



Virginia Commonwealth University
VCU Scholars Compass

Theses and Dissertations

Graduate School

2010

Polytrauma Family Needs Assessment

Schaaf Kathryn Wilder
Virginia Commonwealth University

Follow this and additional works at: <http://scholarscompass.vcu.edu/etd>

 Part of the [Psychology Commons](#)

© The Author

Downloaded from

<http://scholarscompass.vcu.edu/etd/2051>

This Dissertation is brought to you for free and open access by the Graduate School at VCU Scholars Compass. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of VCU Scholars Compass. For more information, please contact libcompass@vcu.edu.

POLYTRAUMA FAMILY NEEDS ASSESSMENT

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of
Philosophy at Virginia Commonwealth University

By: KATHRYN PAMELA WILDER SCHAAF
Master of Science, University of Maryland, College Park, 2003
Bachelor of Arts, University of North Carolina, Chapel Hill, 2001

Director: Steven J. Danish
Professor of Psychology
Department of Psychology

Virginia Commonwealth University
Richmond, Virginia
May 2010

Acknowledgments

"This process of the good life is not, I am convinced, a life for the faint-hearted. It involves the stretching and growing of becoming more and more of one's potentialities. It involves the courage to be. It means launching oneself fully into the stream of life" (Rogers, 1961)

The completion of both this project and the Ph.D. degree should be attributed to more people in my life than this document can hold. I hope to recognize a few people, but also know that it took a village to get me here. The process of being in graduate school has stretched and challenged me in more ways than I could have ever imagined. I am thankful for *both* the process and the end that will bring new beginnings.

Thank you to my most constant support, my husband Matthew, who has been there for me in ways I could not have known. Thank you for loving me through finals, prelims, internship, dissertation, and many other trying and happy moments. Thank you to my family: Mom, Dad, Jennie, Erik, Jack, Audrey, and Julie for keeping my grounded and humble (as usual). Thank you to my friend Connie for keeping me well rounded and faithful to my 6:00 am therapy throughout school. Thank you to my classmates at VCU, especially Rachel. You all have provided me with much knowledge, empathy, and comic relief. Thank you to the many wonderful faculty and staff at VCU. You have prepared me for the next step and provided me with a strong foundation for my career. Finally, thank you to the many wonderful supporters I have found on internship at the Minneapolis VAMC. You have

cemented all the pieces together and helped me to feel confident and peaceful about the next step in my career.

Table of Contents

| | Page |
|-------------------------------------------------------------------------|------|
| Acknowledgments..... | ii |
| List of Tables | vii |
| List of Figures | ix |
| Abstract..... | x |
| Introduction..... | 1 |
| Background and Significance..... | 1 |
| Blast Injury and Traumatic Brain Injury | 2 |
| Etiology of TBI | 4 |
| Determining TBI Severity | 6 |
| Consequences of TBI | 8 |
| Polytrauma System of Care | 10 |
| Purpose | 14 |
| Literature Review..... | 15 |
| Family Systems Theory Overview | 15 |
| Family Systems Theory and TBI..... | 16 |
| Literature Review Part I: Families and Patients in the PRC | 18 |
| Literature Review Part II: Family Needs in the Civilian Literature..... | 22 |
| Factors that Affect Family Stress in the TBI Literature | 23 |
| Parental Stressors | 25 |
| Child Stressors..... | 25 |
| Spouse Stressors | 25 |
| Family Needs in the Rehabilitation Literature | 26 |
| Family Needs as Described Using the FNQ..... | 29 |
| Family Needs as Described Using Qualitative Studies | 31 |
| Family Needs Outside of TBI | 32 |
| Statement of the Problem | 35 |
| Primary Hypotheses | 36 |
| Exploratory Hypotheses | 37 |
| Additional Analyses | 39 |
| Method | 39 |
| Participants | 39 |

| | |
|---------------------------------------------------------------------|----|
| Measures..... | 42 |
| Demographics Questionnaire | 42 |
| Family Needs Questionnaire | 43 |
| Supplemental Family Needs Questions..... | 43 |
| Procedure..... | 44 |
| | |
| Results..... | 45 |
| Data Screening | 45 |
| Missing Data | 45 |
| Internal Consistency Reliability..... | 46 |
| Testing of Main Hypotheses | 47 |
| Rank Order of Needs | 47 |
| Hypothesis 1 Result | 48 |
| Hypothesis 2 Result | 50 |
| Hypothesis 3 Result | 52 |
| Hypothesis 4 Result | 54 |
| Exploratory Analyses..... | 56 |
| Proportional Indices of Needs..... | 56 |
| Comparison of Proportional Indices of Need | 57 |
| Testing Assumptions..... | 58 |
| Determining Variables Related to Indices of Need | 58 |
| Exploratory Hypothesis 1 Results..... | 59 |
| Exploratory Hypothesis 2 Results..... | 60 |
| Exploratory Hypothesis 3 Results..... | 61 |
| Exploratory Hypothesis 4 Results..... | 62 |
| Exploratory Hypothesis 5a Results..... | 63 |
| Exploratory Hypothesis 5b Results..... | 64 |
| Exploratory Hypothesis 6 Results..... | 63 |
| Additional Analyses..... | 66 |
| | |
| Discussion | 67 |
| Purpose..... | 67 |
| Summary of Findings..... | 68 |
| Examination of Exploratory Hypotheses | 71 |
| Discussion of a Single Item Viewed Differently Across Samples | 72 |
| Supplementary FNQ | 73 |
| Implications..... | 74 |
| Limitations | 76 |
| Future Directions | 78 |

| | |
|---------------------------------------------------|----|
| List of References | 80 |
| Appendices..... | 87 |
| A Demographics Questionnaire..... | 87 |
| B Family Needs Questionnaire..... | 80 |
| C Supplemental Family Needs Questionnaire..... | 94 |
| Vita..... | 95 |

List of Tables

| | Page |
|---------------------------------------------------------------------------------------------------------------------------------------|------|
| Table 1. Determining the Severity of TBI | 7 |
| Table 2. Glasgow Coma Scale | 8 |
| Table 3. Comparative Review of Family Needs Research Studies | 28 |
| Table 4. Demographic Characteristics of Family Member Participants | 41 |
| Table 5. Internal Consistency Reliability for FNQ in PRC Populations and Civilian Populations..... | 46 |
| Table 6. Ten Needs Most Frequently Rated as “Important” or “Very Important” with Comparison Ranks from Civilian FNQ Needs Study | 49 |
| Table 7. Ten Needs Most Frequently Rated as “Not Important” with Comparison Ranks from Civilian FNQ Needs Study | 51 |
| Table 8. Ten Needs Most Frequently Rated as “Met” with Comparison Ranks from Civilian FNQ Needs Study | 53 |
| Table 9. Ten Needs Most Frequently Rated as “Not Met” with Comparison Ranks from Civilian FNQ Needs Study..... | 55 |
| Table 10. Comparison of PRC and Civilian FNQ Importance Ratios and “Met” Ratios | 57 |
| Table 11. Report of Ratio Skewness..... | 58 |
| Table 12. Relationship Among Needs Ratios and Race | 60 |
| Table 13. Relationship Among Needs Ratios and Sex | 61 |
| Table 14. Relationship Among Needs Ratios and Income | 62 |
| Table 15. Relationship Among Needs Ratios and Relationship to Patient..... | 63 |
| Table 16. Relationship Among Needs Indices and Time Since Injury (90 days).. | 64 |
| Table 17. Relationship Among Needs Indices and Time Since Injury (180 days) | 65 |

| | |
|------------------------------------------------------------------------|----|
| Table 18. Relationship Among Needs Indices and Location of Injury..... | 66 |
| Table 19. Descriptives of Importance Ranks for Supplemental FNQ | 66 |
| Table 20. Descriptives of “Met” Ranks for Supplemental FNQ | 67 |

List of Figures

Page

Figure 1. Polytrauma System of Care13

Abstract

POLYTRAUMA FAMILY NEEDS ASSESSMENT

By Kathryn Pamela Wilder Schaaf, M.S.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2010

Major Director: Steven J. Danish
Professor
Department of Psychology

There is a great deal of literature in civilian rehabilitation settings that documents the tremendous impact a brain injury has on both the injured person and the family as a whole. TBI is a leading cause of both death and disability world-wide and is often cited as the signature injury of the ongoing OEF/OIF conflict. In 2005, Congress recognized the severity of injuries that military personnel were encountering in the OEF/OIF conflicts and created the Polytrauma System of Care (PSC). While the PSC has made great efforts to provide innovative and effective treatment for active duty and veteran patients, little is known about the needs of their family members. Given the tremendous impact TBI has on families and the important caregiving role assumed by many, there is an urgent need to better understand their needs. The Family Needs Questionnaire (FNQ) was administered to 44 family members of

patients at the Polytrauma Rehabilitation Center (PRC) at McGuire Veterans Affairs Medical Center (VAMC) over a 30 month period. Family members rated 40 needs indicating the importance and extent to which needs were met. Results were compared with findings from similar studies in civilian rehabilitation settings. A review of the rated needs indicated that PRC families rated the needs in the Health Information domain as most important and most frequently met. In addition, PRC family members rated Emotional Support and Instrumental Support as least important and most frequently unmet. Overall results were consistent with findings in civilian rehabilitation research, but subtle differences were examined.

Exploratory analyses were conducted to examine a subset of family variables associated with needs indices. Needs were rated differently based on respondents', gender, income, relationship to patient, and time since injury. Results highlight similarities across family needs in rehabilitation settings. However, there remains a need for further research within VAMC PRC's that include a larger more diverse sample and participants utilizing both inpatient and outpatient services.

This document was created in Microsoft VISTA.

Polytrauma Family Needs Assessment

Background and Significance

The introduction chapter will provide a broad overview of blast injury and traumatic brain injury (TBI). Specifically, the introduction will discuss the etiology of TBI, provide an understanding of how the severity of TBI is determined, and the consequences of TBI. Next, the Polytrauma System of Care (PSC) will be introduced including the inception of this program in veterans' hospital and the general structure of the program. This chapter concludes with a statement purpose for the dissertation project.

In initiating Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF), our country launched the largest ground military operation since the Vietnam War. Since 2001 more than 1.5 million U.S. Military personnel have been deployed to either Iraq or Afghanistan (Hoge et al., 2008). Over 4,900 of those military personnel have been killed and 34,000 have been wounded (Fischer, 2009). With the onset of OEF/OIF, the ratio of wounded to dead has dramatically shifted from 2:1 wounded to dead soldiers in World War II, 3:1 in Vietnam, and now 8:1 in Iraq (Roehr, 2009). OEF/OIF warfare has been marked by blast injuries or physical injuries caused by an explosive devices. Blast injuries account for the majority of combat related injuries and can be caused by improvised explosive devices (IEDs), rocket and mortar shells, artillery, booby traps, aerial bombs, etc. (Sayer et al., 2008). These types of injuries have introduced new challenges for trauma care and recovery.

This change in the injury trajectory for OEF/OIF is due to a number of prevention and intervention factors. As a result of improved trauma care as well as new technology in

body armor, military service members are now more likely to survive blast injuries than in previous United States wars (Okie, 2005). While this new technology protecting armed forces in the line of duty should be applauded for the preservation of life that it allows, unforeseen consequences have emerged. One of the most notable has been the number of service members who have multiple non-fatal, yet nonetheless serious injuries due to warfare blasts. These polytraumatic injuries include amputations, fractures, loss of hearing, skin burns, and traumatic brain injury (TBI) (Friedemann-Sánchez, Sayer, & Pickett, 2008). Polytraumatic injuries, or “two or more injuries to physical regions or organ systems, one of which may be life threatening, resulting in physical, cognitive, psychological, or psychosocial impairments and functional disability” (VHA Handbook, pg. 3), are a common consequence of blast injuries.

Blast Injuries and Traumatic Brain Injury

Blast-related TBI's are increasingly common in these wars as IED's are often used in terrorist and insurgent activities. IED's are primarily responsible for the trend of polytraumatic injuries that have emerged. Although explosives have been used during other conflicts, OEF/OIF is unique in the high amount of explosives that have been utilized (Warden, 2006). Okie (2005) estimates that almost 60% of blast injuries will result in TBI. There are four different types of injuries that can occur as a result of IED's. Primary blast injuries occur as solid or liquids are instantly converted to a gas form, resulting in atmospheric pressure change. These types of injuries most often affect parts of the body that have air-fluid interfaces (lungs, bowels, and inner ear. Secondary blast injuries occur when

objects are put into motion as a result of the IED (Taber, Warden, & Hurley, 2006). Metallic fragments imbedded in the IED cause penetrating wounds that are one of the leading causes of death and injury in terrorist attacks. Tertiary blast injuries occur because either people are being put into motion as a result of the blast or because of structural collapse and fragmentation. Like secondary blasts, any part of the body can be affected and cause fractures, traumatic amputations, and open and closed brain injuries. Both secondary and tertiary blasts may affect any part of the body causing limb loss, internal organ damage, etc. (DePalma, Burris, Champion, Hodgson, 2005). Quaternary blast injuries are caused by the gas and heat that result from an explosion. A common injury within this category is a burn. The brain is most susceptible to secondary and tertiary blast injuries, but there is some evidence that the brain is also vulnerable to the effects of primary blast injuries (Taber, Warden, & Hurley, 2006). One hypothesis for the unique nature of injuries due to IED's is that the primary blast injuries have an additional effect on whatever injury is caused by the secondary or tertiary injury (Warden, 2006). TBI's sustained from IED's blast injuries are often the primary injury. It is important to note, however, that the TBI can be further complicated by the additional medical problems often sustained due to blast injury such as limb loss, PTSD, burns, and stroke.

Victims of TBI endure a number of structural and chemical changes to the brain. Neuroanatomic changes include both pathophysiological changes (damage to neuronal fiber) which are characterized by axonal swelling and eventual attempts at regeneration as well as neurochemical changes (changes in potassium concentrations which lead to metabolic

depression), that occur even if cells are not mechanically damaged. That is, when neurochemical changes occur, cells that are not damaged are still susceptible to metabolic changes resulting in possible depression and behavior changes. Damage caused by head injuries results from two processes: primary injury and secondary effects. The primary injury occurs at the point of trauma. Although the trauma is time limited, it spurs physiological and metabolic processes that generate the secondary effects, which are often more damaging than the primary injury. Secondary effects can include destruction of brain tissue due to surgical removal of penetrating objects, edema (swelling of brain tissue), brain infection, bleeding, posttraumatic epilepsy, etc. (Lucas, 2003).

Etiology of TBI

TBI is a leading cause of both death and disability world-wide (Lipper-Gruner, Maegele, Haverkamp, Klug, & Wedekind, 2007), and is often cited as the most common component of polytraumatic injuries. TBI is caused by an external mechanical force with trauma that is sufficient to cause alterations in consciousness, neurological impairment, or cognitive deficits (Lucas, 1999; Snyder & Nussbaum, 1998). TBI is widely considered the signature injury of OIF and OEF (Hoge, et al., 2008; Okie, S., 2006). With head and neck injuries being reported in up to 25% of service members evacuated from either Iraq or Afghanistan, medical and rehabilitation services have had to adapt to the circumstances of this war.

TBI occurs when a sudden trauma to the head “is sufficient to cause alterations in consciousness, neurological impairment, or cognitive deficits” (Lucas, 2003, p.243).

Patients with TBI can sustain an open head injury or a closed head injury. Open head injuries involve the penetration or crushing of the skull, and are more likely to be fatal. Closed head injuries leave the skull mostly intact. Both open and closed injuries begin with a primary injury that creates secondary effects, but the process by which this occurs differs. One reason why open injuries are often more fatal is because the secondary effects of the injury are more severe. That is, with both open and closed injuries, ischemia (interrupted blood flow to the tissues) and edema (swelling of brain tissue) are likely to occur. With open head injuries, however, there are additional potential secondary effects that increase lethality such as destruction of brain tissue during removal of foreign objects, brain infections, and posttraumatic epilepsy (Lucas, 2003).

Symptoms of TBI can be classified as mild, moderate, or severe depending on the extent of the injury. Patients with mild TBI typically remain conscious or only lose consciousness (an awareness of both self and environment) for a few seconds. Symptoms may include headache, dizziness, blurred vision, ringing in the ears, sleep pattern change, trouble with memory, and behavioral/mood changes (National Institute of Health [NIH], 2007). Patients who experience moderate to severe injuries will show cognitive impairments across all domains of functioning. While patients with the most severe injuries may show impairments in all cognitive abilities, those with more moderate injuries are likely to have unique patterns of cognitive functioning that demonstrate some impairments and some preserved abilities (Lucas, 2004).

Determining TBI Severity

Head injuries are classified using a number of measures. Scores on the Glasgow Coma Scale (GCS), the amount of time that the patient remains unconscious, and length of posttraumatic amnesia are measures commonly used in conjunction with each other to determine severity (see Table 1). The GCS (Teasdale & Jennett, 1974) makes use of a scale from 3-15 to measure verbal responses, eye opening behavior, and best motor responses (see Table 2). Although the GCS is sensitive to moderate and severe head injuries, it is less useful when assessing mild head injuries. Loss of consciousness (LOC), which can occur at the moment of impact or injury, is characterized with suppressed reflexes and changes cardiopulmonary functioning. While an individual's vital signs will often return to normal within seconds, he/she may not regain consciousness. The amount of time that it takes for the individual to regain consciousness is another indicator of the severity of the brain injury (see Table 1). Finally, the length of posttraumatic amnesia (PTA), or a disturbance of memory following a head injury, can also help predict both severity of injury and recovery time. PTA occurs when neurological mechanisms responsible for memory and encoding are interrupted (Lucas, 2003). Diagnosing mild head trauma in a combat setting can often be more challenging than diagnosing head injuries in the civilian population. Service members within the context of war are less likely to report symptoms of a mild TBI when they are surrounded by comrades with more severe injuries. Thus the symptoms may be overlooked and ignored when there is a perceived "greater need" (Helmick, Parkinson, Chandler, &

Warden, 2007). This will no doubt have future implications for the personnel when their injuries go undetected and subsequently untreated.

Table 1.

Determining the Severity of Traumatic Brain Injury.

| <i>Severity</i> | <i>Glasgow Coma Scale</i> | <i>Loss of Consciousness</i> | <i>Posttraumatic Stress Amnesia</i> |
|-----------------|---------------------------|------------------------------|-------------------------------------|
| Mild | 13-15 | < 1 hour | < 24 hours |
| Moderate | 9-12 | 1-24 hours | 24 hours to < 7 days |
| Severe | 3-8 | >24 hours | 7 days or more |

Note: Table adapted from: Helmick, K.M., Parkinson, G.W., Chandler, L.A., Warden, D.L. (2007). Mild traumatic brain injury in wartime. *Federal Practitioner*, 58-65.

Table 2.

Glasgow Coma Scale

| | | |
|----------------------|-----------------------------------------------------|----------|
| Eye Opening Response | Spontaneous--open with blinking at baseline | 4 points |
| | Opens to verbal command, speech, or shout | 3 points |
| | Opens to pain, not applied to face | 2 points |
| | None | 1 point |
| Verbal Response | Oriented | 5 points |
| | Confused conversation, but able to answer questions | 4 points |
| | Inappropriate responses, words discernible | 3 points |
| | Incomprehensible speech | 2 points |
| | None | 1 point |
| Motor Response | Obeys commands for movement | 6 points |
| | Purposeful movement to painful stimulus | 5 points |
| | Withdraws from pain | 4 points |
| | Abnormal (spastic) flexion, decorticate posture | 3 points |
| | Extensor (rigid) response, decerebrate posture | 2 points |
| | None | 1 point |

Note: Table adapted from: Teasdale, G., & Jennett, B. (1974). Assessment of coma and impairment of consciousness: A practical scale. *Lancet*, 2, 81-84.

Consequences of TBI

As already noted, advances in body armor and improvements in trauma care have improved survival rates from injuries during OEF/OIF. These survivors now have complicated injuries with which medical personnel may have limited experience. TBI is one of the most common pieces of polytraumatic injuries. Survivors of TBI must deal with neuropsychological problems that affect multiple facets of life (work, social activity, etc.)

Deficits are both cognitive and emotional in nature, and can include problems with executive functioning, learning and memory, and general independence with daily living. Many patients who have a TBI also report sleep disturbance, chronic pain, headaches, depression, irritability and other distinct personality changes (Lippert-Gruner et al., 2007; Keltner, N. & Cooke, B, 2007). Further complications arise with war-related TBI that may not be present within the civilian population. TBI may trigger an overlay of PTSD that results in additional behavioral changes. In addition, many service members may sustain other injuries in addition to a TBI (limb loss, hearing loss, burns, etc.).

Although polytraumatic injuries are challenging by nature, the difficulties are multiplied when a TBI is present. This is due to the fact that TBI symptoms often include agnosognosia or a lack awareness of the cognitive, behavioral, and emotional deficits that he or she has as a result of the injury (Port, Willmott, & Charlton, 2002). Individuals with a TBI experience: a) intellectual deficits (inability to understand that functioning has been impaired), b) emergent awareness deficits (inability to recognize a problem or issue when it arises), and c) anticipatory awareness deficits (inability to anticipate problems that might occur as a result of their deficits) (Crosson et al, 1989). Although family members realize that their loved one with a TBI has acquired deficits, there is a developmental trajectory for realizing the full extent of the injury. Port et al. (2002) point out that up to two years after injury family members may still not fully realize the consequences of the injury. This may be due to that fact that the TBI patient may not have been fully emerged into a functional context, and thus changes during everyday events may not have been observed. This study

highlights the fact that services for TBI polytrauma patients must evolve as the patients continue to heal and change. The needs of family members will not disappear once the patient leaves inpatient care, but will simply change as the patients adjust to their new context and environment.

Polytrauma System of Care

The emergence of the PSC is unique to OEF/OIF conflicts. In 2002, the first Polytrauma patient was admitted to the VA System even before the PSC was officially created. It was not until March 2003 (the initiation of combat operations in Iraq) that Polytrauma services became more of a pressing need (Sigford, 2008). Polytraumatic injuries grew in numbers as explosive devices were increasingly used in the OEF/OIF conflicts. In 2005, Congress recognized the severity of injuries that military personnel were encountering. As part of a national Memorandum of Agreement with the Department of Defense (DOD), four Department of Veterans Affairs (VA) TBI Lead Rehabilitation Centers were established to provide specialized rehabilitation care to severely combat-injured personnel requiring inpatient brain injury rehabilitation (VHA Directive 2005-024, June 08, 2005, Polytrauma Rehabilitation Centers). These four sites (Tampa, FL; Richmond, VA; Minneapolis, MN; and Palo Alto, CA) were chosen as TBI lead sites in 1992 and thus were a natural fit as Polytrauma Rehabilitation Centers (PRC), as this new pattern of injury often includes a TBI diagnosis.

The Polytrauma Rehabilitation Centers (PRC's) are one component of the PSC (see Figure 1) and offer the highest level of care. PRC's are regional facilities that have built on

the expertise acquired as designated TBI lead sites. These sites are for military personnel who have received severe polytraumatic injuries and need acute medical, surgical, and rehabilitation care. Staff members employed by the PRC's are specially trained to deal with all areas of polytraumatic injuries. PRC's exist within an environment reflecting the age of the service members that they house (i.e., internet and media services are available that are appropriate for the age interests of those on the unit). Transitional apartments through the Polytrauma Transitional Rehabilitation Program (PTRP) may be available for patients who are able to practice independent living skills prior to discharge (Sigford, 2008).

PRC rehabilitation is centered on a collaborative process that involves an interdisciplinary team (IDT) (physiatry, rehab nursing, neuropsychology, physical therapy, speech therapy, recreational therapy, low vision specialists etc.) patients, and family members. An important aspect of the rehabilitation process is that goals set are addressed by multiple disciplines and reinforced in a number of settings. In addition, members of the PRC will often co-treat and treat in a variety of settings as a means of optimizing community functioning and independence with goals (Collins & Kennedy, 2008).

Although PRC's provide a high level of care for returning veterans with polytraumatic injuries, these services are limited by location and by severity of injury (e.g. not all injuries warrant this level of care). In response to needs outside of the specialized PRC's, 21 Polytrauma Network Sites (PNS) were created in 2005 to provide immediate services for post-acute sequelae of polytrauma injuries and lifelong services for veterans living in the vicinity. Although all PNS's have specially trained rehabilitation staff, these

centers can sometimes be limited in the number in the consultation services they can provide. PNS's were also created as an initial center for evaluation for service members who sustained polytraumatic injuries that did not warrant the level of care provided in PRC's (Sigford, 2008).

The final tier of the PSC is the Polytrauma support clinic teams and the Polytrauma points of contact. The Polytrauma support clinic teams are most often located closer to the homes of veterans and are intended to help veterans manage more stable symptoms. These centers are not able to provide the same level of expertise and consultation that the PNS and PRC offer. Instead, these centers monitor the conditions of veterans and make referrals back to PNS if complications emerge that supersede the capabilities of the center. The Polytrauma points of contacts are often trained social workers who have a specific knowledge of the PSC. Although these points of contact will not provide Polytrauma services they do provide referrals to the appropriate branch of the PSC. The four facets of the PSC work to ensure that veterans receive appropriate services across the lifespan. In addition, this specialized national system is working to address the unique nature of the polytrauma injury (Sigford, 2008).

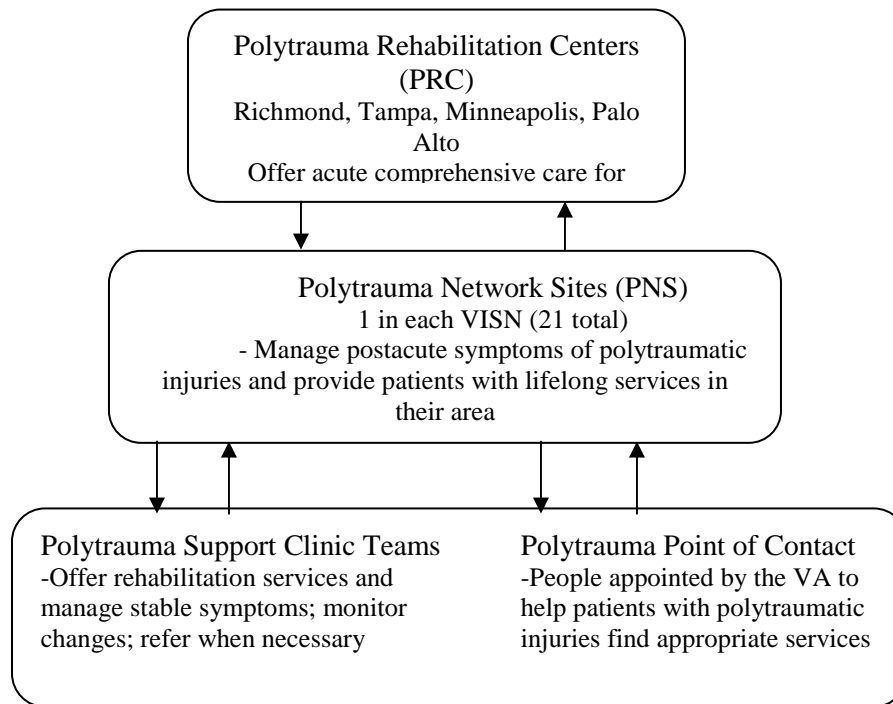


Figure 1. The Polytrauma System of Care.

Purpose

Friedemann-Sánchez, et al. (2008) note that injuries emerging from OEF/OIF require specialized forms of treatment from multidisciplinary teams. In addition, the authors recommend that programs to help family members and providers should be considered a priority for this vulnerable population. As medical personnel struggle to provide the best care for military personnel so that they may return home, families too must feel informed and educated about how to best care for their loved one and adapt to changes polytraumatic injuries will present. The growing number of military personnel returning with polytraumatic injuries mandates an increased focus on treating and rehabilitating this population. Similar efforts should be made to help families learn how to help their wounded members recuperate and rehabilitate. To date there are no peer reviewed studies that specifically address the needs of families with a patient in Polytrauma System of Care (PSC). Polytraumatic injuries clearly result in lifelong changes for men and women who are dealing with them. This lifelong injury has understandable consequences for family members who most often resume caretaking once a patient has been discharged.

There is a great deal of literature within the civilian demographic which documents the tremendous impact a brain injury has on both the injured person and the family as a whole. However, there is little precedence for what is known about the family of polytrauma patients and what their needs are during an inpatient stay. There is an immediate need to better understand these injured men and women and the families who will care for them. This study will describe the needs of family members during an acute rehabilitation stay at a

veteran's hospital. The objective of the study will be to describe what needs are most and least important to this population. In addition, “Met” and unmet needs will be described. In addition, the study will compare findings to family needs in a civilian rehabilitation setting.

Literature Review

This literature review will begin with an overview of family systems theory which highlights the complexity of the family system and this system's response to change. For the purpose of this study, the literature is then divided into two parts. The first part encompasses what we know about family members who are a part of the polytrauma system of care. The second part includes research with civilian families who have encountered TBI. This chapter concludes with a statement of the problem which summarizes the literature and addresses the author's hypotheses.

Family Systems Theory Overview

The family system is very broadly defined by the roles and relationships family members fulfill in their day to day lives. This system is a dynamic and ever changing entity which develops rules, communication patterns, problems solving, and negotiating techniques (DePompei & Williams, 1994). Although cultural wisdom often suggests that age brings autonomy and independence, family systems theory maintains that there remains a strong link to the family that provides identity and validation throughout the lifespan (Leaf, 1993). The family system provides a basis of interconnection and interdependence that cannot be avoided regardless of developmental stage or level of individual differentiation.

Systems theory has four key ideas that underlie each family system. First, individuals within the system are all connected. The relationship between mother/father, parent/child, and sibling1/sibling2 are all connected and interactions are numerous. Second, the family system develops over the life-span. As components are added to or taken away from the system (e.g. marriage, birth, death, etc.) the system changes and adjusts. Third, a change to one part of the system changes the entire system. If the rules or patterns of the system are disrupted by one member of the system, all parts of the system are disrupted as well. Fourth, every system is unique. Even if families have similar circumstances or environment, the structure and rules can often be different. The rules from one system cannot be generalized to the next even if the families may seem similar in nature (Rosenthal & Young, 1988; Leaf, 1993).

Family Systems Theory and TBI

When applying family systems theory to a rehabilitation or health care setting, there are a number of family factors that should be closely considered. First, understanding who makes up the family system must be established. Although families are often defined by blood relation and marriage, this assumption can be false, particularly in time of crisis. That is, as the family system deals with the TBI and injury, close friends may be included in the family system and contribute to the family dynamics. In addition, it is important to remember that identified patient (IP) or the person with the TBI is always a part of the family system. The family members that emerge and the relationship they pursue with the IP remains important for long term care of the patient.

A second consideration for family systems theory and TBI is how the family functions in response to the TBI. Previous family functioning is often a good predictor of how families will respond to crisis. In a health care setting, however, the benefit of observing previous functioning is rare, making interaction and assessment of family members a key factor in intervention. Depending on the rules of the family, the IP may be blamed or held accountable for dysfunctional patterns that emerge within families. In these cases the family may view themselves as separate from the patient. The IP, however, may also be celebrated and be seen as the person who has brought a family together in time of crisis. Further, the family's communication style is essential in crisis situations. Whereas some families send representatives to deal with crisis, other families may come in groups and become a large presence in the health care setting. Some families may be adept at and open to interacting with health care professionals while other families may be disengaged and more dependent on one another (DePompei & Williams, 1994). Regardless of how family members respond, the differences in the manner in which they respond should be considered when conceptualizing an approach that is effective for the family.

Finally, the roles that each family member takes on in response to TBI bring important information. When an emotional event happens within the family system, this event can bring on changes in the roles that family member play. When one member of the family sustains a brain injury, this requires other members of the family to take over the role that person played in the family. With this transition may come feelings of being overwhelmed, angry, and burdened. The loss experienced in the system can take on many

forms and echoes throughout the entire family. For example, a father who fulfilled the "breadwinner" role is no longer able to work after his accident. The mother may fill the financial burden by working more hours or changing jobs, but the children may take on addition burdens as well. The oldest child may feel a responsibility towards overseeing and providing emotional support in the mother's absence. In addition, the younger children will feel the change in caretaking and dependence that once seemed taken for granted (Uomoto & Uomoto, 2009). In sum, the family system absorbs change as a whole. Members of the system will react to the TBI differently, and each must adjust through taking on new roles within their family system.

Overall, because TBI is an unexpected event that brings on feelings of loss and grief, certain considerations should be given to each family system that is forced to deal with these circumstances. The line between function and dysfunction is often thin, and behaviors that might seem as unacceptable outside of the given situation may change with the circumstances that TBI presents to the family system.

Literature Review Part One: Families and Patients in the PRC

Dealing with blast-related TBI's and a polytraumatic injury is a phenomenon that has largely developed out of the OEF/OIF conflicts. Medical technology, prompt care, and protective gear have allowed life after blast injuries that would not have been possible in previous conflicts. Because polytrauma care is an emerging area of study, there are a limited number of studies conducted in this area. This section will review the articles that have been

published and provide the reader with a broad characterization of what has been published about the patients and family members in the PRC.

Patients admitted into the PRC are different than patients previously cared for by the VAMC system. Friedman-Sanchez et al. (2008) used a rapid assessment process (RAP) methodology that allowed for in-depth qualitative information to be gathered in a relatively short amount of time through interview and a review of relevant records. Using this methodology, the authors noted that patients with polytraumatic injuries were both clinically and demographically diverse. Friedman-Sanchez et al. (2008) divided the PRC patient populations into two distinct groups. The first group was characterized as younger than the typical rehabilitation patient (late teens-mid twenties), joined the military immediately after completing high school, and had limited job experience outside of the military. The second group was characterized as reservists in their 30's and 40's who often left behind partners as well as civilian jobs. Membership within each of these distinctive groups has affected treatment. The younger group was reportedly more concerned about changes to their physical appearance (particularly those who are single) and welcomed the use of technology in rehab as well as for pleasure on the unit (e.g. using social websites and other entertainment outlets). The older population was more concerned about memory loss and problems with mobility (Friedman-Sanchez et al., 2008).

Much like the patients in the PRC, their families are also unique. Families in the PRC are characterized as "intensely involved" with the care of their loved one. While other areas of the VA have family involvement, the level of participation within the PRC is considered

unmatched. Upon arrival at the PRC, families may have already endured months of treatment, often starting at Landstuhl Regional Medical Center, the military medical facility in Germany. Families are allowed to stay on VA grounds so that they may be bedside with their loved one whenever needed, and are also an integral part of the treatment team. This involvement not only helps the long-term recovery of the patient, but can also fulfill the family's need to be involved with care. The severe nature of polytraumatic injury means that families can sometimes be demanding of critical care. PRC service providers must be sensitive not only to the patient's and family members' grief and loss, but also to external pressures such as financial difficulties due to work absence, navigating the difficult health care system and other issues that the families face (Friedman-Sanchez et al., 2008).

Collins and Kennedy (2008) have added to our knowledge of the PRC with an article that broadly discusses the PRC population, family-centered care philosophy, and ambiguous loss theory as it applies to the PRC. In introducing their perspective the authors reiterate that there are a number of contextual factors and stressors that should be taken into consideration when dealing with a PRC population. Collins and Kennedy (2008) note a distinct difference between inpatient TBI rehab families prior to the war and current PRC families. These differences can be accounted for, in part, by stress brought on by the deployment. Deployment requires family members to be separated for long periods of time. With this separation comes more responsibility for the family members who remain at home as well as an underlying fear that their loved one will be injured or die. In addition, while family members will have considered that physical injury occurs during deployment, few anticipate

long-term personality changes or neurobehavioral impairments that can accompany TBI (Collins & Kennedy, 2008).

Additional stressors occur once the family member learns of the injury and the patient is housed in the PRC. One source of stress is attributed to the unique nature of the injury being treated. Polytraumatic injuries can show more instability and less predictability which can create significant emotional ups and downs for family members. Thus the nature of the injury and the ambiguity that surround recovery can be difficult for family members. Stress may also stem from transferring an active duty Polytrauma patient from a military hospital to the VAMC facility. Family members may experience this transfer to the PRC as a loss, and perceive the change as a loss of comfort and security once provided by the military culture. Family members may also encounter another form of loss called ambiguous loss (Collins & Kennedy, 2008). Lezak (1986) describes ambiguous loss as a stage in the evolution of family reaction after the patient returns home saying: it is a "socially unacceptable task of mourning for a living person...there are no social supports or institutionalized rituals...it is an isolated and often secretive sorrowing." (p. 247). Collins and Kennedy (2008) note this is a process that comes on while still in the PRC, long before the family member goes home. A final factor which affects all areas of stress in the PRC is the geographic separation from friends and family. As there are only four PRC's in the United States, family often have to travel long distances to be with their loved on in the PRC. Family members are removed from their support systems, sometime have to take a leave of absence from work, and may have to rely on other family to take care of children left at home (Collins & Kennedy, 2008).

This separation can amplify the other stressors and leave family members feeling unsupported or alone.

To date, these findings encompass what has been published by clinicians and researchers who work within the PRC. Although these authors have provided an important base for knowing how the patients and family members respond to the PRC, more empirical research is needed to understand more specific stressors, concerns, and needs that will emerge from this population.

Literature Review Part Two: Family Needs in the Civilian Literature

Because blast-related TBI's are a relatively new phenomenon, the health care field has drawn from previous research on TBI for treatment and intervention purposes. Although certainly aspects from the previous TBI literature are generalizable, there are important factors that differentiate TBI in the civilian population from TBI/polytraumatic injuries in the military population. These include the dynamics involved with acquiring the injury during combat, IED-induced injury changes, the distance families must travel to participate in the PSC, and the approach to care provided by civilian vs. veteran hospitals. Despite these differences, overlap does exist and it is important to examine what is known about TBI in the civilian sector. The following research was conducted with families in civilian hospital settings who have dealt with TBI, but not necessarily polytraumatic injuries. This second section of the literature review will discuss some of what TBI literature has taught us about the needs of patients and families in the civilian rehabilitation settings.

Factors that Affect Family Stress in the TBI Literature

While having a family member with a TBI stresses the entire family system including the patient, a number of factors may exacerbate this stress. One of these factors is neurobehavioral problems or personality changes that occur as a result of injury. These changes may manifest within the emotional, cognitive, and behavioral domains (Ergh, Rapport, Coleman, & Hanks, 2002). Marsh, Kersel, Havill, & Sleigh (1998) found that out of all these domains, changes in emotional control (mood swings, aggression, and argumentative nature) are the most distressing. A second factor is the neuropsychological functioning of patients. Ergh et al. (2002) report that although the literature has not revealed consistent findings in this domain, impaired executive functioning does have some impact on caregivers. The inconsistent findings may be a result of measurement error (often subjective measures are used in this domain), and impaired executive function requiring additional supervision from caregivers. A third factor is the patient's awareness of his or her deficits. While patients who lack awareness of deficits are less likely to experience dysphoria, they often have less success when rehabilitating. In addition, patients who are less aware of their deficits also require additional supervision and help from their caregiver (Prigatano, 1996).

Family members who are TBI caregivers find themselves taking on a multitude of tasks. Caregiving involves not only providing emotional, instrumental and financial assistance to the patient, but also requires becoming the patient's advocate among the many service providers. Caregivers' burden can thus affect their own mental and physical well-

being (Winstanley, Simpson, Tate, & Myles, 2006). In a qualitative study of TBI patients and their caregivers, caregivers surveyed from all four phases of care (acute care, in-patient rehabilitation, the return home transitional period, and community integration) reported that they desired additional information. Caregivers in the acute and inpatient phase stated that explanations of injuries were often hard to understand and there needed to be more talk about implications of these injuries. Caregivers in the inpatient phase also requested more treatment for the patients' emotional and behavioral changes that would result from the TBI. Caregivers in all phases of treatment stated that financial assistance, guidance (answers to all questions and extended face-to-face time with health care professionals), and the need to address family emotional and mental health should be included. Caregivers in the first two phases (acute and in-patient rehab) discussed: 1) needing to know their loved one was receiving quality services, 2) needing to be involved in decision making, 3) wanting to be prepared for discharge, 4) wanting staff to be supportive and caring, and 5) needing their employers to understand the circumstances of being at the hospital and not penalizing them for their absence (Rotonid, Sinkule, Balzer, & Harris, 2007).

All families regardless of caregiver status share some common frustrations and stressor including social isolation, strained finances, limited independence, guilt, and frustration. However, all family members within the family system may experience these stressors differently given their role and relationship with the patient. Lezak (1988) discussed how traumatic brain injury can be perceived differently by family members depending on the nature of the relationship with the patient. Specifically, the stress of a

parent vs. child vs. spouse presents different challenges for each person given the developmental role played in the system.

Parent Stressors

Although parental stressors differ given the age of the patient with the TBI, some core issues remain regardless of age. The experience of being the patient's parent is marked with the knowledge that responsibility for their child will only terminate with death. Parents must become accustomed to the idea of limited freedom during retirement depending on the patient's level of independence. Further, older parents who have seen their children beyond the adolescent stage, may find that the child regresses and that old conflicts are reawakened (Lezak, 1988).

Child Stressors

Children who experience a parent with a TBI quickly notice a decrease in attention from that parent. This decrease in attention is often accompanied by the child being given additional family responsibilities or chores to help ease the burden of the primary caregiver in the family. Children often report some guilt for the shame or frustration they feel because of their "different" family status. Children also experience loss around the fact that their family is unable to participate in community activities as frequently and may feel more isolated as a result (Lezak, 1988).

Spouse Stressors

When examining a person whose spouse experiences a TBI, Lezak (1988) differentiates between couples who previously were in healthy versus unhealthy marriages.

Spouses who considered themselves in a healthy relationship before the TBI often feel a sense of appreciation for their experiences before the accident along with a sense of guilt and fear of rejection due to the family's current status. Partners must mourn the loss of their former partner which is often difficult when their partner is still alive. When a marriage has been unsatisfactory, TBI often only prolongs that relationship due to fear of evaluation or social rejection that comes with leaving a spouse who is sick or needs care. Regardless of the status of a marriage, all partners will notice a decrease in sexual satisfaction in the relationship. In addition, partners bear the burden of filing all paperwork or claims associated with the TBI, often become the target of the patient's anger or frustration, and struggle with the intensity of the workload associated with caregiving.

Overall, families who are unable to adjust to changes associated with the brain injury are continuously disappointed with each interaction. Those families who do make this transition go through the difficult process of letting go of the old ways of dealing with the patient and developing new ways that are "less flattering, less pleasurable, and less hopeful" (Lezak, 1988, 123).

Family Needs in the Rehabilitation Literature- Beyond TBI

It has been established that TBI is a stressful event that affects both the patient and their families in complex and difficult ways. While there have been significant medical developments that have worked to preserve the life of people with brain injuries, less is known about how to help this population with psychological gains in rehabilitation and recovery stages. Because physical and functional goals are often the focus in the acute

phases of injury, family involvement and discharge planning can be minimized (Kreutzer et al., 2009). Having an accurate understanding of needs is crucial given the limited time frame patients are in a hospital setting compared with the lifetime they will spend with their caretakers.

Much has been written about family needs within the context of the rehabilitation literature. Table 3 presents a compilation of all articles reviewed in the area of family needs. In conceptualizing a review of this area of literature, there were a number of issues to address. First, the review sought to identify articles that address both family needs and traumatic brain injury. Within the area of TBI, the table differentiates methodology (quantitative, qualitative, or both), use of the Family Needs Questionnaire (FNQ; Kreutzer, 1988), and population studied. Differentiating the use of the FNQ was included to note consistency among measure in the needs literature. In addition to studies which address family needs among patients with TBI, the table offers a brief review of the family needs literature outside of TBI including acquired brain injury, pediatrics, and spinal cord injury. These additional populations were included as a means of comparison. That is, working to answer the question of how family needs generalize across populations versus what needs are more specific to the TBI population. Of note, none of the studies included a veteran or military population.

Table 3.

Comparative review of family needs research studies

| Author(s) | Population | Method | FNQ |
|------------------------------------|---------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|-----|
| Armstrong & Kerns (2002) | Parents of 19 children with TBI, 21 with diabetes, and 14 of with orthopedic injuries | Comparative quantitative analysis of needs using a pediatric version of the FNQ | Yes |
| Chwalisz & Stark-Wroblewski (1996) | 27 spouses of persons with brain injury | Qualitative analysis of issues most salient to caregivers | No |
| Bond et al. (2003) | 7 family members of patients with severe TBI | Exploratory qualitative descriptive design- participant asked to describe needs, concerns, and new needs at follow up sessions | No |
| Junque et al. (1997) | 65 family members of adults with head injury | Quantitative questionnaire that included information about the nature of injury, changes, and needs | No |
| Kim & Moon (2007) | 123 caregivers of stroke patients | Quantitative analysis using FNQ | Yes |
| Kolakowsky-Hayner et al. (2000) | 136 caregivers of patients with TBI | Quantitative analysis using FNQ and Service Obstacles Scale | Yes |
| Kolakowsky-Hayner et al. (2001) | 57 caregivers of patients with TBI, >4 years post injury | Quantitative analysis using FNQ and Quality of Life measure | Yes |
| Kreutzer et al. (1994) | 119 family members of patients with primary diagnosis of TBI | Quantitative analysis using FNQ | Yes |
| Meade et al. (2004) | 17 family members of patients with SCI diagnosis | Quantitative analysis using FNQ | Yes |
| Moules & Chandler (1999) | 22 caretakers of patients with TBI | Quantitative (using FNQ and other measures) and qualitative (questions asking the impact of TBI on pt. and caretaker) analysis | Yes |
| Murray et al. (2006) | 66 caretakers of patients with an ABI | Quantitative analysis using FNQ | Yes |
| Witol et al. | 38 family members who | Longitudinal quantitative analysis | Yes |

| Author(s) | Population | Method | FNQ |
|------------------------|--------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| (1996) | had completed the FNQ at multiple time points for TBI | using FNQ | |
| Nabors et al. (2002) | 45 caregivers of patients with moderate-severe TBI-1 year post injury | Quantitative analysis using FNQ, Head Injury Family Interview, Family Assessment Device, and Personality Assessment Inventory (non-support scale only) | Yes |
| Paterson et al. (2001) | 8 survivors of TBI, 7 family caregivers, 4 groups of health care professionals | Qualitative design which sought to understand patient and families' perception vs. health care providers' perception of information and resources given | No |
| Rotondi et al. (2007) | 85 caregivers/support persons of patients with TBI | Qualitative analysis using semi-structured telephone interviews eliciting information about successes, failures, good and bad experiences, and requirements for success | No |
| Serio et al. (1995) | 180 survivors of brain injury and their relatives | Quantitative analysis including FNQ as well as neuropsychological test results and medical records | Yes |
| Waaland et al. (1993) | 49 caregivers of pediatric patients with TBI | Quantitative analysis using FNQ- compared high and low income parents of pediatric patients | Yes |
| Watanabe et al. (2001) | 22 Japanese and British caretakers of patients with TBI | Quantitative and qualitative analysis using needs questionnaires developed by researchers | No |

Family Needs as Described Using the FNQ

As indicated in Table 3, many family needs studies in the literature are making use of the FNQ. With the consistent use of the FNQ, needs across different populations can be compared to have a more clear and accurate understanding of how needs differ or are similar depending upon the population. In addition, use of the FNQ addresses methodological issues

that emerge when working to compare family needs. Within the context of TBI, studies that use the FNQ provide consistent themes with needs. In this review, populations differed in a number of ways including geographical location, ethnicity, time since injury, relationship with patient and income. Despite these variations in the populations, commonalities among perceptions of needs emerged. One of the most consistent findings is that family members report the needs for health information as one of the most important needs (e.g. Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Kreutzer, Serio, & Bergquist, 1994; Moules & Chandler, 1999; Nabors, Seacatt, & Rosenthal, 2002; Serio, Kreutzer, & Gervasio, 1995; Witol, Sander, & Kreutzer, 1996). Specifically, family members cite the need for having questions answered honestly and the need for complete information about the patient as most important within the health information domain. In many of the studies, emotional needs and instrumental support needs are often cited as the least important and least likely to be met domains of need (Kreutzer et al., 1994; Moules & Chandler, 1999; Nabors et al., 2002; Serio et al., 1995). That is, family members did not see needs pertaining to their own lives such as help keeping the house clean, reassurance about negative feelings, and spending time with friends to be as salient as needs that pertained to the patient (Kreutzer et al., 1994; Witol et al., 1996). With use of the FNQ, researchers have been able to quickly identify and compare needs within various populations of TBI. The striking consistency with which family members rate needs has allowed for intervention within the civilian sector to answer the needs of this population through intervention and multidisciplinary treatment.

Family Needs as Described in Qualitative Studies

Although the FNQ was frequently used in the literature to measure family needs, other authors also advocate for the use of qualitative methodology to bring depth of understanding to family needs in TBI populations. Qualitative studies examining needs share some similar findings with the FNQ quantitative research. Qualitative research in the area of family needs highlight the needs for health and medical information, but include a more a more detailed account of what this needs looks like for family members. Rotondi et al. (2007) studied TBI caregivers in four phases of care: P1: acute, P2: in-patient rehabilitation, P3: 3-4 months post discharge, and P4: life in the community. During each phase family members requested a need for information, but distinct types of information was needed during different stages of injury. The first two phases (acute and in-patient rehab) were marked with a need to understand the nature of the injury as well as the implications associated with the injury. The information need in P3 (3-4 months post discharge) evolved into caretakers wanting to know more about how to facilitate improvement, help the family adjust, and how to deal with social isolation. P4, the community integration phase, was marked with the need to understand how to endure change, rebuild their lives, and find community resources. Other themes that emerged from the Rotandi (2007) study mirrored needs discussed on the FNQ including need for financial assistance, need for guidance, need to be involved with decisions, and need for support from professionals.

This need for information and other overarching themes from the FNQ were further reflected in Bond's et al. (2003) qualitative study with family members of patients with

severe brain injury and Chwalisz & Stark-Wroblewski '(1996) study with spouses of brain injured patients. Bond et al. (2003) note that most common phrase stated by family members was "I just need to know." This need for information was expanded on by various family members as a need for consistent accurate information and consistent messages from the health care team. Similarly, family members expressed a need to feel involved with care and to have health care professionals provide them with education on how they can be useful. Chwalisz & Stark-Wroblewski (1996) highlighted that family members often struggled with the information that health care professionals provided. Spouses reported issues such as professionals having a lack of knowledge about brain injury and professionals not spending adequate time with family members. Other needs themes that emerged reflected a desire to have others understand their circumstances including the larger family. Out of this article came Chwalisz & Stark-Wroblewski's (1996) recommendation that education about brain injury should be extended beyond the immediate family to the larger family. This need request reflected the spouse's belief that with education would come more resources and support from an expanded network of family members.

Family needs outside of TBI

In reviewing the literature, it is apparent that family needs are examined in a number of different populations other than adult TBI. A brief overview of these studies is provided because the polytrauma family needs assessment has been conceptualized as its own unique population—separate from civilian TBI research. Thus comparing different populations in terms of family needs may shed additional light on expectations for a polytrauma population.

For this review, family needs studies in pediatric TBI, stroke, and spinal cord injury were evaluated. Each of these studies used the FNQ in addition to other demographic and qualitative measures.

Pediatric TBI studies report similar findings to studies with adult TBI populations. Consistently, the most important needs that family members reported were in the health information domain. Specifically, Armstrong & Kerns (2002) and Waaland et al. (1992) noted that parents placed particular emphasis on getting honest answers and understandable explanations from health professionals (both of these areas fell in the health information domain). Some difference was noted, however, in how parents report needs being met. Armstrong & Kerns (2002) reported that parents of pediatric TBI patient report a much larger proportion of their overall needs are unmet. Conversely, Waaland et al. (1992) evaluated satisfaction with met needs and found that the rate of met needs was proportional to the adult population. Interestingly, this study also compared low and high income families and reported largely congruent family needs results across both populations.

A family needs study of caregivers of stroke patients reviewed family needs and compared these needs for patients in different phases of care and care facilities in South Korea. Kim and Moon (2007) looked at caregivers in both the acute and post-acute phase as well as caregivers with patients in inpatient, outpatient, and day hospital settings. Consistent with other family needs literature, caregivers from all groups rated needs in the health information domain as the most important need. However, caregivers of patients in day hospitals reported a higher level of satisfaction across all need domains. In addition,

although both acute and post-acute caregivers rated needs in the health information domain as most important, caregivers of acute patients rated this domain significantly higher in importance than those in the post-acute phase. The two groups did not rate needs in the other five domains (emotional information, instrumental information, professional information, community network support, and familial support) differently. Additional differences between the acute and post-acute groups were noted in met and unmet needs. Caregivers in the acute phase reported a smaller number of needs met in both the community network and familial network support domains (Kim & Moon, 2007). This finding is different from results in the adult TBI populations that most often indicate emotional needs frequently rated as unmet (e.g. Kolakowsky-Hayner et al, 2000; Kreutzer et al., 1994).

Like the family needs reported in adult TBI, pediatric TBI, and stroke, the broad reoccurring theme around health information is consistent in a study of family needs in a spinal cord injury population. Meade et al. (2004) completed a family needs assessment with 17 family members of spinal cord injury patients in an inpatient rehabilitation program. The top five most important needs reported by the family members were all in the health information domain. Family members specifically reported the need to have questions answered honestly and the need for complete information about medical care and physical problems as the most important needs within the health domain. Needs in the area instrumental support and emotional support were rated with lowest importance. Consistent with other studies, family members seemed less interested in need such as spending time

with friends, being reassured about their own feelings, and having help around the house and gave more emphasis to the present needs of the patient (Meade et al., 2004)

This overview of the family needs literature reveals diversity in both patient population and methodological approaches to assessment and measurement. Regardless of approach to needs, broad themes from the literature reveal that family members consistently report need for medical and health information as most pressing. Needs relating to emotional and social support are often reported as less urgent. This study, hopes to build on the existing TBI literature as well as the preliminary knowledge we have of PRC caregivers to better understand the needs of and provide better care for both veterans and their families.

Statement of the Problem

There is not a clear understanding or research data regarding what family members in the PRC look like and need. While it has been established that these families face unique stressors that may exacerbate the difficulty associated with adjusting to a brain injury, it is not known how this affects their needs. Because OEF/OIF has brought a new cohort of service members who require substantial rehabilitation, government funding channels have made great efforts to accommodate patients classified with polytraumatic injuries. Despite these funding efforts, little has been published about the family members of PRC patients. Dealing with this complicated pattern of symptoms and changes requires that families make a great deal of adjustment. The implementation of the Polytrauma System of Care has begun to address the unique injuries that have emerged from OEF/OIF, but additional intervention and services are needed to support these veterans as well as their families who care for them.

The family needs literature in the context of brain injury and rehabilitation is growing. Research continuously reports that families are a crucial part of the rehabilitation process and that TBI has an enormous impact on the family (Gleckman & Brill, 1995; Kreutzer, et al., 1992; Lezak, 1988). Both quantitative and qualitative studies have worked to understand family needs during various stages of recovery and within different population demographics. In addition, the family needs literature has grown to encompass other areas of rehabilitation including spinal cord injury (SCI) and acquired brain injury (ABI). In looking at an overview of the literature (see Table 3), to date, there aren't any peer reviewed studies in the literature which either 1) assesses family needs using the FNQ within the military population or 2) compare military family needs to civilian family needs in a rehabilitation setting. This study seeks to fill that gap in an attempt at understanding family needs within the context of veteran rehabilitation and care. Four primary hypotheses and four exploratory hypotheses were derived from the previous literature review. These hypotheses are based on previous FNQ findings in rehabilitation civilian hospital settings

Primary Hypotheses

Hypothesis 1. Needs in the Health Information domain will receive the highest importance ratings from PRC family members.

Hypothesis 2. Needs in the Instrumental and Emotional Support domains will receive the lowest importance ratings from PRC family members

Hypothesis 3. Needs in the Health information domain will receive the highest "Met" rating from PRC family members

Hypothesis 4. Needs in the Emotional Support domain and Instrumental Support domain will receive the lowest "Met" ratings from PRC family members.

Exploratory Hypotheses

Exploratory analyses will be implemented to examine factors which may relate to needs indices. For each family participant, an index will be calculated to determine the percentage of needs rated as "Important" or "Very Important" and "Met" or "Not Met." Based on previous research (Kreutzer, Serio, & Berquist, 1994; Nabors, Seacat, & Rosental, 2002; Serio, Kreutzer, & Gervasio, 1995) these family need proportional indices differ among various groups of family members. Nabors et al., 2002 found differences between how needs were rated among white and African American caregivers. Kreutzer et al., (1994) found need differed due to gender, household income, and greater post injury time. Serio et al. (1995) reported differences between needs rated by spouses and parents of patients. Exploratory nonparametric analyses will determine if these group differences exist among the PRC populations as they have with civilian populations. Although not previously addressed in the literature, an additional hypothesis was made re: possible difference between family members of patients in injured while deployed in OEF/OIF and family members of patients who were injured stateside. Note that nonparametric analyses were used as the Importance and "Met" Ratios violated assumptions of normality needed for parametric tests. These hypotheses are exploratory given group size.

Exploratory Hypothesis 1. White PRC family members will report a greater percentage of “Important” and “Very Important” needs as “Met” in comparison to Nonwhite PRC family members.

Exploratory Hypothesis 2. A higher proportion of needs will be rated as “Important” or “Very Important” for female PRC family members in comparison to male PRC family members.

Exploratory Hypothesis 3. PRC family members who report income less than or equal to \$40,000 will report a greater percentage of Unmet Needs in comparison to PRC family members who report income greater than \$40,000.

Exploratory Hypothesis 4. PRC family members who identify their relationship as spouse will report a greater percentage of “Important” and “Very Important” needs in comparison to family members who define their relationship as parent.

Exploratory Hypothesis 5a. PRC family members of patients with time since injury equal to or less than 90 days will report a greater percentage of "Unmet" needs in comparison to PRC family members of patients with injuries that have reported time since injury greater than 90 days.

Exploratory Hypothesis 5b. PRC family members of patients with time since injury equal to or less than 180 days will report a greater percentage of "Unmet" needs in comparison to PRC family members of patients with injuries that have reported time since injury greater than 180 days.

Exploratory Hypothesis 6. PRC family members of patients injured in OEF/OIF will report a greater percentage of “Important” and “Very Important” needs in comparison to PRC family members of patients injured stateside.

Additional Analyses

Additional analyses were run on the Supplemental FNQ. This scale was previously developed from dissertation research (Harmon, 2007) and was intended to capture the unique needs that military/veteran families face at the PRC. Cronbach alpha was calculated to determine measure reliability of the scale. Means and standard deviations were calculated for each item across participants. Items were then rank ordered in terms of Importance. Of the items ranked “Very Important” or “Important”, further rankings were calculated based on how participants scored “Met” criteria.

Method

Participants

Demographic information is presented in Table 4. Participants included 44 family members of patients admitted to the Polytrauma Rehabilitation Center at Hunter Holmes McGuire Veterans Administration Medical Center in Richmond, Virginia. Family members were defined as those who are: spouses, fiancés, blood relatives, listed as emergency contacts, power of attorney, or on military orders (the military has provided funding for an individual to be bedside for a patient due to the severity of illness or injury). Twenty eight family members refused to participate in the study (parent = 10; spouse = 12; sibling = 4; fiancé = 1; grandparent = 1).

Fifty one family members provided survey responses. Family members' responses were examined in depth if they completed 65% of the Family Needs Questionnaire (65% based on cut scores from previous civilian FNQ study (Kreutzer et al., 1994)). Forty four family members were included in the final sample. The mean age of the sample was 42.93 years old ($SD = 14.50$), ranging from 19 to 68 years old, and most (75%) were married. Respondents were primarily female (70.5%), white (84.1%, 4.5% Black/African American, 4.5% Hispanic/Latino, 4.5% “unknown”), and were employed full time (45.5%, 13.6% employed part time, 18.2% unemployed, 15.9% retired, 4.6% student, 2.3% student/employed part time). When describing their relationship to the patient, most family members identified themselves as parents (47.7%, 34.1% spouse, 9.1% sibling, 2.3% child, 6.8% other).

Table 4.

Demographic Characteristics of Family Member Participants.

| Variable | Number of Participants | Percent |
|--------------------------------|------------------------|---------|
| Age | | |
| 19-29 | 13 | 29.5% |
| 30-39 | 3 | 6.8% |
| 40-49 | 14 | 31.8% |
| 50-59 | 8 | 18.2% |
| 60-69 | 6 | 13.6% |
| Gender | | |
| Male | 13 | 29.5% |
| Female | 31 | 70.5% |
| Race | | |
| Black or African American | 2 | 4.5% |
| White | 37 | 84.1% |
| Hispanic | 2 | 4.5% |
| Unknown | 2 | 4.5% |
| Missing | 1 | 2.3% |
| Marital Status | | |
| Single | 2 | 4.5% |
| Married | 33 | 75% |
| Separated/Divorced | 9 | 20.5% |
| Relationship to Patient | | |
| Parent | 21 | 47.7% |
| Spouse | 15 | 34.1% |
| Sibling | 4 | 9.1% |
| Child | 1 | 2.3% |
| Other | 3 | 6.8% |

| | | | |
|------------------------|--------------------------------------|----|-------|
| Income | | | |
| | \$0-\$20,000 | | |
| | \$20,001-\$40,000 | 6 | 13.6% |
| | \$40,001-\$60,000 | 6 | 13.6% |
| | \$60,001-\$80,000 | 15 | 34.1% |
| | \$80,001-\$100,000 | 8 | 18.2% |
| | \$100,001+ | 1 | 2.3% |
| | Missing | 5 | 11.4% |
| | | 3 | 6.8% |
| Employment | | | |
| | Employed Full Time | 20 | 45.5% |
| | Employed Part Time | 6 | 13.6% |
| | Unemployed | 8 | 18.2% |
| | Retired | 7 | 15.9% |
| | Student | 2 | 4.6% |
| | Student Part Time/Employed Part Time | 1 | 2.3% |
| Injury Location | | | |
| | Iraq | 7 | 15.9% |
| | Afghanistan | 15 | 34.1% |
| | Outside Continental USA | 4 | 9.1% |
| | Stateside | 18 | 40.9% |

Note. Percentages may not add to 100 due to rounding.

Measures

Demographics Questionnaire. This questionnaire gathered demographic information from participants including ethnicity, race, gender, age, relationship status, estimated income, and employment status. Participants were asked questions pertaining to their injured family member including 1) their relationship to the injured family member, 2) the injured family member's geographic location at time of injury, and 3) several subjective

questions pertaining to the severity of the family member's injuries. This measure was developed by the PRC staff. See Appendix A for a copy of this measure.

Family Needs Questionnaire. The FNQ is an empirically supported family needs assessment designed to address diverse family needs evident in the acute and post-acute phases after injury and includes six discrete scales: health information, emotional support, instrumental support, professional support, community support network, and involvement with care (Kreutzer, 1988). For each item, the participant is asked to rate on a scale from 1-4 the importance of the stated need, and then note if the need is currently being met using "yes", "partially", and "no" response options. As an index of internal consistency, Spearman-Brown split-half reliability was computed (Kreutzer et al., 1994). A coefficient of 0.75 was considered acceptable, as the content of the FNQ items is diverse, and some variability between respondents was anticipated. In addition, a factor analytic study has been completed on the FNQ. This study indicated alpha reliability coefficients for the six scales that ranged from .78 to .89 (Serio, Kreutzer, & Witol, 1997). The FNQ has been used in a number of studies with families after TBI (e.g. Kolakowsky-Hayner et al., 2000; Kolakowsky-Hayner et al., 2001; Kreutzer et al., 1994; Kreutzer et al., 2009; Serio et al., 1995; Witol et al., 1996). See Appendix B for a list of items included on the measure.

Supplemental Family Needs Questions. Six additional items were appended to this measure. These items were derived from dissertation research (Harmon, 2007) and informed by results of this study of 10 TBI-Polytrauma family members in an IRB-approved study at the McGuire VAMC. These items follow the same format as the FNQ, but include items that

family members dealing with a polytraumatic injury specifically identified as important. For example: “I need...to have a military representative from my injured family member’s branch of service to turn to for help with military related administrative issues”. Participants then respond on a scale of 1-4 the importance of the need (1 = “Not Important” and 4 = “Very Important”) and also state whether then need has been met (Y = Yes, P = Partially, and N = No). See Appendix C for a copy of this measure.

Procedure

From July 2007 through January 2010, family members of PRC patients presenting for treatment within Hunter Holmes McGuire Veterans Affairs Medical Center were approached to participate in a survey to assess family needs within the context of rehabilitation as well as related health and mental health indicators. As part of the established patient treatment planning process, a PRC licensed clinical psychologist met with family members of the injured service member. During this meeting, the PRC psychologist determined if the family members were appropriate for the study, competent to consent to the study, and interested in hearing more information about the study. All family members were granted a 72 hour period before approached, to allow time for them to orient and adjust to the unit. After this period, an investigator or research assistant on this study approached select family members of Polytrauma admissions following their family member’s admission to unit 2B (Polytrauma Rehabilitation Center).

During the initial meeting with family members, an investigator or research assistant reviewed the study via the informed consent form and answered questions. If potential

participants were willing to participate in the study, they signed the informed consent document. Potential participants were informed that they could take as much time as they need to review the informed consent, and that they did not have to make a decision to participate or not to participate at that time. Participants completed these questionnaires at any point during their family member's stay on the PRC. Family members were also able to mail in their surveys if they were not able to complete them while with the PRC. All procedures were approved by the local Institutional Review Board.

Results

Data Screening

Prior to analyzing the data, appropriate steps were taken to check for errors in the data set. Frequencies were inspected for the categorical variables to ensure that the minimum and maximum values for each item were within the range of potential responses. Descriptive statistics were run on the continuous variables to inspect the minimum, maximum, and mean values. All variables were found to be within the range of possible responses. Data fidelity checks were conducted by randomly picking 5 questionnaire packets (10% of the data set). The questionnaires were checked for and were entered with 100% accuracy.

Missing Data

During data screening, missing values were identified. Based on cut scores used in a previous analysis of the FNQ (Kreutzer et al., 1994) if more than 35% of items were missing from the FNQ, the participant was excluded. If less than 35% of the items were missing, the item was coded as missing and that cell was ignored in the selected analyses. Seven

participants had data that could not be imputed due to excessive missing data. Consequently the final sample consisted of data derived from 44 of the 51 original participants.

Internal Consistency Reliability

Cronbach's alpha was computed to assess internal consistency reliability on all scales of the FNQ (see Table 5). Values from the scales were found to be similar to those reported in previous research (Serio, Kreutzer, & Witol, 1997) when tested with a civilian outpatient TBI caregiver population. Each scale demonstrates good internal consistency reliabilities (above .70) with the exception of the Need for Involvement with Care scale ($\alpha = .66$) and the Need for Health Information scale ($\alpha = .66$). Notably the Need for Involvement with Care scale is based on only three items from the total FNQ. Further, when examining the Cronbach's Alpha if items were deleted for Need for Health information, this scale would have demonstrated $\alpha = .79$ if Item 14 was deleted (I need to have complete information on drug and alcohol problems and treatment). Reasons for the discrepancy between need for this item among PRC family members and family members in civilian settings will be further addressed in discussion. For the present study, scale scores were not used in hypothesis testing; therefore all reliability estimates were considered adequate.

Table 5.

Internal Consistency Reliability for FNQ Scales in PRC Population and Civilian Population.

| Factor | No. Items | PRC Mean | Civilian Mean | PRC Alpha | Civilian Alpha |
|--------------------|-----------|----------|---------------|-----------|----------------|
| Health Information | 10 | 3.74 | 3.71 | .66 | .89 |
| Emotional Support | 8 | 2.85 | 3.02 | .88 | .88 |

| | | | | | |
|------------------------------|---|------|------|-----|-----|
| Instrumental Support | 6 | 2.98 | 2.98 | .74 | .88 |
| Professional Support | 5 | 3.65 | 3.49 | .73 | .83 |
| Community Support Network | 5 | 3.36 | 3.38 | .75 | .81 |
| Involvement with Care | 3 | 3.37 | 3.01 | .66 | .78 |
| Supplemental FNQ | 6 | 3.40 | N/A | .76 | N/A |

Testing of Main Hypotheses

The focus of the main hypotheses was to 1) examine how PRC family members are ranking needs in terms of both Importance and Met/Not Met and 2) examine if PRC family members are reporting needs in a similar way to family members of patients being treated in civilian rehabilitation centers report needs. Data analyses were organized around each of the four hypotheses.

Rank Order of Needs

For each of the six domains of the FNQ, means and standard deviations were calculated for both ratings of importance and degree to which needs were met vs. unmet. FNQ items were then rank ordered to determine the importance of the family needs. Table 6 lists the 10 needs most frequently rated as “Important” or “Very Important” with the PRC Family population and compares those ranks with Kreutzer et al. (1994) ranks from a study examining the FNQ with family members of civilian outpatient TBI population. Similarly, Table 7 lists the top 10 needs rated as “Not Important” with the same comparison to the civilian needs study. Of the needs that were rated as “Important” or “Very Important”,

further ranking was completed to determine which of these needs were most frequently rated as “Met” (Table 8) and Unmet (Table 9).

Hypothesis 1. Needs in the Health Information domain will receive the highest importance ratings from PRC family members.

Hypothesis 1 Result. Consistent with the FNQ literature, PRC family members rated needs within the domain of Health Information most frequently as “Important”. Out of the 40 possible needs that participants could rate, PRC family members and family members of TBI patients in a civilian setting (Kreutzer, et al., 1994) rated 8 out of 10 needs as “Important” or “Very Important” in a similar order.

Table 6.

Ten needs most frequently rated as “Important” or “Very Important” with Comparison Ranks from Civilian FNQ Needs Study.

| Rank in PRC TBI Needs Study | Scale | Rank in Civilian TBI Needs Study |
|--------------------------------------------------------------------------------------------------------------------------------------------|----------------------|----------------------------------|
| 1. To be assured that the best possible medical care is being give to the patient | Health Information | 3 |
| 2. To be told about all changes in the patient's medical status | Health Information | 5 |
| 3. To have my questions answered honestly | Health Information | 2 |
| 4. To have complete information on the patient's problems in thinking (e.g. confusion, memory, or communication) | Health Information | 1 |
| 5. To have information on the patient's rehabilitative or educational progress | Health Information | 7 |
| 6. To have a professional to turn to for advice or services when the patient needs help | Support Network | 4 |
| 7. To be shown that medical, educational, or rehabilitation staff respect the patient's needs or wishes | Health Information | 9 |
| 8. To have enough resources for the patient (e.g. rehabilitation programs, physical therapy, counseling, job counseling) | Professional Support | Not Ranked in Top 10 |
| 9. To have complete information on the patient's physical problems (e.g. weakness, headaches, dizziness, problems with vision or walking) | Health Information | 6 |
| 10. To have enough resources for myself or the family (e.g. financial or legal counseling, respite care, counseling, nursing or day care). | Professional Support | Not Ranked in Top 10 |

Hypothesis 2. Needs in the Instrumental and Emotional Support domains will receive the lowest importance ratings from PRC family members.

Hypothesis 2 Result. Consistent with the FNQ literature, PRC family members identified needs within the Emotional Support domain and Instrumental Support domain most frequently rated as less important. Out of the 40 possible needs that participants could rate, PRC family members and family members of TBI patients in a civilian setting (Kreutzer, et al., 1994) rated 7 out of 10 needs that were “Not Important” in a similar order.

Table 7.

Ten needs most frequently rated as “Not Important” with Comparison Ranks from Civilian FNQ Needs Study.

| Rank in PRC TBI Needs Study | Scale | Rank in Civilian TBI Needs Study |
|---------------------------------------------------------------------------------------------------|----------------------|----------------------------------|
| 1. To be reassured that it is usual to have strong negative feelings about the patient | Emotional Support | 2 |
| 2. To be have help keeping the house (e.g. shopping, cleaning, cooking etc.) | Instrumental Support | 1 |
| 3. To spend time with my friends | Instrumental Support | 5 |
| 4. Help getting over my doubts and fears about the future. | Emotional Support | 10 |
| 5. Help preparing for the worst | Emotional Support | Not Ranked in Top 10 |
| 6. To have my partner or friends understand how difficult it is for me | Emotional Support | Not Ranked in Top 10 |
| 7. To have complete information on drug or alcohol problems and treatment | Health Information | Not Ranked in Top 10 |
| 8. To discuss my feelings about the patient with someone who has gone through the same experience | Emotional Support | 9 |
| 9. To have my significant other understand how difficult it is for me | Emotional Support | 6 |
| 10. To be encouraged to ask others to help out | Emotional Support | 8 |

Hypothesis 3. Needs in the Health information domain will receive the highest "Met" rating from PRC family members.

Hypothesis 3 Result. Consistent with the FNQ literature, PRC family members identified needs within the Health Information domain ranked most frequently as “Met.” Out of the 40 possible needs that participants could rate, PRC family members and family members of TBI patients in a civilian setting (Kreutzer, et al., 1994) rated 7 out of 10 needs that were “Met” in a similar order.

Table 8.

Ten needs most frequently rated as “Met” with Comparison Ranks from Civilian FNQ Needs Study.

| Rank in PRC TBI Needs Study | Scale | Rank in Civilian TBI Needs Study |
|---------------------------------------------------------------------------------------------------------|-----------------------|----------------------------------|
| 1. To have explanations from professionals given in terms I can understand | Health Information | 6 |
| 2. To have my questions answered honestly | Health Information | 2 |
| 3. To have a professional to turn to for advice or services when the patient needs help | Support Network | 9 |
| 4. To be shown that medical, educational, or rehabilitation staff respect the patient's needs or wishes | Health Information | 4 |
| 5. To have different professionals agree on the best way to help the patient | No scale* | 3 |
| 6. To be told why the patient acts different, difficult or strange | No scale* | Not Ranked in Top 10 |
| 7. To be assured that the best possible medical care is given to the patient | Health Information | 1 |
| 8. To give my opinions daily to others involved in the patient's care, rehabilitation, or education | Involvement with Care | Not Ranked in Top 10 |
| 9. To be told about all changes in the patient's medical status | Health Information | 5 |
| 10. To discuss my feelings openly about the patient with other friends or family | Support Network | 10 |

*This scale is an earlier version used before factor analysis was completed in the literature. Three items were deleted after the factor analysis and did not load onto any of the 6 scales.

Hypothesis 4. Needs in the Emotional Support domain and Instrumental Support domain will receive the lowest "Met" ratings from PRC family members.

Hypothesis 4 Result. Consistent with the FNQ literature, PRC family members identified needs within the “Emotional Support” and “Instrumental Support” domains rated most frequently as “Not Met.” Out of the 40 possible needs that participants could rate, PRC family members and family members of TBI patients in a civilian setting (Kreutzer et al., 1994) rated 6 out of 10 needs that are “Not Met” in a similar order.

Table 9.

Ten needs most frequently rated as “Not Met” with Comparison Ranks from Civilian TBI Needs Study.

| Rank in PRC TBI Needs Study | Scale | Rank in Civilian TBI Needs Study |
|---------------------------------------------------------------------------------------------------|----------------------|----------------------------------|
| 1. Help preparing for the worst | Emotional Support | 3 |
| 2. To have the patient's friends understand his/her problems | Support Network | Not Ranked in Top 10 |
| 3. To have help keeping the house (e.g. . . . shopping, cleaning cooking, etc.) | Instrumental Support | 10 |
| 4. To pay attention to my own needs, job, or interests | Instrumental Support | Not Ranked in Top 10 |
| 5. To be shown what to do when the patient is upset or acting strange | Professional Support | 6 |
| 6. To discuss my feelings about the patient with someone who has gone through the same experience | Emotional Support | 1 |
| 7. To get enough rest or sleep | Instrumental Support | Not Ranked in Top 10 |
| 8. To spend time with friends | Instrumental Support | Not Ranked in Top 10 |
| 9. To have my significant other understand how difficult this is for me | Emotional Support | 5 |
| 10. To get a break from my problems and responsibilities | Instrumental Support | 4 |

Exploratory Analyses

Proportional Indices of Needs

Response patterns were further examined by computing proportional indices for both importance of needs and degree to which needs were met. The Importance indices indicated the percentage of needs out of the total items that participants indicated were “Important” or “Not Important”. An importance percentage was calculated for each family member by dividing the number of needs rated as “Important” or “Very Important” by the total number of items. The mean Importance Percentage was 83.1% ($SD = 14.0$). Similarly, another percentage was calculated by dividing the total number of “Not Important” needs by the total number of items. The mean percentage of needs rated as “Not Important” was 4.3% ($SD = 5.3$). Note that percentages do not add to 100 as the “Slightly Important” ratio is not included.

In addition to calculating indices around the importance of needs, percentages were calculated to determine the extent to which needs were met. The “Met” indices indicated, out of the needs rated as “Important” or “Very Important”, the percentage of needs rated as “Met,” Partly “Met,” and “Not Met.” First, a set of percentages was calculated using only needs that participants rated as “Important” or “Very Important.” Second, the number of needs rated as “Met,” “Partly Met,” or “Unmet” was divided by the number of items rated as “Important” or “Very Important.” The mean percentage of “Important” or “Very Important” needs rated as “Met” was 55.4% ($SD = 26.7$), and the mean percentage of needs rated as

“Partly Met” was 37.1% ($SD = 23.9$). The mean percentage of needs rated as “Unmet” was 7.6% ($SD = 9.7$).

Comparison of Proportional Indices of Need

Needs ratio scores were compared between the PRC sample and Kreutzer et al., (1994) civilian family sample. An independent samples t test was used to compare the groups. Results indicate a significant difference between reports of “Not Met” ($d = .48$) and “Partially Met” ($d = -.42$) needs. That is, civilian family members ($M = 17.2$) are reporting significantly more needs that they consider to be “Important” or “Very Important” as “Not Met” compared to PRC family members ($M = 7.57$). However, PRC family members ($M = 37.08$) are reporting significantly more needs they consider “Important” or “Very Important” as “Partially Met” compared to civilian family members ($M = 27.6$).

Table 10.

Comparison of PRC and Civilian FNQ Importance Ratios and “Met” Ratios.

| Outcome Ratio | Civilian M | Civilian SD | Civilian N | PRC M | PRC SD | PRC N | Effect** Size | CI Lower | CI Upper |
|----------------|--------------|---------------|--------------|---------|----------|---------|---------------|----------|----------|
| Importance | 84.3 | 16.20 | 119 | 83.12 | 13.99 | 44 | 0.08 | -0.27 | 0.42 |
| Not Importance | 7 | 11.30 | 119 | 4.26 | 5.27 | 44 | 0.27 | -0.08 | 0.62 |
| Not Met | 17.2 | 22.80 | 119 | 7.57 | 9.74 | 44 | 0.48* | 0.13 | 0.83 |
| Met | 55.2 | 32.60 | 119 | 55.35 | 26.68 | 44 | 0.00 | -0.35 | 0.34 |
| Part Met | 27.6 | 22.40 | 119 | 37.08 | 23.98 | 44 | -.42* | -0.76 | -0.06 |

*Significant at the 0.05 level

**Hedges g (weighted) calculations were made to account for group size differences, but did not reveal any differences in effect size values.

Testing Assumptions

Preliminary analyses were conducted to determine if assumptions of parametric analyses were met. Assessment for outliers and the normality of the distribution for each variable was completed through visual inspection of histograms. In addition a skewness z scores were computed to determine the significance of the skewness for each value. Table 11 outlines these numbers and indicates that not all variables are normally distributed. When this assumption is violated, non-parametric tests are required to test differences between conditions.

Table 11.

Report of Ratio Skewness.

| | Importance Ratio | Not Importance Ratio | Met Ratio | Partially Met Ratio | Not Met Ratio |
|-----------------------|------------------|----------------------|-----------|---------------------|---------------|
| Skewness | -.739 | .987 | 1.47 | .069 | .115 |
| SE of Skewness | .357 | .357 | .357 | .357 | .357 |
| Z_{skewness} | -2.07* | 2.77* | 4.12* | .193 | .32 |

* An absolute value of the z score greater than 1.96 is significant at $p < .05$

Determining Variables Related to Indices of Need

Analyses were conducted to test whether certain demographic variables (race, sex, relationship to patient, reported income, and times since injury) were associated with reported family needs.

Between group, nonparametric analyses focused on the relationship between needs indices (“Important”, “Not Important”, “Met”, “Partially Met”, and “Not Met”), patient characteristics (time since injury), and family member characteristics (race, sex, income, relationship to patient). Mann Whitney U tests were used to compare white with nonwhite ethnicity, women with men, <\$40,000 income with \geq \$40,000, spouses with parents, and <90/180 days post injury with \geq 90/180 days post injury. Effect size estimates (Rosenthal, 1991) were calculated for each group comparison. If effect size analyses indicated an estimated small, moderate, or large effect, post hoc power analyses with the G*power program (Faul, Erdfelder, Lang, & Buchner, 2007) were conducted to determine if there was adequate power to generalize findings beyond the Richmond VAMC sample.

Exploratory Hypothesis 1. White PRC family members will report a greater percentage of “Important” and “Very Important” needs as “Met” in comparison to Nonwhite PRC family members.

Exploratory Hypothesis 1 Results. Overall, race was not shown to be related to any of the needs ratios. This finding was not consistent with Hypothesis 1. However, given disproportionate group sizes (white = 37; nonwhite = 4), a larger more diverse sample is needed to make generalizations beyond the Richmond VAMC sample.

Table 12.

Relationship Among Needs Ratios and Race.

| | Important | Not Important | Met | Part Met | Not Met |
|----------------------|-----------|---------------|-------|----------|---------|
| Mann-Whitney U | 61.5 | 56.0 | 62.0 | 58.5 | 70.0 |
| Z | -.55 | -.83 | -.53 | -.68 | -.18 |
| r | -.086 | -.13 | -.082 | -.106 | -.028 |
| Exact Sig (2-tailed) | .60 | .438 | .619 | .875 | .515 |

Grouping Variable: Race

Exploratory Hypothesis 2. A higher proportion of needs will be rated as “Important” or “Very Important” for female PRC family members in comparison to male PRC family members.

Exploratory Hypothesis 2 Results. Males ($n = 13$) and females ($n = 31$) did not report Importance, “Met”, or “Partially Met” ratios differently. However, females reported 1) significantly more “*Not Important*” needs than males, $U = 103.0, z = -2.67, p < .01, r = -.40$. In addition, females reported 2) significantly more “*Not Met*” needs than males, $U = 88, z = -3.03, p < .01, r = -.46$. This finding was not consistent with the hypothesis that males and females would report *importance* of needs differently. To determine whether this finding can be generalized beyond this sample, post hoc power analyses were conducted. Test description, group sample size, effect size, and α error probability were entered for both findings from exploratory hypothesis 2. The post hoc power analysis for finding 1) indicated power $(1-\beta) = .21$ and for finding 2) power $(1-\beta) = .26$. Given Cohen’s (1988) recommended

power of .80, these results should be interpreted with caution and not generalized beyond this sample.

Table 13.

Relationship Among Needs Ratios and Sex.

| | Important | Not Important | Met | Part Met | Not Met |
|----------------------|-----------|---------------|-------|----------|---------|
| Mann-Whitney U | 171.0 | 103.0 | 201.0 | 155.0 | 88.0 |
| Z | -.79 | -2.67 | -.01 | -1.20 | -3.03 |
| r | -.12 | -.40 | -.002 | -.18 | -.46 |
| Exact Sig (2-tailed) | .44 | .006 | .995 | .24 | .002 |

Grouping variable: Sex

Exploratory Hypothesis 3. PRC family members who report income less than or equal to \$40,000 will report a greater percentage of Unmet Needs in comparison to PRC family members who report income greater than \$40,000.

Exploratory Hypothesis 3 Results. PRC family members who reported income less than or equal to \$40,000 a year ($n = 12$) did not report “Met”, “Partially Met”, “Not Met”, or “Not Important” needs ratios any differently than PRC family members who reported income greater than \$40,000 yearly ($n = 29$). However, PRC family members who reported income less than or equal to \$40,000 a year reported significantly more “Important” needs, $U = 98.5$, $z = -2.17$, $p < .05$, $r = -.34$ than family members who reported income greater than \$40,000. This finding is inconsistent with the hypothesis that income would affect report of “Not Met” Needs. To determine whether finding related to “Important” needs could be generalized beyond this sample, post hoc power analyses were conducted. Test description, group

sample size, effect size, and α error probability were entered into the G*Power program. The post hoc power analysis indicated power $(1-\beta) = .16$. Given Cohen’s (1988) recommended power of .80, this result should be interpreted with caution and not generalized beyond this sample.

Table 14.

Relationship Among Needs Ratio and Income.

| | Important | Not Important | Met | Part Met | Not Met |
|----------------------|-----------|---------------|-------|----------|---------|
| Mann-Whitney U | 98.5 | 117.5 | 156.0 | 170.5 | 130.0 |
| Z | -2.169 | -1.712 | -.516 | -.100 | -1.308 |
| r | -.34 | -.27 | -.081 | -.02 | -.20 |
| Exact Sig (2-tailed) | .029 | .091 | .62 | .93 | .20 |

Grouping variable: Income

Exploratory Hypothesis 4. PRC family members who identify their relationship as spouse will report a greater percentage of “Important” and “Very Important” needs in comparison to family members who define their relationship as parent.

Exploratory Hypothesis 4 Results. PRC family members who identified their relationship as spouse ($n = 15$) did not report “Important”, “Not Important”, “Met”, or “Partially Met” needs ratios differently than family members who identified their relationship as parent ($n = 21$). However, spouses reported significantly more *Unmet* needs, $U = 77.0$, $z = 2.65$, $p < .01$, $r = -.44$ than parents. This finding is inconsistent with the hypothesis that family members who identified as spouse would report more “*Important*” needs than family members who identified as parents. To determine whether this finding related to *unmet*

needs could be generalized beyond this sample, post hoc power analyses were conducted.

Test description, group sample size, effect size, and α error probability were entered into the G*Power program. The post hoc power analysis indicated power $(1-\beta) = .23$. Given Cohen's (1988) recommended power of .80, this result should be interpreted with caution and not generalized beyond this sample.

Table 15.

Relationship Among Needs Ratio and Relationship to Patient.

| | Important | Not Important | Met | Part Met | Not Met |
|----------------------|-----------|---------------|-------|----------|---------|
| Mann-Whitney U | 132.5 | 131.0 | 122.5 | 148.5 | 77.0 |
| Z | -.80 | -.88 | -1.12 | -.29 | -2.65 |
| r | -.13 | -.15 | -.19 | -.05 | -.44 |
| Exact Sig (2-tailed) | .43 | .39 | .27 | .78 | .007 |

Grouping variable: Relationship to Patient

Exploratory Hypothesis 5a. PRC family members of patients with time since injury equal to or less than 90 days will report a greater percentage of "Unmet" needs in comparison to PRC family members of patients with injuries that have reported time since injury greater than 90 days.

Exploratory Hypothesis 5a Results.

PRC family members with patients who had been injured within 90 days or less of taking the survey ($n = 26$) did not report needs indices differently than PRC family members with patients who had been injured more than 90 days of taking the survey ($n = 18$).

Table 16.

Relationship Among Needs Ratios and Time Since Injury (90 days).

| | Important | Not Important | Met | Part Met | Not Met |
|----------------------|-----------|---------------|-------|----------|---------|
| Mann-Whitney U | 177.0 | 206.5 | 165.0 | 163.0 | 224.0 |
| Z | -1.36 | -.69 | -1.65 | -1.70 | -.247 |
| r | -.21 | -.10 | -.04 | -.25 | -.26 |
| Exact Sig (2-tailed) | .18 | .50 | .10 | .09 | .81 |

Grouping variable: Time Since Injury (90 days)

Exploratory Hypothesis 5b. PRC family members of patients with time since injury equal to or less than 180 days will report a greater percentage of "Unmet" needs in comparison to PRC family members of patients with injuries that have reported time since injury greater than 180 days.

Exploratory Hypothesis 5b Results.

PRC family members of patients who were injured within 180 days of taking the survey ($n = 34$) did not report any differences in “Met”, “Partially Met”, and “Not Met” needs indices from family members of patients who had been injured more than 180 days ($n = 10$). However, PRC family members of patients who had been injured for more than 180 days reported 1) a greater number of “Important” needs, $U = 94.0$, $z = -2.13$, $p < .05$, $r = -.32$. In addition, PRC family members of patients who had been injured for more than 180 days reported 2) significantly less “Not Important” needs compared to family members of patients who had been injured for less than or equal to 180 days, $U = 104$, $z = -1.95$, $p < .05$, $r = -.29$. To determine whether this finding can be generalized beyond this sample, post hoc power

analyses were conducted. Test description, group sample size, effect size, and α error probability were entered for both findings from exploratory Hypothesis 5b. The post hoc power analysis for finding a) indicated power $(1-\beta) = .14$ and for finding b) power $(1-\beta) = .12$. Given Cohen's (1988) recommended power of .80, these results should be interpreted with caution and not generalized beyond this sample.

Table 17.

Relationship Among Needs Indices and Time Since Injury (180 days.)

| | Important | Not Important | Met | Part Met | Not Met |
|----------------------|-----------|---------------|-------|----------|---------|
| Mann-Whitney U | 94.0 | 104.0 | 119.5 | 136.0 | 157.0 |
| Z | -2.13 | -1.95 | -1.42 | -.95 | -.38 |
| r | -.32 | -.29 | -.21 | -.14 | -.06 |
| Exact Sig (2-tailed) | .03 | .05 | .16 | .35 | .72 |

Grouping Variable: Time Since Injury (180 days)

Exploratory Hypothesis 6. PRC family members of patients injured in OEF/OIF will report a greater percentage of “Important” and “Very Important” needs in comparison to PRC family members of patients injured stateside.

Exploratory Hypothesis 6 Results. Overall, location of injury was not shown to be related to any of the needs ratios. Although the literature has reported that OEF/OIF families deal with a number of unique stressors, these families are not rating FNQ needs differently than family members who were injured stateside.

Table 18.

Relationship Among Needs Ratios and Location of Injury.

| | Important | Not Important | Met | Part Met | Not Met |
|----------------------|-----------|---------------|-------|----------|---------|
| Mann-Whitney U | 139.5 | 194.0 | 185.5 | 174 | 163.5 |
| Z | -1.59 | -.12 | -.34 | -.65 | -.98 |
| r | -.25 | -.02 | -.05 | -.10 | -.16 |
| Exact Sig (2-tailed) | .113 | .91 | .74 | .52 | .33 |

Grouping Variable: Location of Injury

Additional Analyses

Descriptive statistics (M, SD, Minimum, Maximum) were run on the Supplement FNQ (Harmon, 2007) and reported in descending order (most important- least important/most often reported as met, least often reported as met). This measure has not been previously tested in any population and was created from qualitative interviews with PRC families. Thus these analyses were meant to provide information how family members viewed Importance of the needs measures (Table 18). In addition, as with the FNQ, “Met” ranks were calculated for needs that family members scored as “Important” or “Very Important” (Table 19).

Table 19.

Descriptives of Importance Ranks for Supplemental FNQ.

| I need... | Min | Max | M | SD |
|------------------------------------------------------------------------------------------------------------------------------|-----|-----|------|-----|
| To have complete information on the psychological care of traumatic injures | 3 | 4 | 3.88 | .33 |
| To have a military representative from my family member's branch of service to turn to for help with military related issues | 2 | 4 | 3.79 | .47 |

| | | | | |
|--------------------------------------------------------------------------------------------------------------------|---|---|------|------|
| To have a safe place to process my feelings about my experiences since my family member was injured | 1 | 4 | 3.31 | .92 |
| To have a list and description of community-based organizations I can turn to for additional assistance | 1 | 4 | 3.19 | .97 |
| To have complete information on how to manage my own stress and reactions to what has happened in a healthy manner | 0 | 4 | 3.14 | 1.07 |
| To feel connected to my home community while I am away caring for my loved one | 1 | 4 | 3.07 | 1.02 |

Table 20.

Descriptives of “Met” Ranks for Supplemental FNQ.

| I need... | Min | Max | <i>M</i> | <i>SD</i> |
|------------------------------------------------------------------------------------------------------------------------------|-----|-----|----------|-----------|
| To have a military representative from my family member's branch of service to turn to for help with military related issues | 1 | 3 | 2.56 | .63 |
| To have a safe place to process my feelings about my experiences since my family member was injured | 1 | 3 | 2.48 | .76 |
| To feel connected to my home community while I am away caring for my loved one | 1 | 3 | 2.46 | .69 |
| To have complete information on the psychological care of traumatic injuries | 1 | 3 | 2.36 | .58 |
| To have complete information on how to manage my own stress and reactions to what has happened in a healthy manner | 1 | 3 | 2.15 | .66 |
| To have a list and description of community-based organizations I can turn to for additional assistance | 1 | 3 | 2.03 | .86 |

Discussion

Purpose

The purpose of the present study was: 1) to create a better understanding of PRC family members' needs using the FNQ, a measure previously validated in civilian hospital rehabilitation settings, and 2) to examine how PRC family members rank FNQ needs in comparison to family members in a civilian setting. There has been a great deal published on

the tremendous impact brain injury has on both the patient and the family system affected by brain injury. The literature within the context of military/veteran brain injury is relatively sparse. To date, no studies have been published comparing responses to the FNQ in civilian settings to military/veteran settings. This study seeks to describe the needs of PRC family members and determine how similar or different this description is to previous research conducted in civilian hospital settings.

Summary of Findings

The present study had four major hypotheses and five exploratory hypotheses. The four major hypotheses were based on a review of the FNQ literature dealing with adult brain injury populations in civilian rehabilitation settings (Kolakowsky-Hayner, et al., 2001; Kreutzer, et al. 1994; Serio et al., 1995; Witol, et al. 1996). In order to compare needs across rehabilitation sites, needs rank orderings of PRC family members were compared to a study that examined 119 family members of patients with a primary diagnosis of TBI who were treated in a civilian setting (Kreutzer, Serio, & Berquist, 1994).

The first hypothesis stated that PRC family members would report that their most “Important” needs would be in the domain of “Health Information.” Prioritizing need for health information is found consistently in the FNQ literature across rehabilitation settings and is also reflected in studies examining needs using other measures. The data did support this hypothesis with 7 out of 10 “Need for Health Information” items being ranked in the 10 most “Important” needs. In addition, PRC family members rated 8 out of 10 “Most Important” items similarly to family members in civilian settings.

Despite the situational differences between civilian and military rehabilitation TBI populations (e.g. distance traveled by family members and war/deployment related stress), brain injury is a complicated diagnosis that often does not follow a specified course. For many family members, this may be their first experience with brain injury and the consequences that accompany the diagnosis. Regardless of stage of injury (acute or postacute), information and reassurance about care is always important (Kreutzer et al., 1994). Thus needing specific information related to the injury, information communicating the patient's status and, information that the patient is receiving appropriate care seems universally desired.

The second hypothesis in the present study stated that PRC family members would report that most ““Not Important”” needs would fall in the Instrumental and Emotional Support domains. The data supported this hypothesis. Nine out of 10 needs that had the lowest importance ratings were in the Emotional Support (7/10) or Instrumental Support domains (2/10). In addition, when examining the 10 least important needs, PRC family members and family members from civilian rehabilitation hospitals rated 7/10 similarly. Reasons how family members value these support domains could vary. One hypothesis is that given the lifestyle shift that can be required when dealing with brain injury, family members are not in a place to value their own well-being (feeling understood and worrying about keeping the house or time with friends). Instead, they are more concerned with taking care of the day-to-day realities associated with adjustment to brain injury (e.g. need to provide constant care, shifting family roles etc.) When examining this domain however,

Kreutzer and colleagues (1994) state that this finding should be interpreted with caution. Given that the mean percentage of “Not Important” needs is low (4.3%), these needs are not *as important* to some family members, but remain important to others.

The third hypothesis stated that PRC family members would report needs in the Health Information domain as most frequently “Met”. The data supported this hypothesis with 5/10 items rated in the ten most frequently “Met” group belonging to the health information scale. In addition, when examining the 10 most “Met” needs, PRC family members and family members from civilian rehabilitation hospitals rated 8/10 similarly. When discussing reasons for health information needs being most likely to be “Met”, it is important to consider what each need domain requires from both professionals and family members. First, many of the needs within the context of health information are more tangible. Health information is a common expectation of professionals and is often readily available if asked for. In addition, needs within health information require help from individuals as opposed to communities or systems. That is, family members often have a direct contact for being “told about changes in the patient’s medical status”, but “help preparing for the worst” can involve many people and organizations to be considered met. Thus, while this hypothesis further illustrates what needs are being taken care of in the context of rehabilitation, the mechanism through which needs become met should be considered as well.

The final main hypothesis stated PRC family members would report that needs most frequently rated as “Not Met” would fall in the Emotional Support and Instrumental Support

domains. Again, the data supported this hypothesis with 8/10 of needs rated as “Not Met” belonging to the emotional support (3/8) and instrumental support (5/8) scales. Needs that are rated as unmet within the context of the emotional support domain may be in part due to lack of attention to these needs by rehabilitation professionals (Serio et al., 1995). That is, rehabilitation teams have a primary goal of maintaining physical/medical well-being and attending to emotional well-being of family members may not be of the utmost concern. Conversely, family members are under a great deal of stress and stress affects people in unpredictable ways. Given the stress of brain injury, some family members may also be unwilling or unable to accept support (Serio et al., 1995). This inability to care for oneself is further reflected in the unmet needs within the instrumental support scale. PRC family members reported difficulty with getting adequate sleep, spending time with friends, getting a break from problems, and paying attention to their own needs in general. The fact that these needs are unmet makes sense in the context of great life upheaval and change. However, understanding how to better intervene with family members who are unable to prioritize their own care requires further examination and more complicated intervention than other domains of need.

Examination of exploratory hypotheses

Although family (race, sex, income, relationship etc.) and injury (time since injury and location of injury) characteristics should be considered in the context of family needs, previous literature has not reliably predicted how needs differ based on these characteristics (Serio et al., 1995). Given the inconsistent report of group differences in the literature, the

disproportionate group sizes, and the power needed to generalize effect sizes beyond this population, results should not be interpreted with confidence. However, future research should continue to consider these factors to create a more nuanced understanding of family needs.

Discussion of a single item viewed differently across samples

As already demonstrated, PRC family members seem to report needs fairly consistently with other populations that have been studied in the FNQ and broader family rehabilitation needs literature. When examining individual FNQ items, however, there was one need that continuously did not fit with the PRC population. “I need to have complete information on drug or alcohol problems and treatment” first stuck out when examining the internal reliability of each scale. Although the Need for Health Information scale demonstrated acceptable reliability ($\alpha = .66$) the scale would have had an $\alpha = .79$ if this item had been deleted. In addition, when examining items that family members were most likely to rate as “Not Important”, this was an item included on the PRC list, but not the civilian setting list. One important difference between the two samples being compared is that the PRC family members are in an inpatient setting and the civilian rehabilitation family members are in an outpatient setting. Although the length of stay in a PRC varies greatly (not measured in this study, but based on observation 2 weeks-10 months), inpatient status may have worked to block other periphery concerns. Based on this writer’s personal experiences within the Richmond and Minneapolis VAMC, PRC’s patients were not without substance abuse issues. Given the inpatient status of patients, however, substance abuse issues may not

have been prioritized in the context of overall care. Thus item 14 may operate differently given the priority of issues families have in inpatient vs. outpatient settings.

Supplemental FNQ

The supplemental FNQ demonstrated good internal reliability ($\alpha = .76$). Upon examination of item content (Appendix C), many item ideas overlap with the FNQ (information on care, information on managing stress, safe place to process feelings), but may have belonged to different scales. Of note, "I need to have a military representative from my injured family member's branch of the service to turn to for help with military related issues" did provide a unique need apart from the FNQ. This item, was consistently rated as "Important" ($M = 3.79$) and "Partially Met"/Met ($M = 2.56$) among PRC family members. When examining the Importance ratings across the measure, mean ratings ranged from 3.88-3.07 (score of 3 = "Important") indicating that most family members found all of these items of some importance. In addition, mean Met scores ranged from 2.56-2.03 (score of Partially "Met" = 2) indicating that most of the needs have at least been partially addressed within the PRC setting. Although these items address some issues highlighted in the PRC family literature (influence of military and being away from one's home community), further research is needed to determine if additional military related items could be added (dealing with stress of deployment, reentering Active Duty status post brain injury, medical boarding processes, etc.)

Implications

The present study has sought to first describe the PRC family members and unique circumstances faced by this group and second to compare PRC participants to other family members facing similar patient injuries in outpatient rehabilitation settings. The literature review notes a number of unique circumstances associated with the PRC including possible deployment, complicated injuries caused by IED's, and long-distance travel to be with patients (Collins & Kennedy, 2008). Despite these differences discussed, PRC ranking of “Important” and “Met” needs were remarkably similar to family member reports in outpatient civilian settings. A number of implications can be drawn from this finding.

First, family members of patients with difficult rehabilitation injuries want direct and honest information. The need for information is cited as the most “Important” need across a number of rehabilitation setting with families in various stages of injury (e.g. Kolakowsky-Hayner et al. , 2001; Kreutzer et al., 1994; Moules & Chandler, 1999; Nabors et al., 2002; Serio et al., 1995; Witol et al., 1996). PRC families are no different. While some wisdom might suggest that families dealing with tragic and life changing circumstance might desire information that is optimistic or positive, the FNQ indicates that families want information that is well informed, honest, current, and complete. In general, staff members and providers in rehabilitation settings have gotten this message and are effective at delivering this information. Like families in civilian rehabilitation settings, PRC family members are most likely to rate health information needs as “Met”.

Although there are many similarities between PRC families and other families in rehabilitation settings, the data indicated that subtle differences did remain. An examination of effect size between the two groups indicated medium effects in how families conceptualized “Partially Met” and unmet needs (“Not Met” $d = .48$; “Partially Met” $d = .42$). Examination of needs that were both rated as “Important” and less likely to be met (Table 9) indicates that PRC family members were more likely to report needs in the Instrumental Support domain as “Not Met” (e.g. getting enough sleep, spending time with friends, paying attention to my own needs- job or other interests). This finding may be an artifact of the unique stressors in the PRC. Given that families are struggling with getting some of their own personal needs met, additional research needs to evaluate if there are opportunities to help families feel more supported in these areas. The VAMC is a unique institution that provides life long care for veterans and additional services for veterans injured during service. Given the myriad of services offered and available to families in the PRC, it is possible that more effort should be focused on the number of supports that can be provided for families with injured service members.

Given the overall FNQ similarities, there are several implications regarding family rehabilitation intervention. In general, intervention that has been shown to be effective in civilian rehabilitation settings may also be effective in PRC settings. Although these populations do demonstrate some differences, it seems prudent to try previously tested intervention and evaluate the outcomes in PRC settings. To date, there has not been anything published on evidence based approaches to family support in the PRC. Thus, additional

research needs to be completed evaluating family intervention within the context of a veteran/military setting. Given PRC family members' report of unmet emotional and instrumental needs, programs need to ensure that family interventions help family members to request support when needed, discuss concerns with loved ones, and find ways to share concerns with the patient's friends may aid in effectively helping families to cope.

Limitations

There are several limitations in the present study. First, the study the general PRC population posed a number of concerns. Due to the tremendous amount of stress and pressure PRC family members tend to encounter during an inpatient stay, protective factors were written into the study protocol to ensure additional and unreasonable burden was not placed on participants. Thus, before being approached for the study, family members were given time to settle in and needed to be seen by a PRC staff member to determine appropriateness for the study. These guidelines were well intentioned to protect family members but also presented barriers to recruitment. Some family members were not approached by the researchers due to specific concerns with burden and stress the family member was already encountering. In addition, some family members did not stay with their patient for the entire hospital stay and were not easily accessible after the grace period given for adjustment. Thus, although data collection spanned approximately 2.5 years, sample size continued to be modest.

A second limitation was the variability of patients who presented to the PRC for treatment. Although representative of PRC admissions in general, patients who receive care

in Polytrauma can be vastly different. Time since injury ranged from 17-936 days. PRC's can be used to care for a number of issues including, military personnel or veterans who have been injured stateside, military personnel who have been injured in combat, and military personnel who are in need of a brief (2 week) evaluation for diagnostic clarification but are functioning outside of the hospital setting. Given these various presentations, it is difficult to make sweeping assumptions about the level of acuity in PRC populations in general. However, based on this writer's interactions with other PRC service care providers across the United States, it seems the Richmond VAMC is not unique in the diversity of patients admitted.

Although there is immense diversity with patient presentation, a third limitation is the more limited demographic diversity of the sample. Some of the most notable areas of uniformity in the sample was race (white = 37; nonwhite = 4) and sex (female = 31; male = 13). Small and disproportionate groups limited the generalization of exploratory hypotheses that sought to understand group differences within the context of PRC family members.

A further limitation for this study is that it relied on family member self-report for all data. Having access to additional patient data from the medical chart (severity of brain injury, comorbid psychological diagnoses, additional injuries, etc.) would have been helpful to further characterize the population and provide additional insight into what family members faced at discharge. Given the variable presentation of patients at admission, however, it was not possible to ensure that all patients would have the cognitive capacity to consent to release their information.

Finally, limited access to civilian rehabilitation data provided barrier for comparison. Although information provided within the literature ensured that some point of comparison could be made, this writer did not have access to data about FNQ needs in civilian rehab beyond: *M*, *SD*, frequency ranks, and needs percentages of civilian rehabilitation FNQ. Thus this writer was not able to fully compare all items of the FNQ in the present study.

Future Directions

Although the present study provides a helpful base for studying PRC family needs, there are a number of additional issues to be addressed within this population. First, this paper specifically addressed the PRC population. Although this population faces especially difficult barriers given the complicated nature of polytraumatic injuries, patients in the PRC represent a small proportion of total patients in the Polytrauma System of Care. Future research should address family needs in outpatient populations as well. Research in civilian settings has been clear that families continue to have needs long after discharge and these needs change over time. When evaluating needs long term (4 years post injury), families ask for but frequently don't have access to ongoing long-term case management, web-based support, family therapy, and daily instrumental support (Kolakowsky-Hayner, Miner, & Kreutzer, 2001). Given the variety of services that the VA can provide to patients and families, further research needs to be done to determine what services the PSC families can make use of.

A second area that could be addressed in future research is continued focus on group differences within the context of Polytrauma families. In order to better understand if there

are significant differences between groups such as spouses/parents, racial, ethnic groups, and SES groups, further research with larger sample sizes is needed. Given that the current study only found small to moderate effect sizes with groups, this indicates that a fairly large sample (200+) of family members would be needed to detect differences that could be generalized beyond the Richmond VAMC. Future studies may need to extend data collection to other Polytrauma VAMC's to ensure diversity of sample and adequate numbers to detect a true effect in the sample.

Finally, the use of qualitative research to better understand family needs should be implemented with military and veteran populations as it has been implemented in research within civilian hospitals. In using the FNQ to measure needs with PRC families, findings from the present study indicated that families in military/veteran settings reported needs similarly to families in civilian settings. Given the differences between these settings and stressors that families may face, further qualitative research is needed to understand the subtleties of unmet needs. This research is needed to inform the Polytrauma System of Care and Veterans Affairs Medical Centers how to use resources in a way that better serves veterans with brain injury and the families who care for them.

List of References

List of References

- Armstrong, K., & Kerns, K.A. (2002). The assessment of parent needs following pediatric traumatic brain injury. *Pediatric Rehabilitation, 5*(3), 149-160.
- Bond, A.E., Draeger, C.R.L., Mandleco, B., & Donnelly, M. (2003). Needs of family members of patients with severe traumatic brain injury: Implications for evidence-based practice. *Critical Care Nurse, 23*(4), 63-72.
- Chwalisz, K., & Stark-Wroblewski, K. (1996). The subjective experiences of spouse caregivers of persons with brain injuries: a qualitative analysis. *Applied Neuropsychology, 3*, 28-40.
- Collins, R.C., & Kennedy, M.C. (2008). Serving families who have served: Providing family therapy and support in interdisciplinary polytrauma rehabilitation. *Journal of Clinical Psychology, 64*(8), 993-1003.
- Crosson, B., Poeschel Barco, P., & Welozo, C.A. (1989). Awareness and comprehension in postacute head injury rehabilitation. *Journal of Head Trauma Rehabilitation, 4*, 46-54.
- DePalma, R.G., Burris, D.G., Champion, H.R., & Hodgson, M.J. (2005). Blast injuries. *The New England Journal of Medicine, 352*, 1335-1342.
- DePompei, R., & Williams, J. (1994). Working with families after TBI: A family-centered approach. *Topics in Language Disorder, 15*(1), 68-81.
- Ergh, T.C., Rapport, L.J., Coleman, R.D., & Hanks, R.A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *Journal of Head Trauma and Rehabilitation, 17*(2), 155-174.
- Faul, F., Erdfelder, E., Lang, A.-G. & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191.

- Fischer, H. (2009). United States military casualty statistics: Operation Iraqi freedom and operation enduring freedom. *Congressional Research Service*. Retrieved May 29, 2009 from <http://fas.org/sgp/crs/natsec/RS22452.pdf>
- Friedmann-Sanchez, G., Griffin, J.M., Rettman, N.A., Rittman, M., & Partin, M.R. (2008). Communicating information to families of polytrauma patients: A narrative literature review. *Rehabilitation Nursing, 33*(5), 206-213.
- Friedemann-Sanchez, G., Sayer, N.A., & Pickett, T. (2008). Provider perspectives on rehabilitation of patients with Polytrauma. *Archives of Physical and Medical Rehabilitation, 89*, 171-178.
- Gleckman, A., & Brill, S. (1995). The impact of brain injury on family functioning: Implications for subacute rehabilitation programs. *Brain Injury, 9*, 385-393.
- Harmon, A.L. (2007). A descriptive study of military family needs following a polytrauma. Unpublished doctoral dissertation, Virginia Commonwealth University.
- Helmick, K.M., Parkinson, G.W., Chandler, L.A., & Warden, D.L. (2007). Mild traumatic brain injury in wartime. *Federal Practitioner, 58*-65.
- Hoge, C.W., McGurk, D., Thomas, J.L., Cox, A., Engel, C.C., & Castro, C.A. (2008). Mild traumatic brain injuries in U.S. soldiers returning from Iraq. *New England Journal of Medicine, 388* (5), 453-463.
- Junque, C., Bruna, O., & Mataro, M. (1997). Information needs of the traumatic brain injury patient's family members regarding the consequences of the injury and associated perception of physical, cognitive, emotional, and quality of life changes. *Brain Injury, 11*(4), 251-258.
- Keltner, N.L. & Cooke, B.B. Traumatic brain injury—war related. *Perspectives in Psychiatric Care, 43*(4), 223-226.
- Kim, J.W., & Moon, S.S. (2007). Needs of family caregivers caring for stroke patients: Based on the rehabilitation team phase and the treatment setting. *Social Work in Health Care, 45*(1), 81-97.
- Kolakowsky-Hayner, S.A., Kreutzer, J.S., & Miner, D. (2000). Validation of the service obstacles scale for the traumatic brain injury population. *NeuroRehabilitation, 14*, 151-158.

- Kolakowsky-Hayner, S.A., Miner, K.D., & Kreutzer, J.S. (2001). Long-term life quality and family needs after traumatic brain injury. *Journal of Head Trauma and Rehabilitation, 16*(4), 374-385.
- Kreutzer, J. (1988). *Family Needs Questionnaire*. Richmond, VA: Rehabilitation Research and Training Center on Severe Traumatic Brain Injury, Medical College of Virginia.
- Kreutzer, J.S., Serio, C.D., Berquist, S. (1994). Family needs after brain injury: A quantitative analysis. *Journal of Head Trauma Rehabilitation, 9*(3), 104-115.
- Kreutzer, J.S., Marwitz, J.H., Godwin, E.E., Arango-Lasprillo, J.C. (2009). Practical approaches to effective family intervention after brain injury. *Journal of Head Trauma Rehabilitation,*
- Kreutzer, J.S., Stejskal, T.M., Ketchum, J.M., Marwitz, J.H., Taylor, L.A., & Menzel, J.C. (2009). A preliminary investigation of the brain injury family intervention: Impact on family members. *Brain Injury, 23*(6), 535-547.
- Leif, E.L. (1993). Traumatic brain injury: Affecting family recovery. *Brain Injury, 7*(6), 543-546.
- Lezak, M.D. (1986). Psychological implications of traumatic brain damage for the patient's family. *Rehabilitation Psychology, 31*(4), 241-250.
- Lezak, M.D. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology, 19*(1), 111-123.
- Lippert-Gruner, M., Maegele, M., Haverkamp, H., Klug, N., & Wedekind, C. (2007). Health-related quality of life during the first year after severe brain trauma with and without polytrauma. *Brain Injury, 21*(5), 451-455.
- Loring, D.W. (Ed.). (1999). *INS Dictionary of Neuropsychology*. New York: Oxford University Press.
- Lucas, J.A. (2003). Traumatic brain injury and postconcussive syndrome. In P.J. Snyder & P.D. Nussbaum (Eds.) *Clinical neuropsychology: A pocket handbook for assessment* (pp. 243-265). Washington, DC: American Psychological Association.
- Meade, M.A., Taylor, L.A., Kreutzer, J.S., Marwitz, J.H., & Thomas, V. (2004). A preliminary study of acute family needs after spinal cord injury: Analysis and implications. *Rehabilitation Psychology, 49*(2), 150-155.

- Moules, S., & Chandler, B.J. (1999). A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain Injury, 13*(12), 983-993.
- Murray, H.M., Maslany, G.W., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury, 20*(6), 575-585.
- Nabors, N., Seacat, J., & Rosenthal, M. (2002). Predictors of caregiver burden following traumatic brain injury. *Brain Injury, 16*(12), 1039-1050.
- National Institute of Health (2007). NINDS Traumatic Brain Injury Information Page. Retrieved April 13, 2008 from <http://www.ninds.nih.gov/disorders/tbi/tbi.htm>.
- Okie, S. (2005). Traumatic brain injury in the war zone. *New England Journal of Medicine, 352*, 2043-2047.
- Okie, S. (2006). Reconstructing lives—a tale of two soldiers. *New England Journal of Medicine, 355*, 2609-2615.
- Paterson, B., Kielock, B., & Gmiterek, J. (2001). They never told us anything: Postdischarge instruction for families of persons with brain injuries. *Rehabilitation Nursing, 26*(2), 48-53.
- Port, A., Willmott, C., & Charlton, J. (2002). Self-awareness following traumatic brain injury and implications for rehabilitation. *Brain Injury, 16*(4), 277-289.
- Prigatano, G. (1996). Behavioral limitations that TBI patients tend to underestimate: A replication and extension to patients with lateralized cerebral dysfunction. *Clinical Neuropsychologist, 10*, 191-201.
- Roehr, B. (2007). Cost of US soldiers' health care could reach \$650 billion. *British Medical Journal, 335*, 1011.
- Rosenthal, M., & Young, T. (1988). Effective family intervention after traumatic brain injury: Theory and practice. *Journal of Head Trauma Rehabilitation, 3*, 42-50.
- Rosenthal, R. (1991). *Meta-analytic procedures for social research* (2nd ed.). Newbury Park, CA: Sage Publications.

- Rotondi, A.J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of person who have experienced traumatic brain injury and their primary caregivers. *Journal of Head Trauma Rehabilitation, 22*(1), 14-25.
- Sayer, N.A., Chiros, C. E., Sigford, B., Scott, S., Clothier, B., Pickett, T., et al. (2008). Characteristics and rehabilitation outcomes among patients with blast and other injuries sustained during the global war on terror. *Archives of Physical and Medical Rehabilitation, 89*, 163-170.
- Serio, C.D., Kreutzer, J.S., & Gervasio, A.H. (1995). Predicting family needs after brain injury: Implications for intervention. *Journal of Head Trauma Rehabilitation, 10*(2), 32-45.
- Serio, C.D., Kreutzer, J.S., & Witol, A.D. (1997). Family needs after traumatic brain injury: A factor analytic study of the family needs questionnaire. *Brain Injury, 11*, 1-9.
- Sigford, B.J. (2008). "To care for him who shall have borne the battles and for his widow and his orphan" (Abraham Lincoln): The Department of Veterans Affairs polytrauma system of care. *Archives of Physical and Medical Rehabilitation, 89*, 160-162.
- Taber, K.H., Warden, D.L., & Hurley, R.A. (2006). Blast-related traumatic brain injury: What is known. *Journal of Neuropsychiatry and Clinical Neuroscience, 18*(2), 141-145.
- Teasdale, G., & Jennett, B. (1974). Assessment of coma and impairment of consciousness: A practical scale. *Lancet, 2*, 81-84.
- U.S. Department of Veterans Affairs, Veterans Health Administration. (2005). VHA Handbook: Polytrauma rehabilitation procedures. (VHA Handbook 1172.1). Washington DC: DVA VHA.
- Uomoto, K.P., & Uomoto, J.M. (2009). Impact of traumatic brain injury on the family system and spouse. Retrieved from Brain Injury Association of Washington Online website: <http://www.biawa.org/library.htm>.
- 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*, 1004-1012.
- Waaland, P.K., Bruns, C., & Cockrell, J. (1993). Evaluation of needs of high and low income families following pediatric brain injury. *Brain Injury, 7*(2), 135-146.

- Warden, D. (2006). Military TBI during the Iraq and Afghanistan wars. *Journal of Head Trauma and Rehabilitation, 21*(5), 398-402.
- Watanabe, Y., Shiel, A., McLellan, D.L., Kurihara, M., & Hayashi, K. (2001). The impact of brain injury on family members living with patients: A preliminary study in Japan and the UK. *Disability and Rehabilitation, 23*(9), 370-378.
- Witol, A.D., Sander, A.M., & Kreutzer, J.S. (1996). A longitudinal analysis of family needs following traumatic brain injury. *NeuroRehabilitation, 7*, 175-187.
- Winstanley, J., Simpson, G., Tate, R., & Myles, B. (2006). Early indicators and contributors to psychological distress in relatives during rehabilitation following severe traumatic brain injury: Findings from the brain injury outcomes study. *Journal of Head Trauma Rehabilitation, 6*, 453-466.

Appendix A

Demographics Questionnaire

1. Date: _____
2. Gender: _____ Male _____ Female
3. Marital Status:
_____ Single
_____ Married
_____ Separated/Divorced
_____ Widowed
4. _____ Age
5. What is your race/ethnicity? Please check all that apply:
_____ American Indian/Alaska Native
_____ Asian
_____ Native Hawaiian or Other Pacific Islander
_____ Black or African American
_____ White
_____ Hispanic
_____ Unknown
6. Estimated household income per year:
_____ \$0 - \$20,000
_____ \$20,001 - \$40,000
_____ \$40,001 - \$60,000
_____ \$60,001 - \$80,000
_____ \$80,001 - \$100,000
_____ \$100,000 +
7. Employment status. Please check all that apply:

- employed ()full time ()part time
- unemployed
- retired
- volunteer
- student ()full time ()part time

8. What is your relationship to your injured family member?

- spouse
- parent
- step parent
- sibling
- child
- other Please explain: _____

9. Date your family member was injured:

(day/month/year): _____

10. Date you were notified your family member was injured:

(day/month/year): _____

11. Geographic location where your family member's injury occurred:

- Iraq
- Afghanistan
- Outside the continental United States
- Stateside

12. Date you first saw your family member after he or she was injured:

(day/month/year): _____

13. Where did you first see your injured family member?

- Military Treatment Facility (e.g., Walter Reed Army Medical Center, Bethesda)
- Overseas Military Treatment Facility (e.g., Landstuhl Army Medical Center)
- Private hospital

14. On a scale of 1 to 5 please indicate how serious you thought your family member's injury was **at the time you were notified**. Please circle a number below:

| | | | | |
|--------------------|---------------------------|----------------|---------------------|--------------------------|
| Not serious | Moderately Serious | Serious | Very serious | Extremely Serious |
| 1 | 2 | 3 | 4 | 5 |

15. On a scale of 1 to 5 please indicate how serious you thought your family member's injuries were **when you first saw them**. Please circle a number below:

| | | | | |
|--------------------|---------------------------|----------------|---------------------|--------------------------|
| Not serious | Moderately Serious | Serious | Very serious | Extremely Serious |
| 1 | 2 | 3 | 4 | 5 |

16. On a scale of 1 to 3 please rate the accuracy of the information you initially received about your family member's injury. Please circle a number below:

| | | |
|---------------------|---------------------------|------------------------|
| Not accurate | Partially accurate | Mostly accurate |
| 1 | 2 | 3 |

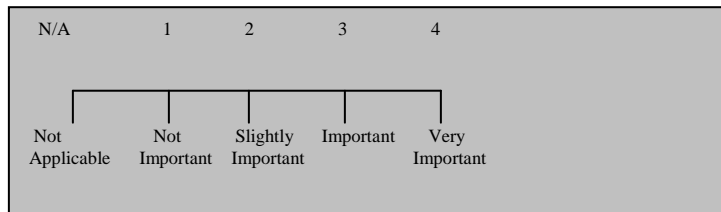
Appendix B

Family Needs Questionnaire (FNQ)

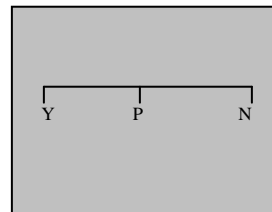
INTRODUCTION: Family and/or friends of persons who have had a traumatic brain injury often find they have their own special needs. These needs may or may not have been taken care of during the patient's rehabilitation. Often, these needs change over time. We are interested in seeing how important some of these needs are to you and whether or not those needs have been met. The information you provide will help us to understand the needs of your family as well as other families of persons with serious injuries.

DIRECTIONS: For each of the following 40 questions please use the scales described below to tell us about your needs. Each question has two parts.

Part I



Part II



Family Needs Questionnaire Items (grouped according to domain):

| Need Domain | Item Number | Need Description |
|-----------------------------|--------------------|-----------------------------------------------------------------------------------------------------------------------------------------|
| Need for Health Information | 1 | To be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes |
| Need for Health Information | 4 | To be told about all changes in the patient's medical status |
| Need for Health Information | 5 | To be assured that the best possible medical care is being given to the patient |
| Need for Health Information | 6 | To have explanations from professionals given in terms I can understand |
| Need for Health Information | 7 | To have my questions answered honestly |
| Need for Health Information | 11 | To have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery). |
| Need for Health Information | 12 | To have complete information on the patient's physical problems (e.g. weakness, headaches, dizziness, problems with vision or walking). |
| Need for Health Information | 13 | To have complete information on the patient's problems in thinking (e.g. confusion, memory, or communication). |
| Need for Health Information | 14 | To have complete information on drug or alcohol problems and treatment |
| Need for Health Information | 18 | To have information on the patient's rehabilitative or educational progress. |
| Need for Emotional Support | 29 | To have my significant other understand how difficult it is for me |
| Need for Emotional Support | 30 | To have my partner or friends understand how difficult it is for me |
| Need for Emotional Support | 34 | To discuss my feelings about the patient with someone who has gone through the same experience |
| Need for Emotional Support | 36 | To be reassured that it is usual to have strong negative feelings about the patient |
| Need for Emotional Support | 37 | Help getting over my doubts and fears about the future |
| Need for Emotional Support | 38 | Help in remaining hopeful about the patient's future |
| Need for Emotional Support | 39 | Help in preparing for the worst |
| Need for | 40 | To be encouraged to ask other to help out |

| Need Domain | Item Number | Need Description |
|-------------------------------|--------------------|------------------------------------------------------------------------------------------------------------------------------------------|
| Emotional Support | | |
| Need for Instrumental Support | 22 | To have help keeping the house (e.g., shopping, cleaning, cooking, etc.) |
| Need for Instrumental Support | 23 | To have help from other member of the family in taking care of the patient. |
| Need for Instrumental Support | 24 | To get enough rest or sleep |
| Need for Instrumental Support | 25 | To get a break from my problems and responsibilities |
| Need for Instrumental Support | 26 | To spend time with my friends |
| Need for Instrumental Support | 27 | To pay attention to my own needs, job, or interests |
| Need for Professional Support | 16 | To be told how long each of the patient's problems is expected to last |
| Need for Professional Support | 17 | To be shown what to do when the patient is upset or acting strange |
| Need for Professional Support | 19 | To have help in decide how much to let the patient do my himself/herself |
| Need for Professional Support | 20 | To have enough resources for the patient (e.g., rehabilitation programs, physical therapy, counseling, job counseling). |
| Need for Professional Support | 21 | To have enough resources for myself or the family (e.g., financial or legal counseling, respite care, counseling, nursing, or day care). |
| Need for a Support Network | 9 | To have a professional to turn to for advice or services when the patient needs help |
| Need for a Support Network | 31 | To have other family members understand the patient's problems |
| Need for a Support Network | 32 | To have the patient's friends understand his/her problems. |

| Need Domain | Item Number | Need Description |
|--------------------------------|--------------------|----------------------------------------------------------------------------------------------------------|
| Need for a Support Network | 33 | To have the patient's employer, coworkers, or teachers understand his/her problems. |
| Need for a Support Network | 35 | To discuss my feelings openly about the patient with other friends or family |
| Need for Involvement with Care | 2 | To be told daily what is being done with or for the patients |
| Need for Involvement with Care | 3 | To give my opinions freely to others involved in the patient's care, rehabilitation, or education |
| Need for Involvement with Care | 8 | To be shown that my opinions are used in planning the patient's treatment, rehabilitation, or education. |

Appendix C

Family Needs Questionnaire-Supplemental

| | | | | | | | | | | | | | | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|-----------------------|-----------|-------------------|---|-------------------|------------------|-----------------------|-----------|-------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|---|---|
| <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%; text-align: center;">N/A</td> <td style="width: 10%; text-align: center;">1</td> <td style="width: 10%; text-align: center;">2</td> <td style="width: 10%; text-align: center;">3</td> <td style="width: 10%; text-align: center;">4</td> </tr> <tr> <td style="border-top: 1px solid black; border-left: 1px solid black; border-right: 1px solid black; padding: 5px;">Not Applicable</td> <td style="border-top: 1px solid black; border-left: 1px solid black; border-right: 1px solid black; padding: 5px;">Not Important</td> <td style="border-top: 1px solid black; border-left: 1px solid black; border-right: 1px solid black; padding: 5px;">Slightly Important</td> <td style="border-top: 1px solid black; border-left: 1px solid black; border-right: 1px solid black; padding: 5px;">Important</td> <td style="border-top: 1px solid black; border-left: 1px solid black; border-right: 1px solid black; padding: 5px;">Very Important</td> </tr> </table> | N/A | 1 | 2 | 3 | 4 | Not Applicable | Not Important | Slightly Important | Important | Very Important | <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 33%; text-align: center;">Y</td> <td style="width: 33%; text-align: center;">P</td> <td style="width: 33%; text-align: center;">N</td> </tr> </table> | Y | P | N |
| N/A | 1 | 2 | 3 | 4 | | | | | | | | | | |
| Not Applicable | Not Important | Slightly Important | Important | Very Important | | | | | | | | | | |
| Y | P | N | | | | | | | | | | | | |

| I NEED..... | PART I How Important Is This Need? | PART II Has this need Been Met? |
|--------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------|---------------------------------------|
| 1. to have a military representative from my injured family member's branch of service to turn to for help with military related administrative issues | 1 2 3 4 | Y P N |
| 2. to have complete information on the psychological care of traumatic injuries | 1 2 3 4 | Y P N |
| 3. to have complete information on how to manage my own stress and reactions to what has happened in a healthy manner | 1 2 3 4 | Y P N |
| 4. to have a safe place to process my feelings about my experiences since my family member was injured | 1 2 3 4 | Y P N |
| 5. to have a list and description of community-based organizations I can turn to for additional assistance | 1 2 3 4 | Y P N |
| 6. to feel connected to my home community while I am away caring for my loved one | 1 2 3 4 | Y P N |

Vita

Kathryn Pamela Wilder Schaaf was born on October 13, 1979 in Little Rock, Arkansas. She graduated from Walter M. Williams High School in Burlington, North Carolina, in 1997. She enrolled at the University of North Carolina, Chapel Hill in the fall of 1997 and received her Bachelor of Arts in Psychology and Sociology in 2001. During her Undergraduate years, Katy worked as a research assistant for Dr. Donald Baucom doing couples communication research. After graduating, she enrolled in the Marital and Family Therapy program at the University of Maryland and received her Masters of Science in Marital and Family Therapy in 2003. Katy worked for a two years with chronically ill adolescents as a psychotherapist for Cumberland Hospital.

Katy enrolled in Virginia Commonwealth University's Counseling Psychology program in the fall of 2005. Since that time, she has worked with her advisor, Dr. Steve Danish, on a community health intervention aimed at rural middle school students. In addition Katy received funding as a predoctoral Rehabilitation Research Fellow to complete research on family needs in polytrauma populations at McGuire Veterans Administration Medical Center. She will complete her internship at the Minneapolis Veterans Affairs Medical Center in the summer of 2010 and expects to graduate in the spring of 2010.