside more frequently. This may therefore not be fully representative of the input of individuals who were present less often at the bedside and therefore may have had less opportunity to receive education and information. Furthermore, the family members who voluntarily participated in the survey may suggest that they are generally more involved individuals who actively seek out information, and therefore it

is possible that the results lack input from less participatory family members. In order to try and reduce this factor, the researcher attempted to contact family members who were not present at the bedside by phone, but there was poor response with this method. Also, as discussed above, the survey did not include answers from providers, so it is uncertain if the provider group would describe a dissatisfaction of current methods of education and information delivery.

Strengths

The sample patients in this quality improvement project included a wide range of TBI severity, with GCS from severe (3T) to moderate (12), and was representative of a variety of ICU length of stay. Type of injury was consistent across the patient sample, and is representative of the most common types of brain injury and mechanism. All three project aims were fulfilled through this quality improvement project. Also, qualitative data was felt to be a rich representative of family member input, and was consistent across family member groups.

Summary

To answer aim 1, the results in general demonstrated a dissatisfaction by staff nurses of the current practice of information delivery and education to family members of patients with moderate to severe TBI. Family members did not report a general dissatisfaction with receiving information and education, but did suggest areas for improvement and recommendations for practice change and standardization. These recommendations by family members were summarized and compared with staff responses and nine categories of themes were developed to guide standardization of education and information delivery. These categories of themes and topics fulfill aim 2 of the project, and are listed in Figure 2. These categories were then used to create a basic model of recommended education and information to be delivered to family

members to help standardize and guide future practice. This model could be expanded on in the

future and tailored to meet patient and family specific characteristics and needs, but this is

outside of the scope of this project. This model is shown below in Figure 3.

FIGURE 3. TBI Family Education Model

This model provides a framework of standardized education that can be used for family

members of patients with moderate to severe TBI. It directs the delivery of information

beginning at ICU admission through the ICU stay, and recommends possible resources and

specific topics to provide to family members, based on categories of themes derived from the

surveys and interviews. On the right side of the figure are additional categories of themes that

must be considered throughout the entire process of education, and do not have a specific timeline. Instead, the concepts of mutual understanding, family worth, consistency, honesty, and face-to-face communication must be continuously considered and implemented in order to optimize information delivery. This model only provides a basic structure, and could be tailored to meet additional needs based on type of injury, family member characteristics, severity of injury, and other factors.

Next Steps and Future Implementation

The TBI Family Education Model could be implemented in future quality improvement projects with the purpose of standardizing and guiding education and information delivery to family members of patients with moderate to severe TBI. As mentioned in the methods section, a PDSA cycle is one approach to implementation of the model through the process of goal setting, introduction and use of the model, assessing the usefulness of the model, and making as needed changes to the new education practice (W. Edwards Deming Institute, 2015). Implementation could first be carried out on a smaller-scale, with fewer patient/family members before applying the model to the entire unit.

The first PDSA cycle on the smaller-scale should begin with choosing 2 to 4 patients with TBI within the ICU, and training of 8-10 nurses on the new model. The "Plan" stage of PDSA would include recruiting the interested nurses first and initiate training on the new model approximately 1 month prior to scheduled implementation. Weekly training sessions would be held during the month of training to prepare for use of the model. Practice sessions would be included at the training meetings, where nurses could role-play some educational scenarios that may be encountered in practice. At the training meetings, the nurses will be able to review and

familiarize themselves with the printed materials, videos, and other resources that will later be used for patient family members. For the "Do" stage of PDSA, the trained nurses will be scheduled to care for TBI patients, but the new model will only be implemented with 2-3 patients during their stay in the ICU, which will vary for each patient. The "Do" stage will only last as long as the initial patients remain in the ICU. Next, the "Study" stage of PDSA will begin when the all of the initial patients chosen are discharged from ICU. This may be days to weeks after the start of implementation. Evaluation in the "Study" stage would consist of hand-written or electronic surveys distributed to both nurses and family members in the first group and would seek input on the strengths and weaknesses of the model and look for recommendations for improvement. These recommendations will be used to update or change either the model or the method of implementation in the "Act" portion of PDSA. At that point, the second PDSA cycle would begin with the updated model and implementation practice and would expand to then gradually train the rest of the nurses on the unit which would allow for larger scale implementation for more patients and family members. The PDSA cycle could repeat as many times as needed until the staff is comfortable with the model and find success in its implementation.

This model seeks to minimize barriers to education and information delivery between ICU nurses and family members of patients with moderate to severe TBI; however, it will not be able to fully eliminate the challenges often encountered with this process. For example, staff nurses frequently battle with time restrictions due to multiple demands and critically ill patients whose stability can be unpredictable and require frequent interventions. This model seeks to streamline the education process and therefore help to make better use of the time that nurses

spend delivering education and information. Also, the model will not be able to address certain characteristics that may occur with certain family members, such as language barriers, lack of family participation or presence, and willingness to learn. The model is planned for use with typical TBI patients, and may not be thorough or detailed enough to address patients with multiple traumatic injuries or confounding illnesses or complications.
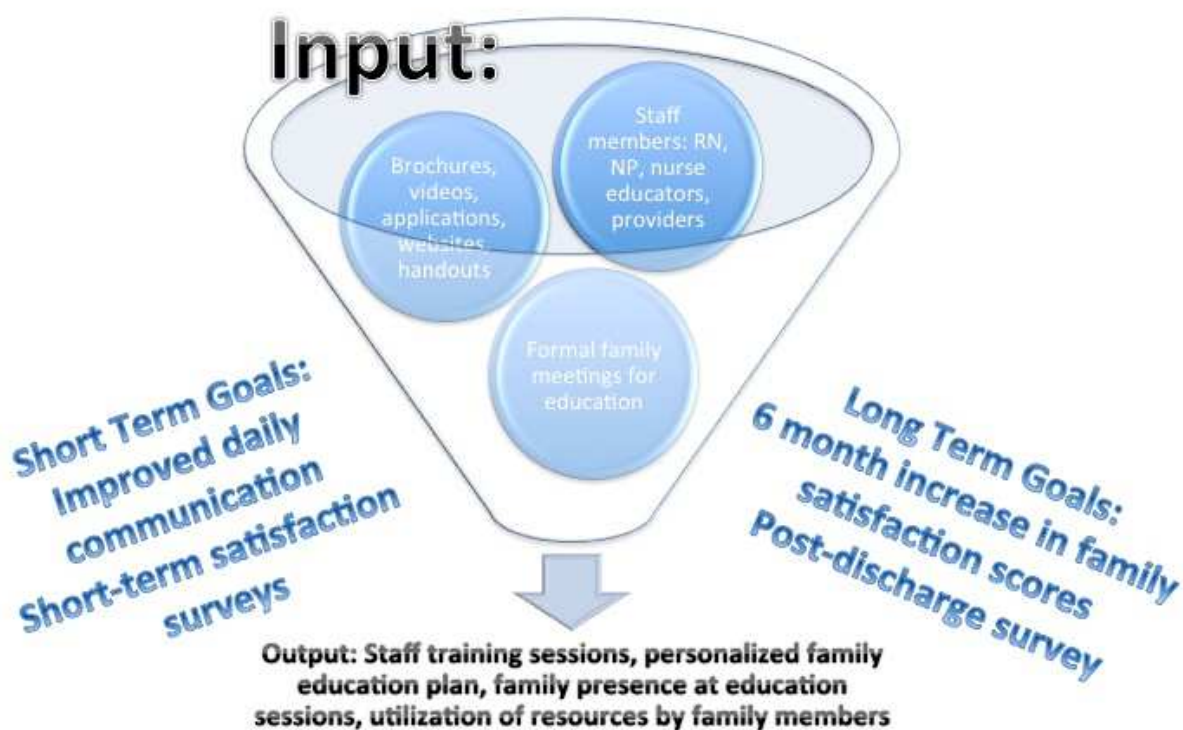
FIGURE 4. A Logic Model for Implementation of the TBI Family Education Model

Part of the implementation process could include a logic model to provide a visual

depiction of the plan for moving the model into practice (W. K. Kellogg Foundation, 2004).

Figure 4 represents an example the necessary inputs, outputs, and outcomes that could be used

for implementation for a medium-sized, urban ICU. As shown, the inputs include the human and

non-human resources needed to deliver the intervention and implement the model by means of

the outputs (including training sessions to familiarize staff members with the new education

process, tailoring the education to family specific characteristics, and planning of family

meetings to deliver patient information and education) in order to accomplish the short and long

term goals.

Once processes have been practiced by staff and modified based on results of the smaller-

scale implementation, this should hopefully increase the chances of success for the larger-scale

implementation, signifying readiness for adoption into practice. Formal adoption to practice

would likely happen at the point where evaluations by staff and family members demonstrate

satisfaction with the process and the model. Additional evaluation of success and usefulness of

the model itself could happen after the model has been in use for 6 months to 1 year and could

assess overall family member satisfaction scores as evidence of an increase in quality. These

evaluations could measure family satisfaction scores prior to model implementation, and at 6

months and 1 year post-implementation. The evaluation tool could be similar to the surveys

administered in this project, and compare the mean scores in each category before and after

model implementation, The sustainability of the model would not only depend on the evaluation

scores, but will also be influenced by the setting in which it is implemented, and by factors such

as staff adherence, organizational and stakeholder support, and modifications to fit unique

demographic and injury-based characteristics.

Conclusion

This project used the concepts in Mishel's Model of Perceived Uncertainty in Illness

(1988) to guide the development of a needs assessment that was then delivered within the ICU at

an urban, Level II trauma center in Boise, Idaho to assess the current level of satisfaction by staff

and family members of patients with moderate to severe TBI. Consistent with the project aims,

the results were used to create categories of themes and topics to be included in family member

education through development of the TBI Family Education Model along with a possible plan

for future implementation. Further research could be done to implement and test the Model in

different settings and contexts as part of a larger quality improvement project with the goal of

increasing family satisfaction for family members of patients with TBI.

APPENDIX A

TABLE OF EVIDENCE

APPENDIX A

TABLE 11. *Table of Evidence*

Author / Year	Research Design/ Study Question	Sample (N) & Setting	Methods & Data Collection	Findings/ Discussions	Sample Specific to Family Members of TBI Patients?
Bailey et al., 2010	Quantitative; Descriptional correlational What is the relationship between informational support, anxiety, and satisfaction with care?	Sample: n=29; family members of patients in ICU for at least 24 hours, age >/= 18, able to read English or French Setting: 22-bed medical/surgical ICU in Montreal, Quebec, Canada teaching hospital	Questionnaire of demographics of family member and patient, as well as ICU experience; CCFNI (modified) assessed perception of information received. Also measured anxiety, and satisfaction with care. Frequency distributions, means, standard deviation performed; Pearson's r test	Informational support and satisfaction with care were significantly & positively correlated (r=0.741, p<0.001). Informational support and anxiety showed no relationship (r=-0.130, p=0.502). Satisfaction with care and anxiety showed no relationship. (r=-0.160, p=-0.406).	No
Chien et al., 2006	Quantitative: Quasi-experimental How does a needs-based education program affect anxiety levels and	Sample: n=66; family member of ICU patient including spouse or blood relative, age >/= 18, able to read Chinese; n=34 experimental group; n=32 control group. Mean age 37.8	Experimental group received hour-long education sessions on days 2 and 3 of admission, content based on results from pre-test needs assessment completed	No differences in demographics between groups (p<0.05). Experimental group showed significant anxiety reduction	No

satisfaction of psychosocial needs of family members of critically ill patients in early hospitalization?	years Setting: 20-bed ICU in Hong Kong, China	on day 1, also received follow up by assigned nurse. Pre-test/post-test; 2 questionnaires used to measure anxiety levels (State-Trait Anxiety Inventory) and needs (C-CCFNI), demographics recorded. Data analyzed with one-way analysis of the covariance (ANCOVA)	$(p=0.006)$ with large effect size Increased satisfaction shown by differences in C-CCFNI scores between experimental & control group $(p<0.01)$ Family member's need for information a primary finding; well-structured family education based on needs assessment regarded as important, should occur in first few days of admission	
Keenan et al., 2010	Qualitative: Phenomenological What are the needs of family members of patients with severe TBI, and do the needs change over time?	Sample: n=25; 44 interviews conducted; family members of patients age 16-65 with severe TBI, family member mean age 44, 84% female, French and English-speaking Setting: Level 1 trauma center/academic health center with critical	Demographic information and semi-structured interviews analyzed thematically and coded; 26 categories and 11 themes described	Information support beneficial for understanding change; need for information important but decreased/changed over time (such as when leaving ICU)	Yes

		care/rehabilitation provided			
Larson et al., 2005	Quantitative: Randomized controlled trial What is the impact of a nurse-led support and education program on quality of life, life situation, well-being, and health in spouses of stroke patients?	Sample: n=100 spouses of patients with stroke (no mention of stroke severity or demographics of spouses) Setting: Danderynd University Hospital in Sweden	Experimental group received support/education program by stroke nurse, 20-30 minute session, 6 times in 6 months. Control group received regular information. Baseline, 6 month, and 12 month assessment of quality of life (visual analog scale), life situation LISS questionnaire), well-being (Bradley's well-being questionnaire), and perceived health (graded visual analog scale) ANOVA with repeated measures, paired Student's *t*-test, Wilcoxon signed rank test used to compare groups and changes over time	No significant differences in variables between intervention and control groups (p 0.37-0.99) Within the intervention group, those attending the program 5-6 times showed decreased negative well-being during first six months and after 12 months (p<0.01, p=0.01, respectively); and increased quality of life after 12 months (p=0.02)	No
Lefebvre et al., 2005	Qualitative: Phenomenological	Sample: n=53: n=8 with moderate to severe TBI,	Semi-structured interviews conducted	Five main themes found:	Yes, but also included

	What is the experience of individuals with TBI, their families, an medical professionals involved in their care?	n=14 family members of the 8 individuals with moderate to severe TBI, n=22 inter-disciplinary healthcare members, n=9 physicians Setting: Tertiary trauma center, two rehabilitation centers, paramedical organization, and association of people with TBI; metropolitan area of Canada	with participants, analyzed inductively and deductively, data categorized until inter-rater reliability of 95% reached	1. Information 2. Uncertainty 3. Relationships 4. Continuity 5. Adaptation Uncertainty results from lack of information, prognosis primary topic of uncertainty	healthcare members and patients
McLaughlin et al., 2013	Quantitative: Randomized controlled trial What is the effect of a Web-based intervention on advocacy skills and life satisfaction in families of patients with brain injury?	Sample: n=201; Family members of adults with brain injury providing support to patient, English-speaking, Internet access Setting: 42 states in the USA, online program	Brain Injury Partners (BIP) website developed, provided training in family advocacy including communication, stress-reduction strategies, provision of services, and determination of needed support; Pre-test/post-test measurement of knowledge, skills, behavior, and life satisfaction through questionnaires, analyzed	Intervention group significantly higher application, knowledge, and attitude scales from pre-test to post-test (p <0.001, p<0.001, p<0.001). Effect size d=1.01, 0.67, 0.70, respectively No significant change in life satisfaction (p=0.054) Intervention effective at teaching skills to	Yes

			through one-way MANCOVA, univariate ANCOVA	family members	
Rotondi et al., 2007	Qualitative: Needs Assessment What are the needs of individuals with TBI and their caregivers?	Sample: n=80 patients with TBI, n=85 caregiver/supports persons; no restrictions of age, sex, time since injury, or rac Setting: Pittsburgh, PA region	Semi-structured phone interviews based on critical incident technique needs assessment method, data analyzed and organized into major themes	18 encompassing themes found; Theme #1 describes the need to understand injuries, treatments, and consequences Need for knowledge is evolving, and inadequate understanding reported, especially in acute care setting. Deficiency reported in areas such as providing understandable and complete information, as well as other topics	No
Shelton et al., 2010	Quantitative: Quasi-experimental What is the effect of a family support coordinator on	Sample: n=114 pre-intervention; n=113 post-intervention; Family members of patients expected to be in ICU >5 days	Intervention included family support coordinator added to team to serve as liaison between family and healthcare team, also addressed	Implementation of a family support coordinator increased family satisfaction of communication with ICU team, significantly for	No

	family satisfaction, length-of-stay, and cost in the SICU?	Setting: SICU, study conducted in two phases. Phase I: 8-month baseline study. Phase II: 10-month intervention study.	communication and information needs as well as other services Family satisfaction survey: Critical Care Family Assistance Program Family Satisfaction Survey; results analyzed with one-way ANOVA	communication with physicians (p=0.0034)	
Sinnakaruppan et al., 2005	Quantitative: Longitudinal, within & between subjects design What is the impact on psychological health of an educational program for family caregivers and patients with head injury?	Sample: n=49 patients age 16-65 with moderate to severe head injury within 7 years; n=50 caregivers of patients; English-speaking Setting: Recruited from previous patients at rehabilitation center in Scotland; community-based intervention	Intervention program included educational sessions of 2.5 hours; 4 sessions for patients and 4 for caregivers, used handouts. Targeted: memory, executive functions, and emotions. Assessed before, at end intervention, and after 3 months using HADS, GHQ-28, RSE, COPE, & FIM Paired t-tests, Chi-square, and one-way ANOVA used for analysis	Intervention caregiver group showed non-significant reduction of psychological stress, other non-significant findings (p=0.062-0.710) Intervention patient group showed statistically-significant improvements in GHQ items such as anxiety, and severe depression (p=0.031, 0.017), among others	Yes
Verhaeghe et al., 2007	Qualitative: Grounded theory	Sample: n=22 family members of n=16	Comparison analyses of interviews, identified	Family members demonstrate the need	Yes

	patients in a coma from traumatic injury	themes and coded	for information, which was found to be related to hope
"How does information influence hope in family members of traumatic coma patients in intensive care unit?"	Setting: Belgian hospitals (university and regional)		

Abbreviations used: ANCOVA: analysis of covariance; ANOVA: analysis of variance CCFNI: Critical Care Family Needs Inventory; C-CCFNI: Chinese Critical Care Family Needs Inventory; FIM: Functional Independence Measure; GHQ-28: COPE: The COPE Scale; General Health Questionnaire-28; HADS: Hospital Anxiety and Depression Scale; ICU: intensive care unit; LISS: Life Situation Among Spouses after the Stroke event; MANCOVA: multivariate analysis of covariance; RSE: Rosenberg Self-Esteem Scale; SICU: surgical intensive care unit; TBI: traumatic brain injury

APPENDIX B

STAFF MEMBER SURVEY

APPENDIX B

Staff Member Survey

Instructions: These questions apply **only to patients with moderate to severe traumatic brain injury (TBI) (defined as Glasgow Coma Scale score of 3-12)**. Please only answer the questions in reference to this patient population. Please be completely honest. Your answers will be anonymous.

Please choose an answer for each line:

What is your role?	Staff nurse	Provider				
How much time do you estimate you spend in family member teaching/support each day?	<15 minutes	15-30 minutes	30-45 minutes	45-60 minutes	>60 minutes	
Providers only: Are you generally able to make contact (in person or via phone) with the patient's family member/s each day?	Yes	No				
Nurses only: How many shifts do you generally spend caring for the same patient with moderate to severe TBI?	1	2	3	4	5	>5

Please choose the number that describes how you feel about the time you spend caring for patients with moderate to severe traumatic brain injury in the intensive care unit.

Question	1=Never/Not satisfied	2=Sometimes/ Somewhat satisfied	3=Usually/ Mostly satisfied	4=Always/ Very satisfied
Are you satisfied with the current method of delivering information and education to family members of patients with moderate to severe TBI?	1	2	3	4
How well do you feel that providers (physicians, nurse practitioners, physician assistants) adequately deliver information and education to family members of patients with moderate to severe TBI?	1	2	3	4
How satisfied are you with the method of organizing/standardizing family education so that information is delivered consistently?	1	2	3	4
How well do you feel the healthcare team delivers all needed information to family members?	1	2	3	4
How satisfied do you perceive that family members are with the current method of receiving education/ information from the healthcare team?	1	2	3	4
How well do you feel that the healthcare team delivers information/education about diagnostic results and laboratory data?	1	2	3	4
How well do you feel that the healthcare team delivers information/education about the type of injury?	1	2	3	4
How well do you feel that the healthcare team delivers information/education about plans for patient transfer?	1	2	3	4
How well do you feel that the healthcare team delivers information about prognosis?	1	2	3	4
How well do you feel that the healthcare team delivers information about unit policies, procedures, and resources?	1	2	3	4

What do you feel could be done better to improve information delivery from doctors (or nurse practitioners/physician assistants) to patient family members?

_____
_____
_____

What do you feel could be done better to improve information delivery from nurses to patient family members?

_____
_____
_____

What do you see as barriers to delivering information/education to patient family members?

_____
_____
_____

What information or communication do you feel is the hardest for patient family members to understand?

_____
_____
_____

What information or communication do you feel is the most important for patient family members to understand?

_____
_____
_____

Additional comments:

_____
_____
_____
_____
_____

APPENDIX C

FAMILY MEMBER SURVEY

APPENDIX C

Family Member Survey

<u>Instructions:</u> Please be completely honest. Your answers will be anonymous.

Please choose an answer for each line:

What is your age?	18-30 years	31-40 years	41-50 years	51-60 years	61-70 years	70+ years
What is your relationship to the patient?	Spouse or Unmarried Significant Other	Parent	Child	Sibling	Friend	Other
About how many hours at a time did you spend during each visit in the ICU with your loved one?	Less than 1 hour	1-2 hours	2.5-3 hours	3.5 to 4 hours	4.5 to 5 hours	More than 5 hours
About how many days per week did you visit the patient?	1	2	3	4	5	6-7
What is your highest level of education?	High school	Some college	Associate's degree	Bachelor's degree	Graduate degree	

Please choose the number that describes how you feel about the time your loved one (referred to as "the patient" in these questions) spent in the Intensive Care Unit (ICU).

Question	1=Never/Not satisfied	2=Sometimes/ Somewhat satisfied	3=Usually/ Mostly satisfied	4=Always/ Very satisfied
Were you satisfied with how often you were able to talk to the doctor (or nurse practitioner/physician assistant)?	1	2	3	4
Were you satisfied with how often you were able to talk to the nurse?	1	2	3	4
Were your questions answered in a way that you could understand?	1	2	3	4
Do you feel that your questions were answered honestly?	1	2	3	4
How well did the ICU nurses explain what was going on with the patient?	1	2	3	4
How well were you explained to about the patient's type of injury?	1	2	3	4
How well were you explained to about the different tests that patient had and what the results were?	1	2	3	4
Were you given directions about what was ok to do and what you couldn't do while visiting the patient?	1	2	3	4
Were you explained to about what the prognosis would likely be, and if not were you told why?	1	2	3	4
Did the nurses tell you enough about the ICU that you felt comfortable while visiting?	1	2	3	4
Were you told about other people that you could talk to if you needed help with something, such as chaplain, social worker, case manager, or others?	1	2	3	4
Did the nurses explain what they were doing to the patient and why?	1	2	3	4
Did the doctors, nurses, and other healthcare personnel introduce themselves and tell you what they would be doing for the patient?	1	2	3	4
Did you feel that there was someone you could talk to if you needed extra help, had questions, or concerns about the care of	1	2	3	4

the patient?				
Did the doctors, nurses, and others speak in language that you could understand?	1	2	3	4
Were you told about plans to transfer the patient out of the ICU ahead of time, and in a way that you could understand?	1	2	3	4
Were you told when the patient had a change in condition?	1	2	3	4
Were you given an update every day by the nurses or doctors about the patient's progress?	1	2	3	4

What do you feel could have been done better to improve receiving information from the doctors (or nurse practitioners/physician assistants)?

_____
_____
_____

What do you feel could have been done better to improve receiving information from the nurse?

_____
_____
_____

What information do you wish you would have received that you didn't, or that you wish you would have received earlier?

_____
_____
_____

What information or communication was the hardest to understand?

_____
_____
_____

Were there any physical factors that made it hard to learn or understand information, such as emotional stress, sleep deprivation, discomfort, or distractions?

_____
_____
_____

Additional comments

_____
_____
_____

APPENDIX D

SURVEY LETTER AND LINK FOR STAFF MEMBERS

APPENDIX D

Survey Letter and Link for Staff Members

Dear Staff,

As you are aware, traumatic brain injury (TBI) affects people of all ages without warning, and can have devastating effects on close family members and friends of these patients. As this can be an uncertain and frightening time, family members need support, information, and education while their loved one is in the intensive care unit. With the understanding that you as care providers are frequently called on to deliver this information and education, I am seeking your input in a quality improvement study regarding the family satisfaction of the way information and education is given while in the intensive care unit.

This study is part of my final doctorate project to complete my Doctor of Nursing Practice degree at the University of Arizona. Your participation is completely voluntary and will consist only of a brief, online survey that should take approximately 10 to 15 minutes to complete. Information will be confidential, and the study results will be available to you after completion of the project in 2016.

By clicking on the link below and completing the survey, you are giving your consent for your responses to be used in the study. Institutional Review Board approval has been given for this study. Your responses will be anonymous. Choosing not to complete the survey will not have any penalties.

Below is the study information:

Title of Project: Assessing the Quality of Education and Information Delivery to Family
                         Members of Patients with Moderate to Severe Traumatic Brain Injury
Researcher: Bonnie Hoewing, MSN, APRN, AGACNP-BC, CCRN
Institution: The University of Arizona/Saint Alphonsus Regional Medical Center
Link: https://uarizona.co1.qualtrics.com/SE/?SID=SV_4N7JESuHTDm8jrv

I appreciate your willingness to dedicate your time and experience to help assess and hopefully improve the quality of education and information delivery for family members of patients with moderate to severe TBI. Feel free contact me for any questions or concerns.

Thank you,

Bonnie Hoewing
208-573-4574
hoewingb@email.arizona.edu

APPENDIX E

SURVEY LETTER AND LINK FOR FAMILY MEMBERS

APPENDIX E

Survey Letter and Link for Family Members

Dear Family Member,

As a nurse in the intensive care unit for nearly 5 years, I have seen the difficulties that family members of patients with traumatic brain injury have endured. A major trial can often be trying to understand what is going on with your loved one, being able to communicate with doctors and other staff members, and keeping informed of changes. As you well know, there is often a lot to learn about traumatic brain injury as well as the environment of the intensive care unit. I am in the process of studying the way that education and information is delivered to family members of patients with traumatic brain injury. You have been selected, based on the injury of your loved one, to participate in this study by giving your input on the quality of education and information delivery within the intensive care unit. You are invited to complete an online survey, which you can access at the link at the end of the letter. Additionally, you are invited to participate in a recorded interview with me, either individually or as a family group, in which your answers to questions will be confidential. Through this interview, I would like to explore further what your experiences were while in the intensive care unit in terms of receiving education and information.

This study is part of my final doctorate project to complete my Doctor of Nursing Practice degree at the University of Arizona. Your participation is completely voluntary and will consist only of a brief, online survey that should take approximately 10 to 15 minutes to complete. Information given will be confidential and anonymous.

By clicking on the link below and completing the survey, you are giving your consent for your responses to be used in the study. Institutional Review Board approval has been given for this study. Your responses will be anonymous. Choosing not to complete the survey will not have any penalties to you or any negative consequences to the care of your loved one.

Below is the study information:
Title of Project: Assessing the Quality of Education and Information Delivery to Family
                         Members of Patients with Moderate to Severe Traumatic Brain Injury
Researcher: Bonnie Hoewing, MSN, RN, CCRN
Institution: The University of Arizona/Saint Alphonsus Regional Medical Center

I appreciate your willingness to dedicate your time and experiences to help assess and hopefully improve the quality of education and information delivery for family members of patients with moderate to severe TBI. Feel free contact me for any questions or concerns.

Thank you,
Bonnie Hoewing
208-573-4574
hoewingb@email.arizona.edu

APPENDIX F

IRB DOCUMENTS

APPENDIX F

IRB DOCUMENTS

	Research		1618 E. Helen St.
	Office for Research & Discovery	Human Subjects Protection Program	P.O.Box 245137 Tucson, AZ 85724-5137 Tel: (520) 626-6721 http://rgw.arizona.edu/compliance/home

Date:	May 24, 2016
Principal Investigator:	Bonnie Jane Hoewing
Protocol Number:	1605582854
Protocol Title:	ASSESSING THE QUALITY OF EDUCATION AND INFORMATION DELIVERY TO FAMILY MEMBERS OF PATIENTS WITH MODERATE TO SEVERE TRAUMATIC BRAIN INJURY
Level of Review:	Deferral of IRB Oversight
Determination:	Approved

Documents Reviewed Concurrently:

   Data Collection Tools: *Hoewing IRB survey letter, questions, and interview.docx*
   HSPP Forms/Correspondence: *Hoewing_f107_verification_of_human_subjects_training_v2016-01_0.doc*
   HSPP Forms/Correspondence: *Hoewing_f204_application_for_ceded_irb_oversight_v2016-02.doc*
   HSPP Forms/Correspondence: *Hoewing IA_201605201158.pdf*
   HSPP Forms/Correspondence: *Signature page.pdf*
   Informed Consent/PHI Forms: *Consent Form_Hoewing.pdf*
   Other Approvals and Authorizations: *Hoewing_IRB initial protocol submission.pdf*
   Other Approvals and Authorizations: *IRB Approval Letter_Hoewing.pdf*

Institution Designated the IRB of Record: When an institution is the designated IRB of record, the UA IRB will not review the project. The University of Arizona agrees that it will rely on the review, approval, and continuing oversight by the institution IRB of those protocols approved by the institution pursuant to the terms of the Institutional Review Board Authorization Agreement (if applicable) and as outlined in the HSPP files.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All documents referenced in this submission have been reviewed and are filed with the HSPP.
- The Principal Investigator should notify the IRB immediately of any proposed changes that affect the LOCAL protocol and report any LOCAL unanticipated problems involving risks to participants or others. Please refer to the Guidance Ceded IRB Review for more information.
- All research procedures should be conducted according to the approved protocol and the policies and guidance of the IRB of record.

This project has been reviewed and approved by an IRB Chair or designee.

Saint Alphonsus

RESEARCH INSTITUTE

22 February 2016

Bonnie Hoewing, MSN, RN, CCRN
University of Arizona, DNP student
17977 Friends Road
Caldwell, Idaho 83607

Re: **Assessing the quality of education and information delivery to family members of patients with moderate to severe traumatic brain injury (TBI)**

Dear Bonnie:

This letter is to acknowledge that the Institutional Review Board (IRB) at Saint Alphonsus Regional Medical Center has granted approval of the protocol noted above via expedited review. This approval will expire on **22 February 2017**. If you wish to continue beyond this date, an application for continuing review will need to be submitted at least 4 weeks prior to the expiration date. Applications must be typed and can be downloaded at http://www.saintalphonsus.org/forms-and-resources.

A stamped, approved copy of the informed consent form is attached. Copies of this stamped consent form are to be used for enrollment purposes.

As a reminder, no changes may be made to the protocol or consent without first submitting the changes to the IRB for approval, and any internal adverse events or unanticipated problems must be promptly reported.

Should you have any questions, please feel free to contact the Office of Research Integrity at (208) 367-8897.

Respectfully,

John Mayberry, MD
Chairperson, SARMC Institutional Review Board

cc: IRB #16-03

Saint Alphonsus
Regional Medical Center

CONSENT AND AUTHORIZATION FOR RESEARCH PURPOSES

Study Name: Assessing the Quality of Education and Information Delivery to Family Members of Patients with Moderate to Severe Traumatic Brain Injury (TBI)

Principal Investigator: Bonnie Hoewing, MSN, RN, CCRN

1. **General Information**

    a. You are invited to be in a research study. Before you decide, it is important for you to understand why the research is being done. Please take time to read the following information and talk about it with friends and family if you wish. Ask the researchers if you are unclear about any part of the study.

2. **Study Purpose**

    a. This is a research study. The purpose of the study is to look at the quality of education and information delivery by healthcare staff to family members of patients with moderate to severe traumatic brain injury. You are being asked to be in this study because you have been identified as a family member, surrogate, or significant individual of a patient with moderate to severe traumatic brain injury. The study will help researchers come up with a standardized method for delivering education and information in the future.

3. **Study Procedures**
    a. After filling out the online survey, you are being asked to participate in an optional, one-time interview with the researcher. This will be to discuss your experiences with receiving education and information about your loved one's brain injury while in the intensive care unit. The interview will be recorded, and all information will be kept anonymous. The interview is expected to last 15 to 60 minutes. The researcher is not being paid to do the study.

4. **Number of People in the Study**
    a. The researchers expect to have 10 to 20 patient family members in this study at Saint Alphonsus Regional Medical Center.

5. **Risks, Discomforts and/or Potential Side Effects of Participation**
    a. Being in this study may involve risks that we do not know about or can predict. Only minor risks are possible, including possible breach of confidentiality. However, safety measures are in place to protect any personal information. It is possible that participating in the interview may cause discomfort to you, such as experiencing grief while discussing your loved one's injury. Because of this, you may exit the interview at any time.

Pt. Initials_____   Page 1 of 3   Revised: 02/01/16
Date: _____

APPROVED
SARMC IRB
02/22/2016

6. **Benefits**
   a. There are no direct benefits to you for taking part in this study. The information we learn may help future patient family members in the way that they receive education and information.

7. **Costs & Payments**
   a. There are no costs associated with this study
   b. You will not be paid to be in this study.

8. **Alternative Treatment**
   a. You do not have to be in this study. The care of your loved one will not be affected in any way if you choose not to be in the study.

9. **Voluntary Participation**
   a. Being in the study is voluntary. If you decide to be in the study, you may stop at any time and without giving a reason.
   b. Your decision not to be in or stop being in the study will not affect the care of your loved one or your benefits in any way. It will not affect the relationship with care providers if you choose not to be in the study.
   c. If you decide to stop being in the study, notify the researcher in person, by phone, or by email that you no longer wish to complete the interview.

10. **Contact Information**
   a. You may call the researcher about any part of this study. The researcher is Bonnie Hoewing and can be called at 208-573-4574.

11. **Confidentiality**
   a. All information in this study is kept confidential. Recorded interviews will be stored on a locked device, and any personal information will be removed to keep your contributions anonymous. Only people who work on this study will have access to this information.
   b. Results of this study may be presented or published. Your identity will not appear in any publication or presentation.

12. **Your Rights**
   a. If you have any concerns about your rights as a research participant or wish to discuss problems about the study you do not feel you can discuss with the researcher, please call the Saint Alphonsus Research Integrity Office at (208) 367-8897.

13. **Consent**
   A. I understand that my participation in this study is entirely voluntary and that I have the right to refuse to continue if I so desire without any fear of prejudice. My signature below indicates that I have decided to participate in the study after having been advised of the risks and benefits, and having read the information provided, and having had the opportunity to ask and have my questions answered.
   B. I understand that the information collected during this study will remain confidential.

Pt. Initials_____   Page 2 of 3   Revised: 02/01/16
Date: _____

APPROVED
SARMC IRB
02/22/2016

C. I understand that a copy of the consent and authorization form I am signing will be returned to me.

_____
Participant name (printed)

_____   _____
Participant Signature   Date

_____
Name & Relationship of Witness

_____   _____
Signature of Witness   Date

_____
Name of Person Obtaining Consent/Authorization

_____   _____
Signature of Person Obtaining Consent/Authorization   Date

Pt. Initials_____   Page 3 of 3   Revised: 02/01/16
Date: _____

APPROVED
SARMC IRB
02/22/2016

REFERENCES

Adams, A. M. N., Mannix, T., & Harrington, A. (2015). Nurses' communication with families in
the intensive care unit—a literature review. *British Association of Critical Care Nurses*
22(2), 70-80. doi: 10.1111/nicc.12141

Bailey, J. J., Sabbagh, M., Loiselle, C. G., Boileau, J., & McVey, L. (2010). Supporting
family in the ICU: A descriptive correlational study of information support, anxiety, and
satisfaction with care. *Intensive and Critical Care Nursing 26*, 114-122.
doi:10.1016/j.iccn.2009.12.006

Bond, A.E., Draeger, C, Mandleco, B., & Donnelly, M. (2003). Needs of family members
of patients with severe traumatic brain injury. *Critical Care Nurse* 23(4), 63-72.

Brain Trauma Foundation. (n.d). TBI statistics. Retrieved February 3, 2015 from
https://www.braintrauma.org/tbi-faqs/tbi-statistics/

Centers for Disease Control and Prevention. (2015). *Traumatic brain injury in the United*
States: Fact sheet. Retrieved January 18, 2015 from
http://www.cdc.gov/traumaticbraininjury/get_the_facts.html

Chien, W. T., Chiu, Y. L., Lam, L. W., & Ip, W. Y. (2006). Effects of a needs-based education
programme for family carers with a relative in an intensive care unit: A quasi-
experimental study. *International Journal of Nursing Studies 43*(1), 39-50.
doi:10.1016/j.ijnurstu.2005.01.006

Coco, K., Tossavainen, K., Jaaskelainen, J. E., & Turunen, H. (2011). Support for

traumatic brain injury patients' family members in neurosurgical nursing: A systematic

review. *Journal of Neuroscience Nursing 43*(6), 337-348.

doi:10.1097/JNN.0b013e318234ea0b

Davidson, J. E., Powers, K., Hedayat, K. M., Tieszan, M., Kon, A. A., Shepard, E., . . . &

Armstrong, D. (2007). Clinical practice guidelines for support of the family in the

patient-centered intensive care unit: American College of Critical Care Medicine Task

Force 2004–2005. *Critical Care Medicine 35*(2), 605-622. doi:

10.1097/01.CCM.0000254067.14607.EB

Eggenberger, S. K., & Sanders, M. (2016). A family nursing educational intervention supports

nurses and families in an adult intensive care unit. *Australian Critical Care 29*(2016),

217-223. doi: http://dx.doi.org/10.1016/j.aucc.2016.09.002

Gay, E. B., Pronovost, P. J., Bassett, R. D., & Nelson, J. E. (2009). The intensive care unit family

meeting: Making it happen. *Journal of Critical Care 24*(4), 629.e1–629.e12. doi:

10.1016/j.jcrc.2008.10.003

Haddad, S. H., & Arabi, Y. M. (2012). Critical care management of severe traumatic

brain injury in adults. *Scandinavian Journal of Trauma, Resuscitation and Emergency

Medicine 20*(12). doi:10.1186/1757-7241-20-12

Institute for Healthcare Improvement. (2015). How to improve. Retrieved October 11, 2015 from

http://www.ihi.org/resources/Pages/HowtoImprove/default.aspx

Keenan, A., & Joesph, L. (2010). The needs of family members of severe traumatic brain injured patients during critical and acute care: A qualitative study. *Canadian Journal of Neuroscience Nursing 32*(3), 25-35. Available at http://www.ncbi.nlm.nih.gov/pubmed/20865832

Lange, M. P. (2001). Family stress in the intensive care unit. *Critical Care Medicine 29*(10), 2025-2026. Available from: CINAHL Plus with Full Text, Ipswich, MA. Accessed February 24, 2015

Larson, J., Franzen-Dahlin, A., Billing, E., von Arbin, M., Murray, V., & Wredling, R. (2005). The impact of a nurse-led support and education programme for spouses of stroke patients: a randomized controlled trial. *Journal of Clinical Nursing, 14*(8), 995-1003. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/16102151

Lefebvre, H., Pelchat, D., Swaine, B., Gelinas, I., & Levert, M. J., (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury 19*(8), 585-597. doi:

Leske, J.S. (1991). Internal psychometric properties of the Critical Care Family Needs Inventory, *Heart & Lung, 20*, 236-244.

Levant, S., Chari, K., & DeFrances, C. (2016). National Hospital Care Survey demonstration projects: Traumatic brain injury. *National Health Statistics Reports 97*. https://www.cdc.gov/nchs/data/nhsr/nhsr097.pdf

Linnarsson, J. R., Bubini, J., & Perseius, K. I. (2010). Review: A meta-synthesis of qualitative research into needs and experiences of significant others to critically ill or injured patients. *Journal of Clinical Nursing, 19*, 3102–3111. doi:10.1111/j.1365-2702.2010.03244.x

O'Malley, K., & Lawrence, S. (2011). Traumatic brain injury education: An effective model for clients and families. *OT Practice 16*(2), 13-17.

Maxwell, K. E., Stuenkel, D., & Saylor, C. (2007). Needs of family members of critically ill patients: A comparison of nurse and family perceptions. *Heart and Lung, 36*(5), 367-376. doi:10.1016/j.hrtlng.2007.02.005

McLaughlin, K. A., Glang, A., Beaver, S. V., Gau, J. M., & Keen, S. (2013). Web-based training in family advocacy. *Journal of Head Trauma Rehabilitation, 28*(5), 341-348. doi:10.1097/HTR.0b013e31824e1d43

Mena, J. H., Sanchez, A. I., Rubiano, A. M., Peitzman, A. B., Sperry, J. L., Gutierrez, M. I., & Norup, A., Welling, K. L., Qvist, J., Siert, L., & Mortensen, E. L. (2012). Depression, anxiety and quality-of-life among relatives of patients with severe brain injury: the acute phase [Abstract only]. *Brain Injury 26*(10), 1192-1200. doi:10.3109/02699052.2012.672790

Mishel, M. H. (1988). Uncertainty in illness. *Journal of Nursing Scholarship* 20(4), 225-232. doi:10.1111/j.1547-5069.1988.tb00082.x

Mishel, M. H., Padilla, G., Grant, M., & Sorenson, D. S. (1991). Uncertainty in illness theory: a replication of the mediating effects of mastery and coping. *Nursing Research 40*(4), 236-240. Available at http://www.ncbi.nlm.nih.gov/pubmed/1857651

Moore, C. D., Bernardini, G. L., Hinerman, R., Sigond, K., Dowling, J., Wang, D. B., & Shelton, W. (2012). The effect of a family support intervention on physician, nurse, and family perceptions of care in the surgical, neurological, and medical intensive care units. *Critical Care Nursing Quarterly 35*(4), 378-387. doi:10.1097/CNQ.0b013e318268fde3

Orb, A., Eisenhauer, L., & Wynaden, D. (2000). Ethics in qualitative research. *Journal of Nursing Scholarship, 33*(1), 93-96. Available at http://www.columbia.edu/~mvp19/RMC/M5/QualEthics.pdf

Pielmaier, L., Walder, B., Rebetez, M. M. L., & Maercker, A. (2011). Post-traumatic stress symptoms in relatives in the first weeks after severe traumatic brain injury. *Brain Injury 25*(3), 259-265. doi:10.3109/02699052.2010.542429

Piyakong, D. (2014). Challenges faced by Thai families when a loved one has a traumatic brain injury. Archives of Psychiatric Nursing 28(3), 220-221. doi: 0.1016/j.apnu.2014.03.001

Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice.* Philadelphia, PA: Wolters Kluwer Health | Lippincott Williams & Wilkins

Puyana, J. C. (2011). Effect of the modified Glasgow Coma Scale score criteria for mild traumatic brain injury on mortality prediction: Comparing classic and modified Glasgow Coma Scale score model scores of 13. *Journal of Trauma 71*(5), 1185-1192. doi: 10.1097/TA.0b013e31823321f8.

Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative

needs assessment of persons who have experienced traumatic brain injury and their

primary family caregivers. *Journal of Head Trauma Rehabilitation, 22*(1), 14-25.

Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/17235227

Shelton, W., Moore, C. D., Socaris, S., Gao, J., & Dowling, J. (2010). The effect of a family

support intervention on family satisfaction, length-of-stay, and cost of care in the

intensive care unit. *Critical Care Medicine 38*(5), 1315-1320. doi:10.1097/CCM.

0b013e3181d9d9fe

Sinnakaruppan, I., Downey, B., & Morrison, S. (2005). Head injury and family carers: A

pilot study to investigate an innovative community-based educational programme for

family carers and patients. *Brain Injury 19*(4), 283-308. doi:

10.1080/02699050400003924

Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness: A

practical scale**.** *Lancet* 2(7872), 81-84. Available at

http://www.ncbi.nlm.nih.gov/pubmed/4136544

Turner-Cobb, J. M., Smith, P. C., Ramchandani, P., Begen, F. M., & Padkin, A. (2016). The

acute psychobiological impact of the intensive care experience on relatives. *Psychology,*

Health, & Medicine, 21(1), 20-26. doi: 10.1080/13548506.2014.997763

Verhaeghe, S., Defloor, T., & Grypdonck, M. (2005). Stress and coping among families of

patients with traumatic brain injury: a review of the literature. *Journal of Clinical*

Nursing 14(8), 1004-1012. doi: 10.1111/j.1365-2702.2005.01126.x

Verhaeghe, S. T., vanZuuren, F. J., Defloor, T., Duijnstee, M. S. H., & Grypdonck, M. H.
F. (2007). How does information influence hope in family members of traumatic coma
patients in intensive care? *Journal of Clinical Nursing, 16*, 1488-1497. doi:
10.1111/j.1365-2702.2006.01807

W. Edwards Deming Institute. (2015). The plan, do, study, act (PDSA) cycle. Retrieved
December 2, 2015 from https://www.deming.org/theman/theories/pdsacycle

W. K. Kellogg Foundation. (2004). *Using logic models to bring together*
planning, evaluation, and action: Logic model development guide. Battle Creek, MI: W.
K. Kellogg Foundation; 2004. Available at
http://www.smartgivers.org/uploads/logicmodelguidepdf.pdf.

Watanabe, T. K., & Marino, M. H. (2014). Traumatic brain injury. In I. B. Maitin & E. Cruz
(Eds), *CURRENT Diagnosis & Treatment: Physical Medicine & Rehabilitation.*
Retrieved February 24, 2015 from
http://accessmedicine.mhmedical.com.ezproxy1.library.arizona.edu/content.aspx?bookid
=1180&Sectionid=70377685