SYMPTOM SELF-MANAGEMENT FOR MILD TRAUMATIC BRAIN INJURY

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A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Nursing

2011

ABSTRACT

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Traumatic brain injury (TBI) affects 1.4 million Americans annually and mild TBI (MTBI) accounts for approximately 75 % of those injured. For those with mild injury that seek treatment in an emergency department, there is inconsistency in the management and follow up recommendations. Approximately 38% of patients treated in the ED for MTBI are discharged with no recommendations for follow up. In addition, there are an unknown number of persons with MTBI that do not seek healthcare following their injury. Persons with MTBI are for the most part managing their concussion symptoms on their own. It is unknown what persons with MTBI do to manage their symptoms, or how well those strategies work at relieving symptoms. The purpose of this study was to describe the symptom experience for persons with mild TBI in terms of presence of symptoms and bothersome nature of symptoms and identify what persons do to manage those symptoms. This study will also describe how well persons report their symptom management strategy as being effective. A better understanding of these concepts by healthcare workers may improve the discharge process of what information is given to persons with MTBI and whether follow up appointments are necessary for this population. This study of 30 persons with MTBI and a 30 person comparison group describes the symptoms that were present following MTBI and compared those symptoms to the non-brain injured group. In addition, the symptom-self management for MTBI questionnaire was used to explore what symptom self-management strategies were used as well as how effective persons rated those strategies to be. Results of this study indicate that persons within three months of their MTBI report an average of 19 symptoms while the comparison group reported 6 symptoms, and that the most frequently reported symptoms are not always the symptoms rated as most severe or most bothersome. Persons with MTBI reported their most common symptoms to be headache (*n* = 25, 83%), feeling tired (*n* = 24, 80%), difficulty thinking and irritable (each *n* = 22, 73%), dizziness, trouble remembering, and forgetful (each 21, 70%). Persons with MTBI use symptom management strategies such as activities/thoughts, complimentary therapies, and exercise to manage their symptoms. There is a significant relationship between overall reports of being bothered by symptoms and the use of symptom management strategies (*F* = 8.322, *p* = .008) and there were no significant relationships among the covariates of age (*F* = .398, *p* = .534), sex (*F* = .030, *p* = .864), education (*F* = .539, *p* = .745), or group (*F* = .095, *p* = .761). There was a significant relationship between strategies used and effectiveness of symptom relief (*F* = 34.63, *p* = .000) and sex (*F* = 4.77, *p* = .04). Symptoms after MTBI are common and persons use strategies such as activities/thoughts, medications, exercise, and complimentary therapies to manage their symptoms. Persons are more likely to use symptom management strategies when they are bothered by the symptoms, and they report their symptom management strategies to be effective at symptom relief. Nurses can assist with symptom self-management for persons with MTBI by educating about the symptoms that can result from the injury, and by providing simple symptom management strategies, through the use of a symptom management toolkit, to assist with the symptom management process. Currently, a symptom management toolkit does not exist for the MTBI related symptoms, and results of this study can be used to develop the toolkit, with future research to validate the tool followed by intervention studies to verify the usefulness of the symptom management toolkit. Early symptom management for the MTBI population may improve the outcomes such as return to work and role functions, for this population.

ACKNOWLEDGMENTS

I would like to acknowledge and thank Dr Barbara Given for her expertise, mentoring, and persistence throughout my doctoral education and dissertation research. Her vast research knowledge has been vital to my ability to complete my research in a scientifically sound manner. She has been supportive and motivating throughout my doctoral education and I am sure that I will continue to learn from her throughout my research career.

I would also like to acknowledge all of the members of my dissertation committee. Dr Alex Von Eye has offered his expertise in research design and statistical analysis. Dr Debra Schutte has provided valuable knowledge on nursing research as well as her clinical expertise in neuroscience. Dr Robert Fabiano has served as the brain injury expert on my committee and has provided a tremendous amount of support with clinical expertise as well as providing links to other providers and institutions in the community. I would like to thank Mei You (Michigan State University) and Yusef Biljek (Bronson Hospital) for their assistance with statistical analysis.

Funding for my doctoral education and research was provided by scholarships from Michigan State University College of Nursing, and Bronson Methodist Hospital. In addition, I would like to thank the Michigan State University Graduate School for their generous Dissertation Completion Fellowship. Funding was provided by Bronson Methodist Hospital Research Fund to hire trained data collectors for my dissertation. I would like to thank the staff at Bronson Hospital, PAR Rehabilitation, Sparrow Hospital, and the athletic trainers at Western Michigan University (Kyle Bletcha) and Kalamazoo College (Scot Michaels) for their support in recruiting research participants.

TABLE OF CONTENTS

LIST OF TABLES vii

LIST OF FIGURES viii

CHAPTER 1
OVERVIEW…… 1
  Mild Traumatic Brain Injury…… 2
  Symptoms…… 4
    Bothersome Symptoms…… 8
    Symptom Self-Management…… 8

CHAPTER 2
CONCEPTUAL FRAMEWORK…… 12
  Symptom Experience…… 14
    Perception…… 14
    Evaluation…… 15
    Response…… 16
  Symptom Management Strategies…… 17
  Outcomes…… 20
    Person, Environment, Health/Illness variables…… 20
  Linkages Within the Model…… 22
  Usefulness of the Model with Mild TBI Population…… 22

CHAPTER 3
LITERATURE REVIEW…… 25
  Symptoms…… 26
    Physical…… 29
    Affective…… 31
    Cognitive…… 33
  Bothersome Symptoms…… 35
  Symptom Self-Management…… 38
  Symptom Relief…… 43
  Variables Associated with Symptom Management…… 47

CHAPTER 4
DESIGN AND METHODS…… 52
  Research Questions…… 52
  Sample and Settings…… 53
  Research Variables…… 55
  Measures…… 56
  Data Collection Schedule and Procedures…… 62
    Training…… 63

Data Analysis…………………………………………………………………… 64
  Research Question 1…………………………………………………………… 65
  Research Question 2…………………………………………………………… 66
  Research Question 3…………………………………………………………… 66
  Research Question 4…………………………………………………………… 66
Power…………………………………………………………………………… 67
Protection of Human Subjects………………………………………………….. 67
Data Security…………………………………………………………………… 68
Recruitment……………………………………………………………………. 68
Facilities and Resources………………………………………………………… 69

CHAPTER 5

RESULTS……………………………………………………………………….. 70
Sample………………………………………………………………………….. 70
  Groups…………………………………………………………………………….. 76
Research Question 1……………………………………………………………. 76
Research Question 2……………………………………………………………. 82
Research Question 3……………………………………………………………. 89
Research Question 4……………………………………………………………. 92

CHAPTER 6

DISCUSSION…………………………………………………………………… 98
Symptoms……………………………………………………………………. 99
  Bothersome……………………………………………………………………….. 103
  Bother and Symptom Management……………………………………………. 106
  Symptom Management Strategies………………………………………………….. 108
  Symptom Self-Management and Effectiveness of Strategies………………………. 113
Limitation……………………………………………………………………….. 115
Implications for Clinical Practice……………………………………………. 117
Implications for Future Research……………………………………………….. 119
Policy Implications…………………………………………………………… 121
Summary………………………………………………………………………... 122
APPENDICES 124
Appendix A: Demographic Questionnaire…………………………………….. 125
Appendix B: The Problem Checklist……………………………………………... 129
Appendix C: Symptom Self-Management Questionnaire…………………………….. 134
Appendix D: Consent…………………………………………………………... 146
REFERENCES 152

LIST OF TABLES

Table 1 Summary of MTBI Studies of Symptoms 27

Table 2 Demographic Comparison of MTBI and Comparison Groups 72

Table 3 Summary for Frequency and Means for Severe and Bother Scores 78

Table 4 Top 5 Symptoms Endorsed by MTBI Group 79

Table 5 Top 5 Symptoms Endorsed by MTBI Group as Most Severe 80

Table 6 Top 5 Symptoms Endorsed by MTBI Group as Most Bothersome 81

Table 7 Most Commonly Reported Symptom Management Strategies and Categories 84

Table 8 General Linear Model Comparison of Effects of Age, Sex, Education, and Group 88

Table 9 Relationship Between the Bothersome Nature of Symptoms and the Use of Symptom Management Strategies 91

Table 10 Symptom Management Strategies Rated as Most Effective at Symptom Relief 93

LIST OF FIGURES

Figure 1 The UCSF Symptom Management Model 13

Figure 2 Schematic diagram of the concepts for this study 23

CHAPTER 1

OVERVIEW

Persons with Mild Traumatic Brain Injury (MTBI)/concussion are typically treated and released from the emergency department (ED) (Bazarian et al., 2005). In many cases, persons are not promptly directed for follow up care (Bazarian, 2005; Blostein & Jones, 2003) and are thus left to manage their symptoms without professional oversight. Given the cognitive difficulties that are likely to exist (Dischinger, Ryb, Kufera, Auman, 2009; Lannsjo et al., 2009), it seems important to understand self-management strategies that are put in place by the person with MTBI.

Up to 62% of persons report at least one symptom following their MTBI with 44% reporting one or more symptom at 3 months post-injury (Lannsjo, 2009). Among the most commonly reported symptoms following MTBI are headache, dizziness, anxiety, dizziness, and fatigue (Lannsjo et al., 2009; Lundin, De Boussard, Edman, Borg, 2006; Yang, Tu, Hua, Huang, 2007). It is unknown whether certain symptoms are more bothersome than other symptoms and thus may become the target of symptom self-management. For those who are managing concussion symptoms without medical oversight, it is unknown what strategies are used and if they effectively reduce symptoms. The symptom self-management process can be complicated by factors such as altered cognitive ability following injury and difficulties that arise with returning to pre-injury roles such as work or school. Healthcare providers may be able to assist with the symptom self-management process by providing education and materials to persons with concussion that can be used as a tool kit for symptom self-management. In order to develop such tools, we need a better understanding of the symptom self-management process.

For persons who are within 3 months of their mild traumatic brain injury using patient self-reports, this study aims to:

1. Identify bothersome symptoms
2. Determine what symptom self-management strategies are being used
3. Determine the extent to which the self-management strategies are effective for symptom reduction.

This study will be addressing characteristics of the symptom experience that are currently unknown, such as the bothersome nature of symptoms, symptom self-management strategies used, and their perceived effectiveness at symptom reduction. An overview of the key variables in this study will be provided in this section, including MTBI, symptoms, bothersome symptoms, and symptom management, including symptom relief.

Mild Traumatic Brain Injury

Mild traumatic brain injury can be defined by a Glasgow Coma Scale (GCS) score of 13-15 and one or more of the following: confusion or disorientation, loss of consciousness for 30 minutes or less, post traumatic amnesia for less than 24 hours, and/or other transient neurological abnormalities (Carroll et al., 2004). Since MTBI accounts for approximately 75% (CDC, 2006) of the 1.7 million brain injuries per year (Faul, Xu, Wald, Coronado, 2010), the annual prevalence is very high. The vast majority of persons with MTBI are treated and released from emergency departments, or do not seek healthcare for their injury. While there are an approximately 1,365,000 emergency department visits for traumatic brain injury annually, there are an unknown number of persons that sustain a MTBI and do not seek care (Faul et al., 2010), thus the true incidence of this injury is unknown. MTBI may be caused by falls, motor vehicle trauma, being struck by something, hitting head on something, assaults or intentional head trauma (including blast injury), and sports related injuries (CDC, 2006; Faul et al., 2010). Neurologic changes that may occur at the time of injury creating a brief loss of consciousness, or a feeling of being dazed and confused appear to result from rotational forces within the brain resulting in electrophysiological disruption to the neurons (Ropper & Gorson, 2007). Cellular changes that occur following brain injury have been described as a neurometabolic cascade, including alterations in neurotransmitter functioning and electrolyte fluctuations at the cellular level (McCrea, 2008; Shaw, 2002). The metabolic changes following MTBI may alter the brain's normal metabolic functions for days to weeks following the injury, which is consistent with the expected symptom trajectory for this population (McCrea, 2008). While symptoms are expected to resolve in days to weeks, these symptoms may be quite bothersome to the person experiencing them, and may be difficult to manage.

Approximately 5.3 million Americans are disabled from TBI, with the CDC estimating direct and indirect costs at $60 billion (Finkelstein et al., 2006). While those with more severe injuries are almost always referred for rehabilitation (Van Baalen, Odding, & Stam, 2008), those with milder injury are usually not following up with rehabilitation specialists (Blostein & Jones 2003; Van Baalen et al., 2008). Persons with MTBI are therefor left to manage the symptoms associated with their injuries on their own. Without guidance to help manage symptoms after their injury, persons may utilize positive, negative, or no symptom management strategies. It is currently unknown what persons with MTBI are doing to self-manage their symptoms or how effective the self-management strategies are. It is important to achieve symptom relief because symptoms that are not alleviated, or persistent symptoms, can lead to disability in terms of return to work or school (Lundin et al., 2006; Yang et al., 2007).

Symptoms

In order to better understand what is known about the symptom experience for persons with MTBI and to identify the gaps in knowledge regarding symptoms and symptom self-management, it is necessary to begin by describing what is currently known about symptoms reported by the MTBI population. Symptoms are defined by Dodd (2001) as "a subjective experience reflecting changes in the biopsychosocial functioning, sensations, or cognition of an individual." Symptoms are important cues to let persons know that changes have occurred that may require attention or management.

Symptoms can be evaluated by persons experiencing them in terms of their presence, intensity or severity, duration, or by how bothersome they are (Dodd et al., 2001). For the MTBI population, the majority of what is known about symptoms is in regard to presence of symptoms following injury, most commonly obtained as self-reported symptoms. The bothersome nature of symptoms have not been described for MTBI, and gaining information on this dimension of symptoms may be useful in future symptom management plans because if certain symptoms are considered very bothersome by persons after MTBI, then targeting those bothersome symptoms in patient education may be beneficial.

Previous research on symptoms with persons following TBI has established that symptoms for those with mild injury follow a trajectory toward resolution of symptoms within weeks (for milder, noncomplicated injuries) to months (longer recovery for those with advanced age, and complicated injuries, i.e., other trauma associated fractures or injuries) (Alexander, 1995; Dikmen, Machamer, & Temkin, 2001; Lannsjo et al., 2009; Lundin et al., 2006; Ponsford, Cameron, & Fitzgerald, 2011; Yang et al., 2007). Predictors of prolonged symptoms following TBI include skull fracture, increased serum 100B (a protein shown to correlate with brain injury severity) levels, dizziness, or headache complaints (Faux et al., 2011) immediately following injury (de Kruijk et al., 2002; Savola & Hillbom 2003). Litigation, seeking financial compensation, and pre injury psychological issues (Kashluba, Paniak, & Casey, 2008) as well as anxiety, noise sensitivity, and female sex have been identified as predictors of prolonged symptom complaints following MTBI.

Symptoms experienced following MTBI are not unique to the TBI population, and can be found in other illnesses or in the general population. For example, headache is a symptom commonly reported after MTBI, but can also be a symptom complaint with a variety of medical illnesses or in otherwise healthy individuals. For this reason, all post-TBI symptoms cannot be guaranteed to be a result of the injury, as they could have been present prior to the injury as well. Asking questions about pre-injury symptoms can be helpful to identify new acute symptom complaints compared to chronic or pre-existing symptoms. This information is useful when educating about symptom trajectory and symptom management strategies as symptoms that are chronic would not be expected to be resolved during the typical post-MTBI course. In addition, prior experience with a symptom, such as headache, can be useful in symptom self-management strategies that may be used to relieve that symptom.

Physical symptom complaints may include headache, dizziness, neck pain, sleep-wake disturbances, and visual difficulties (Alexander, 1995; Kraus, Ayers, & Shen, 2005; Lannsjo et al., 2009; Lundin et al., 2006; Yang et al., 2007). Physical complaints can be due to the mechanism of injury, such as the force of an acceleration/deceleration motor vehicle crash, or from the neural shearing, or combination of both. Headache has been reported as high as 90% soon after injury and present in up to 44% of patients with mild injury at 6 months (Nicholson & Martelli, 2004). Laansjo and colleagues (2009) found the physical symptoms of headache, dizziness, fatigue/drowsiness, to be among the top 5 symptom complaints. In a study of early symptom complaints following mild TBI, Lundin et al. (2006) found that although symptoms did decrease from 1-3 months following injury, sleep disturbance and fatigue were among the most common symptoms reported at three months. In addition, they found that early symptom complaints correlated with later symptom complaints, and that symptoms and disability scores were correlated at three months post-injury. Physical symptoms are common following MTBI, are expected to resolve gradually over time, however, their presence can make returning to normal roles such as work or school very difficult.

Affective symptoms such as depression, anxiety, and irritability can be found within the MTBI populations (Lannsjo et al., 2009; Whelan-Goodinson et al., 2009). Frequency of depression following TBI is reported at approximately 10% (Bryant et al., 2010; Faux et al., 2011). Depressive symptoms have been correlated with worse functional status outcomes (Bryant et al., 2010). Linking depressive symptoms to worse outcomes emphasize the need to create proactive plans of care that include self-management strategies for depressive symptoms, as well as direction for seeking treatment from professionals.

Emotional symptoms such as irritability, mood changes, and anxiety (Lannsjo et al., 2009; Lundin et al., 2006; Yang et al., 2007) are common among all severity of injury groups post-TBI, including those with mild injuries. Kashluba et al. (2004) report irritability (56%) and anxiety (51%) among the top 5 symptom complaints in their mild TBI population. Bay and Bergman (2006) found a significant relationship between symptom frequency and tension/anxiety, anger/hostility, and perceived stress among a community dwelling sample of mild to moderate post-TBI patients.

Stress, including post-traumatic stress disorder (PTSD) has been associated with persons with mild TBI. Persons who sustain a mild TBI as opposed to more severe injuries are more likely to develop PTSD (Bryant et al., 2010). Factors that may increase the likelihood of experiencing PTSD include substance abuse, co-morbid depression, anxiety disorders, or stress of litigation (Feinstein et al., 2000). Links have been identified between post-traumatic stress and other TBI related symptoms, such as pain. Bay et al. (2004) found that pre and post injury stress were related to post-TBI depressive symptoms. reported that among their population of MTBI subjects, those with PTSD reported more post-concussive symptoms, and that post-concussive symptoms were significantly correlated with PTSD symptoms, however as the authors point out, there is overlap among the two sets of symptoms, including concentration deficits, irritability, and heightened startle response.

Cognitive symptoms common after TBI include difficulty with memory (Kraus et al., 2005; Laansjo et al., 2009), attention, concentration (Nolin & Heroux, 2006), problem solving (Rath et al., 2004), and executive functioning (Serino et al., 2007). Mathias, Beall, and Bigler (2004) studied a group of 40 patients with mild TBI and found that during the first month after injury, that they had more difficulty in attention and memory than the controls. Belanger and colleagues (2005) performed a meta-analysis, including 39 studies of mild TBI, and found that soon after injury (<3 months), effects were greatest for problems with delayed memory and fluency. The authors also note that litigation status was associated with stable or worsening cognitive functioning over time, emphasizing the need for this study to include litigation status as a possible confound. It is important for clinicians to be aware of the often subtle but frequently present cognitive difficulties that persons with relatively mild brain injury can experience, especially soon after injury. Consideration of the cognitive symptoms and the impact of those symptoms on person’s ability to self-manage their symptoms must be done in order to optimize persons with MTBI symptom resolution. It is possible that persons who experience more cognitive symptoms may have decreased ability to self-manage their symptoms due to lack of concentration, poor ability to plan, and memory difficulties.

Bothersome Symptoms

The symptom experience included perception, evaluation, and response to symptoms (Dodd, 2001). Determining how bothersome, or disruptive to daily life, a symptom is to the individual experiencing it is part of the symptom evaluation. Several studies, although not in the MTBI populations (Dunn & Croft, 2005; Fultz et al., 2003; Hockenberry et al., 2003; Lee et al., 2011), report on the symptom experience of bother, or most bothersome symptoms and report that the most frequently reported symptoms are not necessarily the most bothersome symptoms. In addition, more bothersome symptoms may be the target of symptom management. For this study, bothersome refers to a symptom being disruptive to daily functioning (Kay et al., 1995; O’Leary, 2005).Adding a dimension such as bothersome to the knowledge base about the symptom experience will contribute to the science of symptom management. It is possible that persons may seek treatment either via healthcare providers or through self-management for those MTBI symptoms that bother them most, as opposed to those that are most frequently reported. Differentiating symptoms by characteristics such as bothersome as compared to other terms such as frequency, may aid in our understanding of the symptom self-management process for this population.

Symptom Self-Management

Persons with MTBI are frequently evaluated and treated in emergency department or ambulatory care settings, or do not seek any treatment for their injury. Symptoms that become problematic at one week or one month post injury may not be present or discussed at the time of the initial injury. The CDC offers a toolkit for healthcare providers to give information to persons with MTBI with regard to symptoms they might expect; however, this toolkit does not give specific information on symptom self-management. Currently, there are no set standards of practice for providing information to persons following MTBI regarding how to self-manage symptoms.

While it is known that certain interventions for symptom management that are implemented by healthcare providers are beneficial (Bell et al., 2008; Ponsford, 2001, 2005), it is unknown what persons with MTBI do to manage symptoms on their own. Having a better understanding of what persons are doing to self-manage symptoms as well as how effective they feel those strategies are will provide important information that can be used to enhance the symptom experience for those with MTBI. It is possible that persons are self-managing their symptoms effectively, and it is also possible that they are not. It will be important to determine if certain strategies that persons use are effective at reducing symptoms as opposed to others, to best help develop future programs of symptom management for persons with MTBI.

Intervention for symptom management that is initiated by healthcare providers for MTBI have been aimed at education to reduce anxiety and symptoms (Ponsford, 2001, 2005) and psychological treatment to reduce severity and duration of symptoms (Bell et al., 2008). Symptom management strategies aimed at the bothersome symptoms have not been described for persons with MTBI. It may be helpful to identify certain symptoms that are frequently reported as “most bothersome” post-TBI and provide information or services to proactively help persons self-manage them. Persons who are able to manage their own symptoms and not be bothered by them, may in turn have better outcomes than those who do not self-manage effectively, however, this idea remains unknown.

General recommendation such as those in the *CDC Management of Mild TBI Toolkit* are for gradual return to physical activities upon resolution of symptoms. Included in this are increased rest periods for fatigue and not driving while symptoms persist. This toolkit of information can be given to patients who seek treatment, or can be downloaded from the CDC website. Persons are therefore at home with this information, most often outside of a healthcare delivery system for assistance. Persons are evaluating their symptoms, determining if they will attempt management strategies or not, and perhaps having improved or worsened symptoms. Other than knowing what symptoms are commonly occurring in the early phase after MTBI, a gap exists in our knowledge of the remainder of the symptom management process.

While the above mentioned studies provide recommendations for what clinicians can suggest to patients to improve symptoms post-TBI, no studies have investigated what patients do on their own to manage symptoms. It is possible that what patients do to manage symptoms is not consistent with what is recommended. There is also potential that patients are managing symptoms well on their own, along with the risk that they are not. Symptoms that are poorly managed may at times lead to poor outcomes such as inability to return to normal work or school functions. This study will contribute to the science and answer important questions about the symptom experience and symptom self-management process by addressing the following research questions.

In order to increase the science behind symptom self-management for persons with MTBI, this study will answer the following research questions. In order to answer them, persons who are within three months of their injury will be asked to complete self-report questionnaires.

Research Questions

1. What symptoms are present and rated as most bothersome? How does bothersome rating compare to frequency or severity ratings?
2. What symptom self-management strategies are used?
3. To what extent are bothersome symptoms the focus of self-management strategies?
4. What is the degree of effectiveness of self-management strategies on symptom relief after MTBI?

The purpose of this study is to describe the symptom experience for persons with mild TBI in terms of presence of symptoms and bothersome nature of symptoms and identify what persons do to manage those symptoms. This study will also describe how well persons report their symptom management strategy as being effective. A better understanding of these concepts by healthcare workers may improve the discharge process of what information is given to persons with MTBI and whether follow up appointments are necessary for this population. This study will be guided by the conceptual framework of the UCSF Symptom Management Model.

This chapter briefly described the concepts to be researched in this proposal. Chapter 2 will provide a detailed description of the conceptual framework used to guide this study. The UCSF Symptom Management Model will be described as well as how it relates to the symptom self-management process for persons with MTBI. Chapter 3 will provide the detailed review of the literature related to the concepts of MTBI symptoms, bothersome symptoms, and symptom self-management. Methodology for the study will be described in Chapter 4 of this proposal, followed by analysis/results and discussion of the findings.

CHAPTER 2

CONCEPTUAL FRAMEWORK

Theories can be applied to analyze existing knowledge, provide a guide to patient management, and to systematically guide research to inform practice (Walker & Avant, 1995). Use of a mid-range theory or model applied to the brain injury population will guide this research by providing a framework that helps with the understanding of symptom management concepts and relationships among the concepts as they relate to the mild traumatic brain injury population. The UCSF Symptom Management Model (Dodd, Miaskowski, & Paul, 2001) is a theoretical model that incorporates the concepts being examined in this study (Figure 1) such as symptom evaluation of bothersome symptoms, symptom self-management strategies, and symptom relief. In addition, the model shows the importance of variables of person, health/illness, and environment and their impact on the symptom management process. This chapter will provide an overview of the UCSF Symptom Management Model followed by the use of this model as it relates to this study and the population of persons with MTBI.

The focus of this study is on whether certain symptoms are evaluated as bothersome and if those bothersome symptoms are the focus of symptom self-managements strategies. The study will explore whether person, environment, health/illness variables about persons with MTBI influence these evaluations. In addition, this research aims to understand the self-management process used to regulate the symptoms that may be experienced following MTBI. Finally, this study will describe whether persons with MTBI self-report that their symptoms were relieved by their symptom management strategies.

The UCSF Symptom Management Model was developed at the Research Center for Symptom Management at the University of California, San Francisco. The group developed and tested the model in order to “develop the subdiscipline of symptom management across health science disciplines and across health care settings by elucidating and testing a Model of Symptom Management.” The model has been used to evaluate symptom management in patients with brain injury (Bay & Bergman, 2006), cancer (Dodd, Miaskowski, & Paul, 2001; Linder, 2010; Swore, Fletcher, Dodd, Schumacher, & Miaskowski, 2008), HIV (Voss, 2005, 2006; Wantland et al., 2008), and diabetes (Skelly, Leeman, Carlson, Soward, & Burns, 2008).

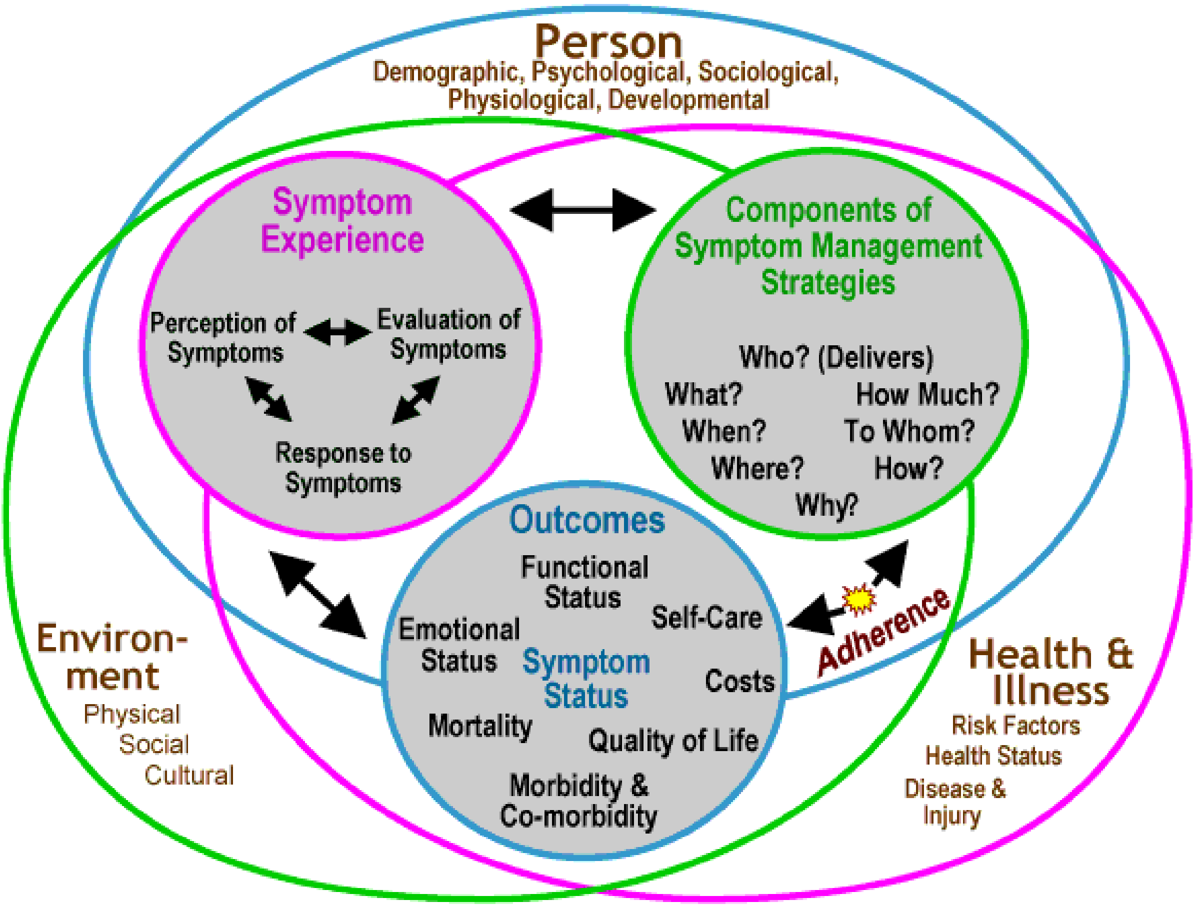

Figure 1. UCSF Symptom Management Model. For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this dissertation.

Used with permission by Blackwell Publishing from Dodd et al. (2001). Advancing the Science of Symptom Management. *Journal of Advanced Nursing*, *33*(5), 668-676.

The model depicts the relationships among three main constructs of (1) symptom experience, (2) symptom management strategies, and (3) outcomes. In addition, the model incorporates the influences of person, environment and health/illness factors on the three main constructs. The concepts in the model are thought to be broad enough that the model should be generalizable to other patient populations (Dodd et al., 2001). No conceptual model has been consistently used in the TBI literature on symptom management.

To best understand the appropriate use of the UCSF Symptom Management Model with the TBI population, the theoretical definitions associated with the constructs and concepts within the model will be discussed. First discuss the model in general and then apply it to your case.

The Symptom Experience

The symptom experience includes the interrelated components of perception, evaluation, and response to symptoms. These three components of the symptom experience dimension are closely related as represented by bi-directional arrows within the model, indicating that they can both affect, and be affected by each other (Dodd et al., 2001). For this study, the primary concept of interest from the symptom experience construct of the model is the evaluation of symptoms. In particular, this study will identify whether certain symptoms are evaluated as bothersome to person's everyday activities and life. All concepts of the symptom experience will be briefly described, with an emphasis on the evaluation of symptoms as bothersome concept. For this study, the presence of the symptom (frequency), the severity, and how bothersome the symptom is will be evaluated.

Perception

Perception of symptoms refers to the individual noticing a change from usual, and identifying the experience as different from the baseline state (Dodd et al., 2001). Perception relies on the ability to detect sensory changes requiring intact afferent pathways, intact cortical functions to interpret these signals and process these symptoms as abnormal (Freeman, 1991). Symptom perception can be impacted by prior experience with a symptom, such as in cases of chronic disease patients being able to detect and describe in detail subtleties of their symptom experience (Dodd et al., 2001). Perception, as far as the ability to recognize symptoms, is not thought to be problematic for persons with mild TBI (Alexander, 1995; Freeman, 1991). Participants in this study will be those with mild injuries, and will be answering symptom self-report questionnaires. Self-reporting of the symptom will imply perception of the presence of the symptoms.

Evaluation

Evaluation of symptoms includes characterizing the symptom with regard to intensity, location, temporal nature, frequency, and affective impact (Dodd et al., 2001). Characterizing a symptom such as how severe it is or how bothersome it is can be useful for both persons experiencing the symptom as well as healthcare providers for better understanding the symptom experience of patients. Symptoms are evaluated as more bothersome when they are disrupting daily life (Ingham & Farooqi, 2003; O'Leary, 2005). For example and hypothetically, a person might evaluate dizziness as highly disruptive to their daily life and be strongly bothered by that symptom while not being bothered by having the symptom of headache. Different people may be bothered by certain symptoms more than others; therefore, bothersome is an evaluation of a symptom that can be specific to the individual experiencing it.

For the MTBI population, frequency of symptoms has been described in terms of presence of symptoms and duration of symptoms. Among the most commonly reported symptoms following TBI are headache, dizziness, anxiety, dizziness, and fatigue (Alexander, 1995; Lannsjo et al., 2009; Lundin, DeBoussard & Edman, 2009; Yang et al., 2009). Duration of symptoms is thought to subside over time, for those with mild injury following a trajectory toward resolution of symptoms within weeks (for milder, noncomplicated injuries) to months (longer recovery for those with moderate injury, advanced age, and complicated injuries, i.e., other trauma associated fractures or injuries) (Alexander, 1995; Lannsjo et al., 2009; Yang et al., 2009). The bothersome nature of MTBI symptoms has not yet been described for the MTBI population.

Experience with a symptom is also a consideration with the concept of evaluation, such that someone who has a history of the symptom may be able to catalog subtleties of the symptom and thus evaluate the symptom with much more detail compared to someone new to the experience (Lenz, Pugh, Milligan, Gift, & Suppe, 1997). For the traumatic brain injury population, persons may have prior experience with the TBI symptoms. In fact, post-TBI symptoms are not unique to the TBI population and have been shown to be present in the general population or healthy controls in research studies (Ponsford et al., 2011) as well as those with chronic pain (Smith-Seemiler, Fow, Kant, & Franzen, 2003). This study will describe the frequency, severity, and how bothersome persons report their symptoms to be. How bothersome persons with MTBI report their symptoms to be has not yet been investigated, and this knowledge may help to develop symptom management strategies for this population.

Response

Response to symptoms includes physiologic, psychological, sociocultural, and behavioral alterations that can impact the symptom experience (Dodd et al., 2001). For example, response to headache could result in increased heart rate and mood changes (Gurr & Coetzer, 2004). Persons generally report more than one symptom in the early phase of their injury, and the effect of multiple symptoms on symptom response is currently unknown for the MTBI population. Responses can also impact evaluation. A response such as depression may cause one to evaluate seemingly minor symptoms as more bothersome. Response to symptoms can also be influenced by an individual's prior experience with a symptom (Dodd et al., 2001). Repeated exposure to a symptom may either heighten the response to a symptom or one may become used to the symptom and have less of a response (Ingham & Farooqi, 2003). Responses to symptoms are not directly measured in this research proposal, however, return to work or school will be measured and can provide some information about the effectiveness of person's responses to symptoms.

Symptom Management Strategies

Symptom management strategies is a construct within the model that identifies the need to not only provide an intervention, but to identify the *what, when, how much, to whom, and why* of what can be done to treat symptoms. According to Dodd and colleagues (2001), the goal of symptom management is to "avert or delay a negative outcome through biomedical, professional, and self-care strategies." The focus of this study is on the self-management strategies used for symptom management. Self-management involves persons being responsible for the day-to-day management (Lorig & Holman, 2003) of their health, their illness, or in this case, their symptoms.

Symptom self-management has been discussed in the cancer (Given et al., 2010; Kruelen & Braden, 2004) and chronic illness literature (Lorig et al., 2001; Newman, Steed & Mulligan, 2004), however, has not been described in the MTBI literature. For those with cancer or chronic illness, persons outside of acute care settings are managing their symptoms, although the difference between those populations and the MTBI population is that cancer and chronic illness are closely tied to healthcare providers and services. Providers for those populations may offer guidance for ways in which persons can best self-manage symptoms. For those with MTBI, there may not be any follow up with healthcare providers, thus self-management of symptoms cannot rely on direct contact with healthcare professionals.

Key concepts in symptom self-management literature include maintaining, changing, and/or creating new behaviors (Lorig & Holman, 2003) or use personal care activities (Kruelen & Braden, 2004) to manage overall health or the effects of illness. Symptom self-management can be affected by the number of symptoms as well as presence of depressive symptoms (Given et al., 2010). In addition, interference in daily life is related to persons enacting self-care strategies that healthcare providers deliver to them (Given et al., 2010). Skills necessary to self-manage include problem solving, decision-making, resource utilization, and taking action (Lorig et al., 2001). Symptom self-management is based on perceived problems of the individual (Lorig et al., 2001), and thus what one person perceives as a problematic or bothersome symptom may not be perceived the same by another person.

Factors in the model such as person, environment, and health/illness may influence the symptom self-management process (Dodd et al., 2001; Kruelen & Braden, 2004). A person’s prior experience with a symptom may impact what strategies they use to self-manage that symptom. Environmental situations, such as availability of recourses can make a difference in whether a person seeks healthcare for a symptom or utilizes other resources such as family, friends, Internet, etc. Health/illness variables such as comorbidity can influence the ability to self-manage such as a person who was not fully functional prior to a MTBI may not have the capacity to initiate symptom management strategies.

For this study, person variables, such as age and employment status will be collected as they may impact person's ability or eagerness to self-manage symptoms. For example, those who need to return to work may have more incentive to self-manage symptoms in order to meet that need. Environment variables such as living arrangements will be considered, to identify if persons living alone or with other people confound their ability or need to self-manage symptoms. Health/illness variables such as severity of injury (to insure all cases are mild TBI), additional injuries, and comorbid conditions will be collected to determine if the presence of other injuries or illness influence person's ability to self-manage.

Symptom self-management may influence the symptom experience by a person having to re-evaluate a symptom after attempting to self-manage, or it may impact an outcome such as symptom status. Each construct of symptom experience, symptom management strategies, and outcomes can continue to impact each other until the symptoms or potential for symptoms are resolved (Dodd et al., 2001). If symptoms do not resolve, persons may choose to continue attempts at self-management, may seek healthcare, or may elect to no longer try to relieve the symptom. Since symptom load can be linked to ability to return to work or school, the success or failure of symptom self-management strategies can impact person's functional status.

Persons with MTBI often experience symptoms soon after their injury. Since persons with mild TBI are often not followed by healthcare providers for their injury, they are left to self-manage their symptoms. It is unknown how well persons with MTBI are doing at symptom self-management. This study will explore the strategies used to self-manage as well as the self-reported effectiveness of those strategies.

Outcomes

Outcomes are the third construct within the model, and can include functional status, symptom status (resolution or continuation of symptoms) emotional status, mortality and morbidity, costs, and quality of life. Outcomes, as depicted by the bi-directional arrows can affect the symptom experience and symptom management. For example, if a symptom is not resolved or relieved, persons may need to re-evaluate the symptom or may want to attempt different symptom management strategies. Once a symptom has resolved, then the evaluation and management of it are no longer pertinent.

This study will include one of the components of outcomes, which is the symptom status. Symptom status is the resolution or continuation of the reported symptom. Symptom status will be evaluated by measuring self-reported symptom relief.   Symptoms are known to naturally decrease over time following MTBI; therefore, this study will be assessing symptoms early in the course of injury (within three months), then asking what symptom self-management techniques were used, and how effective they felt the self-management techniques were at symptom reduction. Information obtained from this study will then be used to design a symptom management toolkit to improve the education provided to persons after MTBI to assist them in symptom self-management strategies.

Person, Environment, and Health/Illness Concepts

As depicted in the model (Figure 1), the concepts of person, environment, and health/illness may impact a single construct, or the symptom management process as a whole.

The Person variable refers to demographic, psychological, sociological, and physiological ways that an individual views and responds to the symptom (Dodd et al., 2001). Developmental stage is one example of a person variable that can affect the symptom experience (such as the way a person evaluates a symptom), symptom management strategies (such as a child having limited ability to self-manage symptoms), and outcomes (such as the elderly being more likely to experience mortality from brain injury).

The Health/Illness variable includes risk factors, injuries, or disabilities unique to the individual (Dodd et al., 2001). Examples of health/illness variables would be severity of injury for a brain injured person, other associated injuries experienced during a trauma, such as fractures, or pre-existing disabilities or illness, such as a person requiring a walker to ambulate. Previous studies have shown that increased age affects persons likelihood to seek medical treatment (Setnik & Bazarian, 2007), and decreases their functional recovery (Jacobs et al., 2010; Livingston et al., 2005; Mosenthal et al., 2004; Senathi-Raja, Ponsford, & Schonberger, 2010). Persons who sustain additional injuries with their MTBI are less likely to return to work and are more likely to report worse physical functioning (Iverson, 2006; Stulemeijer et al., 2006, 2008).

Environment variables are the conditions or context that the symptoms occur, and can include the physical, social, or cultural environments (Dodd et al., 2001). Examples of the physical environment are the home, work, or hospital setting. The social environment can include social support or relationships that may influence the symptom management process either positively or negatively. The cultural environment refers to “beliefs, values, and practices that are unique to one’s identified ethnic, racial, or religious group” (Dodd et al., 2001). For this study, an environmental variable that may confound the results is the living arrangement. Persons who live alone may have to be more resourceful at self-management, or they may have limitations in their resources for guidance of self-care. It is unknown what impact the living arrangement will have on symptom self-management for MTBI.

Linkages Within the Model

The three constructs within the model are linked with two-way arrows indicating that each can impact one another. Each of the main concepts of symptom experience, symptom management strategies, and outcomes can influence each other during the symptom management process. All concepts can be influenced by the variables of person, health/illness, and environment. To illustrate this relationship with the TBI population, consider the person with dizziness, using rest as the management strategy, who is experiencing the outcome of inability to fully care for him or herself, lost productivity at work, and reduced ability to perform complex cognitive tasks. Increasing our understanding of the symptom management process as a whole and the interaction among the concepts is important for developing evidence based symptom management tools that can be used to assist others with MTBI to better self-manage their symptoms.

Usefulness of the Model with Mild TBI Population

Use of the UCSF Symptom Management Model for the TBI population can facilitate better understanding of the symptom process by incorporating information from each of the constructs while considering the effects of the person, health/illness, and environmental variables. Addressing symptoms and their management using the model will better prepare clinicians and researchers to address the multiple constructs and concepts to create more holistic plans of care or research proposals. The UCSF Symptom Management Model was used as a framework to guide this proposal and develop the focused framework for this study shown in Figure 2.

Traumatic brain injury is associated with a variety of symptoms that can have devastating effects on outcomes for many individuals. The UCSF Symptom Management Model provides a

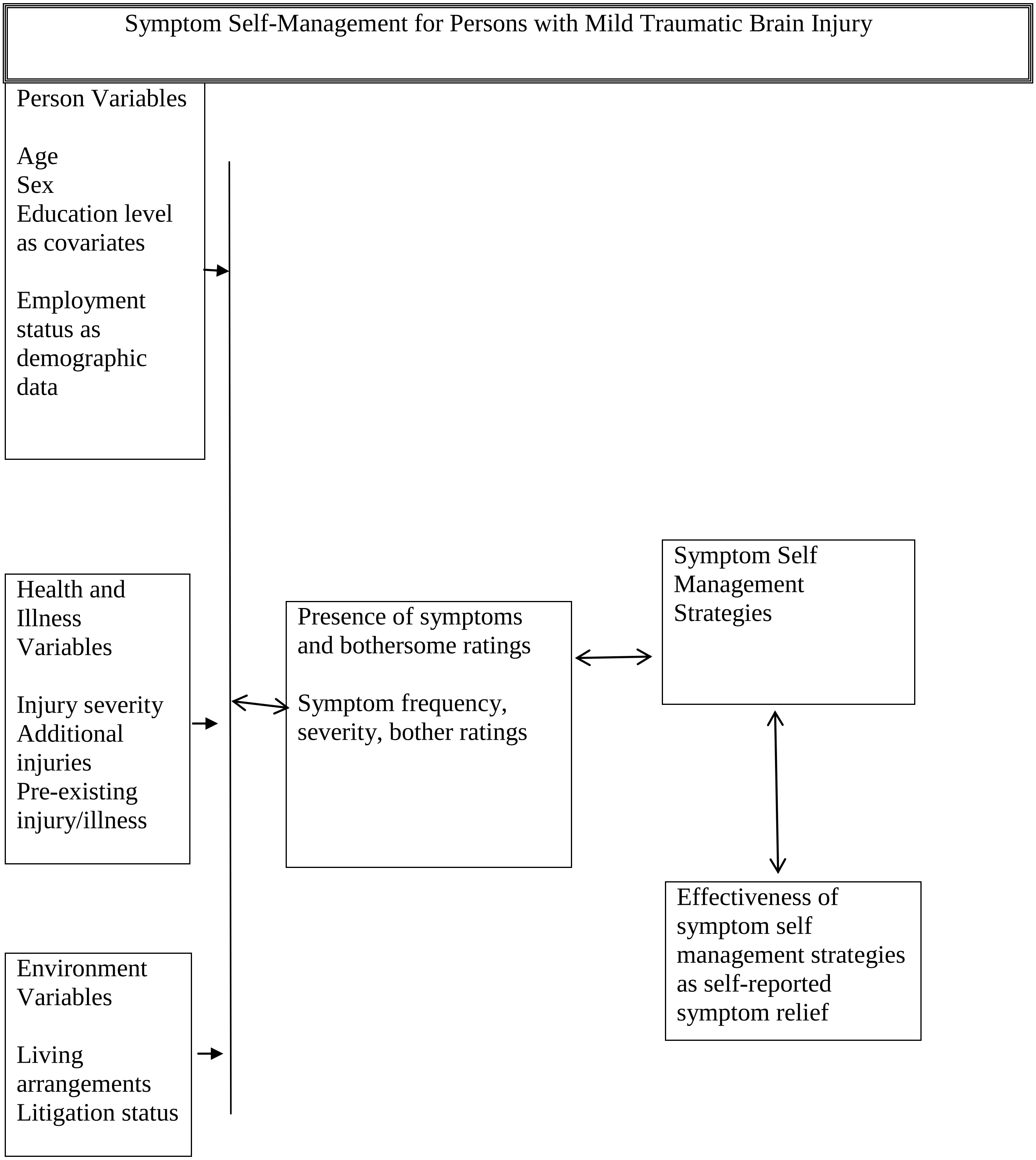

Figure 2. Schematic presentation of concepts for this study.

framework that can be used to guide research and practice for TBI populations. Measures of the model constructs must be congruent with the model and be well matched with the research questions. Use of the model with increased frequency among those researching TBI could promote more uniform approaches to testing symptom management interventions and facilitate building of research programs upon a single framework to promote consistency.

CHAPTER 3

LITERATURE REVIEW

This chapter will present a thorough review of the traumatic brain injury literature published to date that is related to symptoms, symptom self-management, and symptom relief. This review will provide the background for understanding the magnitude of the problem of symptom self-management for the MTBI population. The UCSF Symptom Management Model (Dodd et al., 2001) will be used to guide this literature review. The components of the UCSF Symptom Management Model of symptom experience, symptom self-management strategies, outcomes of symptom relief, and variables (health/illness, environment, person) affecting the process will serve as headings for this literature review. Refer to Figure 1 for the UCSF Symptom Management Model. Descriptive studies as well as longitudinal and randomized clinical trials (RCT's) including interventions will be included. The selection of studies/literature was based on scientific merit, congruence with the UCSF Symptom Management Model and similarity to the research questions.

The review of literature will include an overview of symptoms that are common for the MTBI population to experience after their injury. Post-TBI symptoms can be classified as physical, affective, and cognitive in nature. In addition to the presence of symptoms, the bothersome nature of symptoms will be addressed. Although bothersome has not been specifically described with TBI symptoms, bothersome is described in other literature, and those studies will be summarized with relation to how they can be applied to the TBI population. Symptom self-management literature will be reviewed and gaps in the self-management of MTBI symptoms will be described. Finally, in this review, the variables of person, environment, and health/illness will be addressed to describe their impact on the symptom self-management for persons with MTBI.

There are several definitions for MTBI (Carroll et al., 2004; Servadei, Teasdale, & Merry, 2001), which can complicate the MTBI literature as authors often do not specify the definitions used, and there is not one generally accepted definition. This study uses the definition set by the World Health Organization (Carroll et al., 2004), which defines MTBI as a Glasgow Coma Scale (GCS) score of 13-15 and one or more of the following: confusion or disorientation, loss of consciousness for 30 minutes or less, post traumatic amnesia for less than 24 hours, and/or other transient neurological abnormalities. Manuscripts included in this review of literature will be congruent with the above definition of MTBI in order to make sure that the literature is largely from the mild TBI literature as opposed studies that include all severities of TBI.

Symptoms

Among the most commonly reported symptoms following mild TBI are headache, dizziness, anxiety, memory difficulties, depression, and fatigue (Alexander, 1995; de Kruijk et al., 2001; Dikemen Mahamer, & Temkin, 2001; Kashluba et al., 2004; Lannsjo, 2009; Lundin et al.,2006; Ponsford et al., 2011; Rapoport et al., 2002; Yang et al., 2007) (see Table 1). Overall, these symptoms tend to occur soon after injury and resolve within 3 months post injury (Alexander, 1995; Bazarian & Atabaki, 2001; Dikmen, Machamer, & Temkin, 2001; Lannsjo et al., 2009; Ponsford et al., 2011; Lundin et al., 2006; Yang et al., 2007). Although this symptom trajectory may seem short compared to symptoms with chronic illness, presence of the symptoms has been associated with decreased ability to return to pre-injury activities (Lundin et al., 2006; Yang et al., 2007). This can be problematic for several reasons: (1) persons are usually not followed up by healthcare providers (Bazarian, 2005; Faul et al., 2010), so aside from ED instructions, no further professional help is provided for symptom management (Blostein & Jones 2003); (2) persons are expected to return to work or school, making symptom self-management important; (3) persons who attempt to return to work or school may fail due to symptom load and lack of symptom relief (Yang et al., 2007), and without healthcare follow up may struggle to manage on their own.

Table 1

Summary of MTBI Studies of Symptoms

Author	Study	Most Common Symptoms
Kashluba et al., 2004	Within 3 months post injury	Fatigue, headache, dizziness, irritability, memory difficulties
Kraus 2005	Symptoms 6 months post injury	Fatigue, weakness, memory difficulties, headache, dizziness
Sheedy 2006	1 month post injury	Fatigue, frustration, memory/concentration, headache, irritability
Lundin, DeBoussard, Edman, & Borg, 2006	3 months post injury	Poor memory, sleep disturbance, fatigue, headache, dizziness
Yang et al., 2007	Within 2 months post injury	Headache, dizziness, anxiety, attention deficit, fatigue
Laansjo et al., 2009	3 months post injury	Fatigue, headache, dizziness, memory difficulty, irritability
Ponsford, Cameron, & Fitzgerald, 2011	One week and three months post injury	Headache, fatigue, dizziness, foggy, concentration and memory

Several studies have aimed to show the trajectory of the symptom experience from presence of symptoms to resolution (Laansjo et al., 2009; Ponsford et al., 2011; Yang et al., 2007). By understanding the trajectory, or expected time of symptom course, healthcare providers can inform persons with MTBI what they might expect as far as common symptoms and how long they might last. Bazarian and Atabaki, (2001) performed a prospective observational study including 69 persons with MTBI presenting to the emergency department (ED) and report that 58% of those subjects complained of symptoms related to their injury at 1 month post-injury. Longitudinal studies better describe the trajectory of symptom resolution following MTBI. Lundin et al. (2006) followed their population of 122 persons with MTBI for 1, 7, 14 days and 3 months post injury. They found symptom complaints decreased from 86% of persons reporting one or more symptom on day one to 48% by 3 months post injury without any specific intervention. In addition, they found that symptoms present at 3 months were similar to those presenting early on, suggesting no certain set of symptoms resolve more quickly or slowly than others. Yang and colleagues (2007) report that symptoms decreased from 85% of patients reporting at least one symptom at 1 week, 55% at 2 weeks, 23% at 4 weeks, and 13% at 8 weeks post injury. Lannsjo et al. (2009) examined a large cohort (*N* = 2602) of persons with MTBI asking about symptoms that remained at 3 months since injury. Fifty-six percent of this group reported no remaining symptoms at 3 months, while 10% report one symptom, 7 % two symptoms, and 24% report three or more symptoms. Ponsford et al. (2011) compared long-term outcomes from a group of persons with MTBI compared to trauma controls. This study included 123 persons with MTBI and 100 trauma controls without TBI was to prospectively evaluate the trajectory of post-TBI symptoms as well as the cognitive, psychological, and functional outcomes of the groups. Results indicate that symptoms for both groups decreased from 1 week to 3 months with 30.7% of TBI patients reporting symptoms at 1 week that had resolved at 3 months. A small percentage (17%) had increased symptoms at 3 months compared to 1 week. Symptoms reported at 3 months were similar to those also reported at 1 month, with the exception of an increase in irritability and decrease in dizziness/nausea. These studies support that symptoms decrease over time, usually within the first weeks to months post injury; however, for some, symptoms persist beyond 3 months. Incidence of symptoms persisting beyond 3 months post injury are estimated to be around 35% (Faux et al., 2011)

Symptoms experienced after TBI can be categorized as physical, affective, and cognitive. The following sections will summarize what is known regarding symptoms in each category for persons with MTBI. Knowledge about what is currently known about symptoms post-TBI will provide the background for this study, and this research will expand on current information, to include new knowledge of bothersome symptoms and symptom self-management.

Physical Symptoms

Physical symptom complaints may include headache, dizziness, neck pain, sleep-wake disturbances, and visual difficulties (Alexander, 1995; Kraus, Ayers, & Shen, 2005; Lannsjo et al., 2009; Ponsford et al., 2011). Physical complaints can be due to the mechanism of injury, such as the force of an acceleration/deceleration motor vehicle crash, or from the neural sheering, or combination of both (Alexander, 1995).

Headache has been reported as high as 90% soon after injury and present in up to 44% of patients with mild injury at 6 months (Nicholson & Martelli, 2004). Kraus et al. (2005) reported headache as a symptom complaint in 36% of their study with mild TBI subjects. In a study of early symptom complaints following mild TBI, Lundin et al. (2006) found that although symptoms did decrease from 1-3 months following injury, sleep disturbance and fatigue were among the most common symptoms reported at all time frames from injury through 3 months. In addition, they found that early symptom complaints correlated with later symptom complaints, and that symptoms and disability scores were correlated ($r = .60$, $p < .001$). Yang et al. (2007)

performed a prospective cohort controlled study of 115 patients and measured symptom status at 1, 2, 4, and 8 weeks post MTBI and found that physical symptoms, such as headache and dizziness were prominent early (weeks 1 and 2), while affective symptoms such as depression and irritability were more common later (4 and 8 weeks). Sports injuries (Benson et al., 2011) and military blast injuries (Belanger, Curtiss, Demery, Lebowitz, Vanderploeg, 2011; Bryan & Hernandez, 2011) report similar findings to the general MTBI population with physical symptoms such as headache and fatigue among the most commonly reported symptom complaints.

Physical symptoms such as problems with movement and gait, gross motor, and fine motor movements are more prevalent with severe TBI compared to those with milder injury. Persons with mild injuries do not typically have movement disorders noticeable to themselves or their significant others, however Heitger and colleagues (2006) did identify impairment in oculomotor and upper limb visuomotor measures up to one year following mild TBI. The authors of this study suggest that methods used to assess physical symptoms and limitations following even mild injury may not be sensitive enough to detect subtle symptoms. MTBI assessment and questionnaires may need further refinement in order to detect subtle changes as problems with movement and balance could lead to further injury (second concussion).

Physical symptoms for this study will be assessed using the Problem Checklist (Kay), and will include self-report of symptoms such as headache, dizziness, vision, hearing, and speech difficulties, problems with balance and coordination, and fatigue. Symptoms will be assessed in terms of how often, how severe, and how bothersome they are. For persons who complain of headache and fatigue as symptoms, the symptom self-management questionnaire will be used to identify what strategies are used to attempt to reduce those symptoms.

Affective Symptoms

Affective symptoms such as depression, anxiety, and stress can be found within the TBI populations including those with mild injuries (Lannsjo et al., 2009; Ponsford et al., 2011; Rappaport, Levin, McCauley, & Song, 2002). These symptoms may not be as commonly known to the overall population and therefore information about the possibility of experiencing this type of symptom should be in the management of persons with MTBI. Depression post-TBI has been described as a combination of neuro-anatomic, neurochemical, and psychosocial factors (Rosenthal, Christensen, & Ross, 1998). Rappaport et al. (2002) report that approximately one third of their subjects including all severity groups reported anxiety, depression and irritability problems. Bay et al. (2007) report up to 40% of their outpatient sample of mild to moderate severity TBI to have depressive symptoms. Depression has been shown to be associated with post-injury stress and sense of belonging (Bay et al., 2002) as well as with pre injury psychosocial factors such as employment, living situations, and previous psychological treatment (Dikmen et al., 2004). Bay, Kirsch, and Gillespie (2004) found that pre and post injury stress was able to explain a significant amount of post-injury depression in a population of mild to moderate post injury patients. Post injury depression has been associated with reporting of more TBI symptoms and also more severe symptoms when compared to person with MTBI who do not have depressive symptoms (Lange, Iverson, & Rose 2011). Bryant et al. (2010) conducted a prospective cohort study of 1084 trauma patients to identify psychiatric sequealla of TBI. This study revealed a 7.1% prevalence of new depressive episodes following MTBI, although a non-TBI trauma control group also had a high prevalence of depression. This result indicates that depression can be present following both trauma and trauma with MTBI, so although not unique to the MTBI population, depression is prevalent and should be assessed for following MTBI.

Emotional symptoms such as irritability, mood changes, anxiety, and stress are common among all severity of injury groups post-TBI. Kashluba et al. (2004) report irritability (56%) and anxiety (51%) among the top 5 symptom complaints in their mild TBI population. Bay and Bergman (2006) found a significant relationship between symptom frequency and tension/anxiety, anger/hostility, and perceived stress among a community dwelling sample of mild to moderate post-TBI patients. Ponsford's longitudinal study (2011) of persons with MTBI and trauma controls identified emotional symptom complaints in 31% of those with MTBI compared to 22.5% of trauma controls at one week, and a similar trend at three months of 18% for MTBI and 12.5% for trauma controls. These findings suggest that the emotional symptoms are prevalent after MTBI, however, are not unique to this injury. Management of emotional symptoms is important regardless of whether they are a direct result of the MTBI, were pre-existing, or are new but from other causes (trauma) so that the symptom burden can be decreased and to assist with person's ability to return to pre-injury roles.

Stress, including posttraumatic stress disorder (PTSD) has been associated with persons with mild, moderate, and severe TBI. Factors that may increase the likelihood of experiencing PTSD include substance abuse, co-morbid depression, anxiety disorders, or stress of litigation (Feinstein & Rapoport, 2000) and having a milder TBI (Bryant, 2010). Bay and Donders (2008) report that for their sample of 84 persons with mild to moderate TBI, perceived stress explained about 55% of the variance for depressive symptoms. In addition, this study reports that perceived stress, subjective report of pain, and litigation explain 70% of the variance in the regression model for report of depressive symptoms. Several studies support the presence of PTSD correlating with higher symptom complaints (Belanger et al, 2011; Bryan & Hernandez, 2011; Halbauer et al., 2009). Post-traumatic stress disorder is of particular interest to the military research on MTBI. Post-traumatic stress disorder is common among both veterans that sustain a MTBI and those that do not (Carlson et al., 2011). Rates of PTSD for persons with MTBI range from 12-39%, compared to soldiers returning from duty without MTBI having approximately an 11% prevalence for PTSD (Halbauer et al., 2009). In summary, affective symptoms are common following MTBI. Affective symptoms such as depression and post-traumatic stress can affect symptom reporting, and thus should be measured and considered in MTBI research. Management of affective symptoms is important for persons to be able to return to pre-injury roles. For this study, affective symptoms will be evaluated using the Problem Checklist, assessing for frequency, severity, and bothersome nature of the symptoms. If present, anxiety and depression will be evaluated in terms of what symptom self-management strategies are used to attempt to reduce the symptoms.

Cognitive Symptoms

Cognitive symptoms (Belanger et al., 2011; Lannsjo et al., 2009; Ponsford et al., 2011) common after TBI include difficulty with memory (Kraus et al., 2005), attention, concentration (Nolin & Heroux, 2006), problem solving (Rath et al., 2004), and executive functioning (Serino et al., 2007). Problems with cognitive impairments are most prevalent among those with more severe injuries (Rappaport et al., 2002); however, the same symptoms can be present in those with milder injuries, often in a more subtle and less easily detected form.

Reduction in size or volume of the hippocampus and lateral ventricle enlargement are associated with impaired memory and executive dysfunction. The diffuse axonal injury caused by blunt force injury seems to be responsible for often subtle and frequently not tested deficits such as problems with attention, non-verbal fluency, and verbal memory. Mathias, Beall, and Bigler (2004) studied a group of 40 patients with mild TBI and found that during the first month after injury, they had having more difficulty in attention and memory than the controls. McHugh et al. (2006) studied 26 patients with mild TBI and compared them to matched controls, finding that both symptomatic and asymptomatic MTBI patients performed worse on cognitive testing than the control subjects at three months post injury. Sheedy et al. (2009) studied 100 persons with MTBI and compared to control groups, the MTBI population experienced more problems with memory ($p < .001$), processing speed ($p < .01$), and performed worse on a digit substitution test ($p < .001$) at 3 months of time since injury. Benedictus et al. (2010) found that when persons with cognitive difficulties across all severities of injury had a tenfold increase in difficulties with returning to work than those without cognitive problems. These studies help to emphasize the need for clinicians to be aware of the often subtle but frequently present cognitive difficulties that persons with relatively mild brain injury can experience, and the effect these difficulties can have on person's returning to pre-injury functioning.

This study will explore the self-reported cognitive symptoms experienced such as memory, concentration, planning, and goal setting. These symptoms will be evaluated in terms of how often, how severe, and how bothersome they are for persons with MTBI. What persons do to manage memory difficulties will be evaluated using the symptom self-management questionnaire described in chapter four.

For this study, the literature was reviewed for the most commonly reported symptoms following MTBI in order to be able to measure symptom self-management on those symptoms as opposed to all symptoms. Symptoms common to MTBI will be assessed in this study using The Problem Checklist, which includes physical, affective, and cognitive symptoms, and this measure will be described with further detail in the methods section. The Problem Checklist asks if 43 symptoms common to MTBI are experienced (frequency), how severe, and how bothersome the symptoms are felt to be. This is a self-reported questionnaire. The most commonly reported symptoms from the MTBI population are fatigue, headache, dizziness, depression, anxiety, and memory difficulties, and thus were chosen to assess what persons with MTBI do to manage those symptoms.

Bothersome Symptoms

Bothersome is one way in which persons evaluate symptoms and refers to a symptom being disruptive to daily functioning (Kay et al., 1995; O'Leary, 2005). How bothersome symptoms are to persons with MTBI has not been described. Bothersome, or disruptive to daily life, has been described in other populations, which will be summarized below.

Bothersome has been used as a component of symptom evaluation in the urinary tract disease population such as those with prostate problems for men, and urinary stress in continence for women. O'Leary (2005) describes the use of a "bother score" to evaluate symptoms for benign prostatic hyperplasia. This article describes the importance of bother as playing a central role in decision making for persons to seek treatment of their symptoms. A multinational survey of aging male (MSAM-7) study reports that 90% of the respondents had lower urinary tract symptoms, while only 19% sought medical care, and only 11% were medically treated (Rosen et al., 2003). Results of O'Leary's study support the importance of assessing bothersome symptoms with the findings that the (1) most common symptoms are not necessarily the most bothersome, (2) symptoms that are the most disruptive to daily life are those rated as most bothersome, and (3) persons reported significant differences in the degree that they are bothered by symptoms.

Fultz et al. (2003) performed a study to better understand the bothersomeness of stress incontinence for women. This was a national survey of women; with over 2000 women who responded reporting stress incontinence. Respondents who reported stress incontinence were surveyed a second time to ask the bothersome nature of their symptoms, with 842 persons returning this survey. One fourth of those respondents reported moderate to severe bothersome symptoms of stress incontinence. Factors associated with increased reports of bothersome symptoms were found to be no college education, self-reported depression, presence of co-morbid conditions, and increased duration and frequency of symptoms.

Bothersome was used to evaluate symptoms for women with lower urinary tract symptoms one year after first delivery in a study by Van Brummen et al. (2006). This prospective cohort study included 344 women who answered questionnaires during and after their first pregnancy. Twenty four percent of those women reported having moderate or greatly bothersome symptoms at 36 weeks gestation. Prevalence of bothersome symptoms decreased significantly after childbirth ($p < 0.001$). Predictive factors for bothersome stress incontinence symptoms were increased age and presence of those symptoms at 12 weeks gestation.

Dunn and Croft (2005) note that bothersome was used to describe symptoms for genitourinary diseases, and applied that knowledge to use of “bothersomeness” to classify low back pain patients in primary care. This study assessed 447 patients with back pain at baseline and 6 months and found that at baseline bothersome correlated with pain and disability ($p < 0.001$).

Bothersome as defined for this study as being disruptive to daily functioning may have overlapping meaning with other terms used to describe symptoms, such as interference or impact. Interference is described in the cancer literature as the degree that symptoms interfere with major aspects of daily life (Armstrong et al., 2009, 2011; Cleeland et al., 2011; Jeon et al., 2008; Rosenthal et al., 2007). This definition is very similar to that used for bothersome in this study and likely they represent the same concept. The idea in the cancer literature referenced above is that symptom severity and interference with daily life together represent symptom distress. Impact also may have a similar meaning as bothersome. Impact, as used in a study by Coyne et al. (2004), was defined for this study of persons with urinary urgency and frequency as "interferes with daily life." Based on these few examples, bothersome being defined as disruptive to daily functioning seems similar in definition to impact and interference with daily activities. Construct analysis would be helpful to determine if these terms can be used interchangeably based on their conceptual definitions.

The bothersome nature of symptoms associated with TBI has not been described. Conceptually and operationally there are many ways to describe post-TBI symptoms, with frequency and duration being the most well described aspects of the symptom experience. Beyond what symptoms are present and how long they might last, the bothersome nature of symptoms should be explored to better understand whether certain symptoms are more disruptive to daily life than others. If, for example, dizziness is reported by all who experience it to be "very bothersome" then it may be beneficial for healthcare providers to equip persons with TBI with information or tools that will be useful to help alleviate dizziness. If symptoms found to be most bothersome are also those found to have high interference ratings, perhaps symptom management for those cancer symptoms could be translated for use with the MTBI population. In addition, at an individual level, practitioners may use bothersome to follow up with post-TBI symptoms by asking persons what symptoms they have and how bothersome are they. This may provide a more targeted direction for symptom management strategies to be focused on those symptoms that are most disruptive to daily life, in order to assist them to being able to return to their pre-injury level of functioning. How bothersome symptoms are may also be affecting persons desire or motivation to self-manage their symptoms or seek professional help to relieve the bothersome symptoms. This was the case with the previously described studies of men with prostate disease and urinary tract symptoms, where they only sought treatment when symptoms were most bothersome.

This study will seek to identify if the MTBI population rates certain symptoms as more bothersome than others in order to better understand the symptom experience for this population. In addition to having a better understanding of what symptoms are present, and bothersome, this study will explore what persons with MTBI do to manage common symptoms after MTBI. This study will ask for self-reported use of symptom management strategies and their effectiveness of the symptoms of fatigue, headache, dizziness, depression, anxiety, and memory. It would be too cumbersome for participants to complete the self-management questionnaires on all symptoms experienced, and therefore this study focuses on the most commonly reported. Future studies may be necessary to address other MTBI symptom self-management strategies.

Symptom Self-Management

Self-care management of symptoms for the traumatic brain injury (TBI) population has yet to be described or explored. It is known that even those with mild TBI experience symptoms associated with their injury, especially in the first days, weeks, and months after their injury. Persons with mild TBI are more likely to be discharged from emergency departments without follow up (Bazarian et al., 2005; Blostein & Jones, 2003), compared to those with more severe injuries who require rehabilitation. Because this population is often treated and released from the ED or do not seek medical treatment (Bazarian et al., 2005), they are likely self-managing symptoms associated with their injury on their own. Since symptoms can last from days, to weeks or months, persons with MTBI need to manage those symptoms in order to return to their pre-injury roles such as return to work or school. Although this trajectory of symptoms may seem brief compared to chronic illness, persons with MTBI are usually expected to return to their roles very soon after injury, which can be difficult if they are experiencing symptoms. Imagine, for example, trying to return to work with the symptom of dizziness, it would be difficult.

Discharge instructions for those with mild TBI may include a statement that these symptoms exist; however, the booklet from the CDC does not include information regarding what persons should do to manage the symptoms (www.cdc.gov). Pamphlets, brochures, or symptom management toolkits would likely be helpful to this population if they included information that would be useful for self-care management of the TBI symptoms. It is necessary to understand what persons are doing on their own to manage their symptoms as well as how effective these strategies are in order to develop useful patient education tools for symptom management.

While symptom self-management specific for MTBI has not been described, symptom self-management is well described in chronic illness literature. Studies from the chronic illness literature will be examined to provide the background for the importance of understanding symptom self-management for the MTBI population.

Self-management refers to persons being responsible for their day-to-day care, or management of symptoms, over the length of their illness (Lorig & Holman, 2003). In addition, Lorig and Holman describe self-management as not an alternative to medical care; rather, persons become active partners with healthcare providers. Barlow and colleagues (2002) add to this definition by saying that effective self-management includes the ability to monitor one’s condition and uses a continuous process of self-regulation to maintain a satisfactory quality of life. Lorig and Holman (2003) describe six self-management skills that persons may use to self-manage their symptoms or illness. These skills are problem solving, decision-making, resource utilization, forming a partnership with healthcare providers, taking action, and self-tailoring.

The MTBI population differs from the chronic illness or cancer populations that were the target of discussion in Lorig and Barlow's work to define self-management and describe the skills persons need to self-manage. For most, MTBI is a relatively brief (weeks to months) time to experience symptoms (Laansjo et al., 2009; Lundin et al., 2006; Ponsford et al., 2011). Chronic illness or cancer patients on the other hand have much longer to develop and refine their symptom management strategies. In addition, the cancer and chronic illness populations have more contact with the healthcare providers. As previously stated, those with mild TBI are not typically being seen by healthcare providers for follow up, therefore any information that they need to prepare themselves for optimal symptom self-management may need to be given to them at their initial ED visit (Bazarian et al., 2005), or be available as public knowledge that can be easily accessed. Studies that have shown symptom self-management to be effective can be found in the cancer and chronic illness literature and will be described below. Keeping in mind that the populations differ from the MTBI population in trajectory of recovery and longevity of symptoms, as well as healthcare partnering, some of what is already known from these populations may prove useful to the persons with MTBI.

Newman et al. (2004) provide an excellent summary report on a large number of self-management studies in the diabetes, arthritis, and asthma populations. Their review of studies that would be most similar to persons with MTBI was the symptom management studies for asthma and arthritis. They found that overall there was a 40% improvement in self-reported symptoms with use of a symptom management intervention for these two populations. Several studies, outlined in the Newman article, in diabetes, arthritis, and asthma measured changes in behavior toward positive self-management, with positive results in all, indication that behavior change can be an effective intervention toward symptom self-management. Behavior changes were things like diet, exercise, and self-monitoring, all of which may also be useful in the MTBI symptom self-management process.

Warsi and colleagues (2004) performed a systematic review of 71 trials of self-management education programs for chronic disease. This review found that with self-management education, diabetic patients had reduced glycosylated hemoglobin levels and improved blood pressure, and asthmatic patients experienced fewer attacks. Interestingly, the pooled group of arthritis studies did not have a statistically significant improvement in symptoms. The authors speculated that there is heterogeneity between studies, including osteoarthritis along with rheumatoid arthritis, as well as the fact that symptoms, such as pain might not fully respond to changes in self-management.

Lorig and colleagues (1999) conducted a randomized control trial ($N = 952$) identifying if a self-management program could improve health status and reduce hospitalization. The self-management program included sessions on symptom management techniques. This study compared 6-month outcomes between treatment and control groups with a secondary analysis determining if the intervention had different outcomes between disease categories. Participants in the intervention category demonstrated significant improvement in increased practice of symptom management ($p < 0.01$). Lorig et al. (2001) conducted an additional study of 489 persons with chronic illness who participated in a self-management program consisting of a 7-week, small group intervention aimed at problem solving, decision making, and confidence building as part of self-management. This study was after the results from the randomized control trial showed positive results, and the goal of this study was then to conduct a study in a "real world" setting. By this the authors state that they recruited participants to engage in the intervention rather than as study participants, and the programs were not given in controlled study environments, thus simulating "real world" healthcare settings. Participation in the program resulted in improvement in health behaviors including symptom management ($p < 0.03$).

Chou, Holzemer, Portillo, and Slaughter (2004) conducted a study with persons with HIV/AIDS to determine their self-management strategies for symptom management. This study included 359 participants, who reported using 776 self-management strategies and 526 sources of information for developing those strategies. Management strategies were summarized by the researchers as medications (23.45%), self-comforting (15.21%), complementary treatments (14.69%), daily thoughts and activities (12.89%), diet changing (10.95%), help seeking (9.28%), spiritual care (6.83%), and exercise (6.7%). Information sources were categorized to self, healthcare, provider, personal network, and community.

Given et al. (2010) examined nurse-directed self-management interventions for the cancer population. This study of 333 patients undergoing an 8-week symptom self-management program was to evaluate the nurse's decision regarding delivery of the intervention, patient enactment of the strategies, and success of the intervention. Nurses directed patients to self-manage more symptoms when they were more severe at onset, had a longer duration, and caused greater interference. Patients tried more symptom management strategies when they rated the symptom as higher on the interference scale and those that tried five or more symptom strategies, compared to less than 5, reported a better response to self-management. These findings are supportive of the need to assess the number of symptoms, the severity, and the bothersome nature of symptoms for this MTBI study. The key difference between this study and translation to a MTBI population is that those with MTBI do not typically have follow up opportunities with a nurse, so self-management strategies developed as a result of this study will need to not depend on delivery by a healthcare professional.

Symptom self-management has been useful for persons with chronic illnesses and cancer as described above. Persons with MTBI are likely self-managing their symptoms as they are not usually inpatients in a hospital or rehabilitation setting, nor do they have return contact with the ED physicians, if they did seek care there (Bazarian et al., 2005). Discharge instructions, such as the CDC Toolkit (CDC.gov) provide a list of symptoms that may be experienced, however, do not tell persons specifically how to manage those symptoms, but instead provides general recommendations such as gradual return to activities. In addition to the somewhat vague recommendations for symptom management, it is unknown how many providers are aware of the toolkit or use it with their MTBI patient populations. Improved discharge instructions that provide evidence based self-management strategies for post-TBI symptoms are needed.

This study will utilize a measurement tool to identify what persons with MTBI are doing to manage their symptoms on their own, which will assist in future discharge instruction development. Knowing what methods of self-management are regarded as effective by persons with MTBI and what are not helpful will assist in providing future symptom management recommendations. This study will provide groundwork for future studies to create individualized symptom management toolkits for persons with MTBI. Improved symptom self-management, even if only needed for a short period of time, may improve outcomes of persons with MTBI, allowing them to return to their pre-injury roles more quickly and more successfully.

Symptom Relief

As described in the symptoms section of this paper, the natural trajectory of symptoms for persons with MTBI is that symptoms will resolve in weeks to months for most persons. In that time frame, in fact, likely soon after the injury, persons will be expected to return to normal work, school, or home activities. Because they will be attempting to perform their normal role functions, symptom reduction in this early stage may be beneficial. What persons do on their own, such as symptom self-management for MTBI is not yet known, however, several studies have shown healthcare driven management techniques that have been helpful.

Ponsford et al. (2001) performed a study with 130 children with MTBI to measure the effect of providing an information booklet on outcomes, including symptom resolution. The booklet for the intervention included information about symptoms associated with MTBI and suggested coping strategies. The group of children that were not seen at one week post injury and were not given the information reported more symptoms at three months post-injury than those who received the intervention ($z = -2.2$, $p < 0.03$). Ponsford, in a later review article (2005), suggests that in addition to providing information early after injury, there is a need to determine if other modes of intervention would also be useful. This article suggests that because it is known that psychological factors can potentiate symptoms and slow symptom resolution, perhaps therapies aimed at cognitive behavioral intervention may be helpful, but would require rigorous efficacy studies to determine the benefits.

Wade and Colleagues (1997, 1998) performed two randomized control trials aiming to determine the efficacy of follow-up for persons with TBI. These two studies included persons admitted to hospitals or EDs, of all severity groups. The first study included 1,156 persons who were randomized to either early follow up that was approached at 7-10 days post-injury and offered information, advice, support, and further intervention, or the control group who were not contacted early after injury. Both groups were followed at 6 months post-injury. This study did not find significant differences between groups relating to symptom resolution or functional outcome. This study had a major limitation of combining all severity groups and also the 59% loss to follow-up rate.

Wade's 1998 second RCT again included all severity groups for an N of 14. For this study, all persons were contacted at 7-10 days after injury, and now, the intervention group received outpatient intervention and additional telephone support as needed. In this study, the intervention group had significantly less symptom complaints ($p = 0.02$) at 6 months than the control group.

Paniak et al. (1999) studied the effect of using a single session of information or a treatment as needed mode of education post-TBI, randomizing 111 patients to the two treatment groups. The two groups improved their symptoms in a similar fashion when evaluated 3-4 months post-injury. The authors concluded that the brief educational intervention given once soon after injury is sufficient for most persons with MTBI. Paniak et al. (2002) performed a randomized trial comparing single-session treatment to treatment as needed for persons with MTBI, this time using a 1-year follow up. This study included 105 persons recruited from two hospital ED's and randomly assigned to the two groups. This study showed a small and non-significant decrease in symptoms at 12 months in the treatment as needed group over the single session group. The authors conclude that providing information to persons with MTBI is important and likely sufficient when given soon after injury.

More recently, Bell et al. (2008) performed a randomized trial evaluating the effect of telephone counseling on symptom reduction following MTBI. This study recruited subjects with MTBI who were seeking treatment in the emergency department. Subjects were randomized to standard of care or the treatment group. Standard of care included a patient instruction handout, and any other standard outpatient treatment. The treatment group received telephone contact aimed at symptom reduction and resumption of normal activities. The phone calls were scheduled at 2 days, and 2, 4, 8, and 12 weeks post injury. Persons assigned to the treatment group had significantly improved symptom resolution compared to control group ($p = 0.016$) at the 6-month follow up.

Sayegh et al. (2010) performed a systematic review of studies describing treatment of post-concussion syndrome. Many of the trials summarized indicated no significant effect in treatment, acknowledging that the science behind post-MTBI symptom management is still not fully understood. Cognitive behavioral therapy, reassurance and education, and rehabilitation programs including psychotherapy may have a role in MTBI symptom management. Of these, education is likely to be the source that can be delivered either in the emergency department when persons seek treatment, or via other mechanisms such as websites for those who don’t seek treatment, in order for persons to self-manage their symptoms.

The above studies show that persons with MTBI do have symptom relief improved with brief interventions given soon after injury, compared to those who receive standard of care. Standard of care is likely limited to use of discharge instruction sheets from emergency departments, which may describe symptoms but not offer self-management suggestions. Improving the discharge instructions to offer symptom self-management technique suggestions may prove to be as effective and less labor intensive than the described phone calls or follow up visits.

Variables Associated with Symptom Management

Person variables as shown in the UCSF Symptom Management Model and in the study model, may include demographic, psychological, sociological, physiological, and developmental characteristics. Of the person variables, age and psychological status are best described in the literature as having an impact on the MTBI symptom management process. For this study, employment status and education level will also be collected as demographic variables.

Thornhill et al. (2000) performed a prospective cohort study of 2,692 persons with all injury severity levels to examine disability at one year post injury. They performed a separate analysis on the 362 mildly injured persons and found that age greater than forty (odds ratio 1.8, 1.11 to 2.91) was an independent predictor of outcome. In contrast, Nolin and Heroux (2006) found age and sex not to be correlated with the outcome of return to work in their study of 85 persons with MTBI. Pertaining to symptoms, Chan (2005) found that female sex ($p < 0.005$) and litigation status ($p < 0.0004$) were associated with increase symptom complaints. This study population of 92 subjects was recruited from an outpatient clinic which likely means that the population was biased to persons who actively seek treatment and those who seek treatment for support of their litigation status.

Pre-injury psychological conditions have been estimated at approximately 29% (Mooney & Speed, 2001), with a two to three fold increase in psychiatric conditions after the accident. Subjects for this study were 80 adult patients who were referred to an outpatient mild TBI clinic, and therefore were characterized to have difficult recoveries. This study found no significant relationship between prior mental health problems and post-injury psychological difficulties. They did however find that post injury psychiatric conditions were associated with poor recovery (x^2=11.38, $p = 0.007$). Kashluba, Paniak, and Casey (2008) performed a study with 110 adults with MTBI recruited from hospital ED's. Participants were evaluated by a neuropsychologist at 3 weeks and 3 months post-injury. Persons in this study that reported higher severity of symptoms also reported more prior to injury life stressors ($t = -2.13$, $p < .05$) and pre-trauma psychological difficulties ($x^2 = 6.11$, $p < .05$). The WHO Collaborating Task Force on MTBI recommends that psychological distress be a variable measured in studies of mild TBI to produce more sound methodological research (Carroll et al., 2004), and thus psychological factors will be addressed in the methods section of this research.

Environment variables can include the physical, social, and cultural environment in which persons live. Litigation status is a variable that has been studied as a contributing factor to MTBI recovery. Chan (2005) found that the symptomatic MTBI group reported being involved in litigation ($p < .0004$) more often than those who were less symptomatic. Kashluba et al. (2008) study also supports this finding (Chi^2 10.23, $p < .001$).

In addition to litigation status, the environment variable of living arrangements will be assessed in this study. It may be important to know whether persons live alone, where they will not have family support for assisting with self-management of symptoms, or if they live with others that may help or hinder the process. For example, it may be helpful for a young adult to be living at home post-MTBI, while a young adult living in a dormitory or apartment with others may not be helpful for symptom management. Living arrangements will therefore be collected as a demographic variable that may or may not prove to be a confounding variable as this variable has not yet been described in the literature for MTBI.

The health/illness variable included risk factors, health status, and disease/injury that persons have. Persons who have a prior history of head injury tend to have worse outcomes following other TBI (Thornhill et al., 2000). This study found odd ratio for those with a prior history of brain injury to be (OR 2.07, 1.33 to 3.86) for predicting poor outcome in a population of persons with MTBI. Current MTBI literature also supports a cumulative effect of multiple brain injuries. The effects of recurrent brain injury is largely a concern for the concussion in sports population, and although there is some support for negative effects of repeated concussions or MTBI, controversy over how many are too many, still exists. Guskiewicz et al., 2003 studies a large cohort of 2,905 college football players and found those with greater than three concussions had slower recovery times compared to those athletes with a single injury. The authors also looked at the timing of the repeat concussions and found that second concussions most commonly occurred within 10 days of the original concussion.

Severity of injury can affect symptoms, symptom management, and outcome for persons with brain injury (Rappaport et al., 2002; Thornhill et al., 2000). There is a severity range even within the mild TBI diagnosis, such that those with lower Glasgow Coma Scale scores may have worse outcomes than those with higher, less severe, scores. Kirsch et al. (2006) divided his 145 MTBI persons into three severity groups and found no significant differences in symptom reporting among the three groups. Studies that observe severity of injury with outcomes tend to have more significant differences within the groups. Heitger et al. (2007) examined several independent variables, including injury severity in their study of 37 persons with MTBI and found that injury severity by GCS was associated with short-term outcome as measured by SF-36, but no significant association existed beyond 3 months post injury. Kashluba et al. (2008) created subgroups within their MTBI population of persons with low severity and high severity, comparing outcomes. For this study, the higher severity group took significantly more days to return to work than the less severe MTBI persons ($t = -2.88$, $p < .01$).

In addition to severity of injury, the co-existence of additional injuries should be considered. Stulemeijer et al. (2006) studied 299 persons with MTBI, 89 of which had additional extra-cranial injuries. At six months post-injury, 44% of those with additional injuries were still seeking treatment for their injuries compared to 14% of the isolated MTBI group. In addition, those with additional extra-cranial injuries were less likely to return to work and had worse functional status than those with isolated TBI. Pre-existing injury or illness will also be collected as demographic data to describe the study population.

While this review of the literature sheds light onto what is known about symptoms and symptom management, it is known that there are many gaps in our current knowledge of symptom self-management for MTTBI. What symptoms are present following MTBI is well described. The importance of "bothersome" as a way of evaluating those symptoms is supported in the non-TBI literature, and with similar constructs in the chronic disease and cancer literature, however has not been described for the MTBI population.

What healthcare workers do to help with symptom reduction is described in the MTBI literature, while what persons do on their own (self-management) once they leave the healthcare system is unknown. Symptom self-management is well described in the cancer and chronic illness literature, with results supporting person's ability to self-manage symptoms in these populations. Persons with MTBI need to self-manage their symptoms with less influence from the healthcare community, but also typically for shorter time frames than those with chronic illness.

Since it is unknown what persons are doing to self-manage their symptoms post-MTBI, it is also unknown how effective those strategies are for symptom relief. This study will contribute the science of symptom management for MTBI by describing what symptoms are considered most bothersome, and identifying if the bothersome symptoms are the target of self-management strategies. In addition, this study will provide the initial information about what symptom management strategies persons with MTBI use as well as how effective they rate those strategies.

CHAPTER 4

DESIGN AND METHODS

This chapter will present and describe the sample and setting, experimental variables, instruments, data analysis plan, and human subject protection plan for this research. This descriptive study will assess the presence of symptoms and bothersome ranking, along with symptom self-management strategies, and effectiveness for persons within three months of their injury.

Overall this study will address the question: After mild traumatic brain injury what symptoms are present and rated as bothersome, what are persons with MTBI doing to manage those symptoms, and how effective are those symptom management strategies in terms of self-reported symptom relief. The specific research questions are as follows, for persons who are within three months of their mild traumatic brain injury:

Research Questions

1. What symptoms are present and rated as most bothersome for persons with MTBI and the comparison group? How is bothersome related with symptom frequency and severity rating adjusting for patient's age, sex, and education?
2. What symptom self-management strategies are used?
3. To what extent are bothersome symptoms related the focus of self-management strategies adjusting by patient's age, sex, and education?
4. What is the degree of effectiveness of self-management strategies on symptom relief after MTBI?

Sample and Settings

Participants were recruited for this study that were diagnosed with mild traumatic brain injury at one or more trauma centers in southwest Michigan (Bronson Hospital, Sparrow Hospital, and PAR Rehabilitation). Persons without emergency department diagnosis of MTBI were also enrolled but represented a small portion of this study. Thirty persons with MTBI were recruited. In addition, 30 persons without MTBI were recruited to serve as a comparison group. Nurses in the emergency departments and trauma units were educated about the study and identified potential participants based on diagnosis of concussion or MTBI (Glasgow Coma Scale (GCS) score of 13-15 and one or more of the following: confusion or disorientation, loss of consciousness for 30 minutes or less, post traumatic amnesia for less than 24 hours, and/or other transient neurological abnormalities) (Carroll et al., 2004). Potential participants identified by the nurses were given a flyer that described the study and offered them an opportunity to give their contact information if they were willing to speak to the Principal Investigator (PI). The PI contacted persons who submitted their contact information, and a meeting was scheduled to answer study questionnaires. Persons that were not treated in the emergency department were also recruited by advertisements allowing for self-reported MTBI to participate. They were asked questions consistent with the above MTBI definition to support the self-reported injury, such as did they lose consciousness or have concussion symptoms immediately after the accident.

The questionnaires (Appendices A, B, and C) for this study were answered by persons with MTBI in an office setting with the PI or trained data collector. This meeting was scheduled to be within three months of time since injury to capture persons who are in different stages of the symptom trajectory. At this initial meeting, written informed consent (Appendix E) was obtained by either the PI or a trained data collector. Demographic information (Appendix A) as well as questionnaires of The Problem Checklist (Appendix B), and Symptom Self-Management Questionnaire (Appendix C) were collected. Persons were thanked for their participation in the study. Data collection for this study was cross-sectional within the three month time frame in which persons with MTBI are most likely to be experiencing symptoms. Inclusion and exclusion criteria are as follows:

Inclusion:

- Diagnosis Mild TBI Glasgow Coma Scale (GCS) score of 13-15 and one or more of the following: confusion or disorientation, loss of consciousness for 30 minutes or less, post traumatic amnesia for less than 24 hours, and/or other transient neurological abnormalities (Carroll et al., 2004)
- Age 18-75
- Able to speak English
- Able to complete questionnaires

Exclusion:

- Age less than 18
- Age greater than 75
- Inability to complete questionnaires, such as incarcerated, long term hospitalization, or rehabilitation
- Psychiatric history including treated or untreated mental illness, psychosis, bipolar disorder
- Known substance abuse

- Neurologic conditions such as Parkinson’s, Multiple Sclerosis, previous stroke, HIV, spinal cord injury
- Previous traumatic brain injury

Inclusion criteria are designed to obtain an accurate sample of persons who have MTBI and are able to complete the questionnaires in the given time frame. Exclusion criteria are for advanced age and prior TBI in order to limit the confounding effect of mild cognitive impairment that can occur with age or prior brain injury. Neurologic conditions excluded may impair the participant’s ability to accurately describe symptoms and/or to participate in self-management activities. In addition, other neurologic disorders may have overlapping features with symptoms and symptom self-management strategies. Chronic substance abuse is an exclusion due to the likelihood that persons would not accurately describe their symptom experience and self-care methods while under the influence of alcohol or drugs.

Research Variables

Variables to be measured for this study include demographic data (Appendix A) on age, sex, date of injury, mechanism of injury (car accident, fall, etc.), initial Glasgow Coma Score, litigation status, prior health history (comorbidities, prior head trauma), education level, living arrangements, social support, and current medications. These demographic variables were collected to describe the sample population and also as potential covariates. Presence of self-reported symptoms along with a severity and bothersome rating of existing symptoms were evaluated using The Problem Checklist (Appendix B). Symptom management strategies for common post-TBI symptom complaints will be assessed using the Symptom Self-Management for TBI questionnaire (Appendix C). The symptom self-management questionnaire was used to evaluate the self- reported effectiveness of the strategies used.

Measures

The Problem Checklist (PCL) (Appendix B) was used to measure self-reported symptom complaints as well as the severity and bothersome nature of symptoms being experienced. The PCL (Kay et al., 1995) is an instrument within the Head Injury Family Interview (HIFI) that is used to collect symptom information from persons with mild, moderate, or severe brain injuries. The PCL is a 43-item symptom checklist that asks how often persons experience the symptom (0-4 scale; never-most days of week), how severe the symptom is (0-4; not severe-very severe), and how bothersome the symptom is (0-4; not at all bothersome-very much bothersome). If symptoms are not present then the severity and bothersome questions are not answered. Symptom choices include physical, affective, and cognitive symptoms that are commonly experienced after traumatic brain injury. Examples of physical symptoms in the questionnaire are fatigue, coordination difficulties, headache, and dizziness. Examples of affective symptoms include irritability, mood changes, anxiety, and depression. Symptoms such as difficulty concentrating, remembering, and organizing are examples of cognitive symptoms that the PCL includes. The instrument can be completed in approximately ten minutes.

Validity of the PCL was established in a multicenter study of 177 persons with head injury. Factor analysis of persons with head injury as well as responses from significant others revealed a three-factor structure, including affective, cognitive, and physical symptom factors. Cronbach’s alpha ranged from .30-.78, agreed with clinical and neuropsychological expertise and thus support the face validity. When compared to a measure of functional status, the PCL showed the expected negative correlations of higher symptom complaint ratings correlating with worse functional status ratings, supporting its construct validity. Reliability of the PCL is supported by tests of internal consistency showing Cronbach's alpha scores ranging from .65-.87 (Kay et al., 1995).

Paniak et al. (1999) compared the PCL to two other measures commonly used in TBI research to determine the sensitivity of the instruments for use with mild TBI. This study included 120 persons with MTBI and 120 healthy controls. Presence of symptoms and severity of symptoms self-reported were compared between the MTBI and control groups. Five of six categories of symptoms were reported as significantly worse for brain injured persons compared to controls ($F = 14.07$, $p < .001$). The presence of affective symptoms scores was not significantly different between groups. Paniak also calculated effect sizes for the six categories of symptoms with results ranging from .23 for the affective symptoms present score, to much higher effects from the remaining scales ranging from .80-1.71 ($p < .001$).

Responses from the PCL will be used to answer research questions regarding symptoms, symptom severity and bothersome nature of symptoms. Ratings on the bothersome scale will be used to identify which symptoms are rated as most bothersome (higher scores indicate the symptom is more bothersome).

Symptom Self-Management Scale adapted for TBI (SSMS-TBI) was used to measure what persons do to self-manage their symptoms. This scale is a revised version of the Self-Care Symptom Management for People living with HIV/AIDS questionnaire (Holzemer et al., 2001). The original scale asks what persons with HIV/AIDS to do manage the six common symptoms of anxiety, depression, diarrhea, fatigue, nausea, and neuropathy. The revised scale is directed at symptoms common for persons with mild TBI and includes headache, anxiety, depression, fatigue, memory difficulties, dizziness, (Lannsjö et al., 2009; Lundin et al., 2006; Yang, Tu, Hua, & Huang, 2007). Symptom self-management strategies for this initial study of self-management with MTBI were limited to these six due to their being frequently reported symptoms for MTBI and questionnaires for each possible symptom would be cumbersome to the participants. Study participants only answered the self-management questionnaire for the symptoms that they report, for example if they do not complain of dizziness they will not complete the dizziness self-management questionnaire. For each of the symptom complaints, participants indicated the frequency of use for activities or thoughts that they employ to manage symptoms. Frequency response choices include: not used, rarely used, monthly, weekly, daily, and several times per day. If the item is scored as "not used," then the second category of "how well does it work" was not answered. Persons who use a particular self-management strategy were asked to rate how well it works. Rating choices are that the method works never, rarely, sometimes, often, or always. See Appendix C for symptom self-management scales.

The symptom management checklists include questions regarding activities or thought, exercise, medications, complementary therapies, and substance use for symptom management strategies. In addition, they include an "other" category for people to write in any additional approaches that they have used to manage symptoms that were not listed on the questionnaire. A question regarding seeking help from healthcare providers or others was added to each of the six questionnaires.

Because this scale is a revision of the original scale used for HIV/Aids, it was pilot tested with a sample of 14 persons with MTBI and 14 healthy controls. The pilot study confirmed that methods from all areas on the questionnaire were used, such as thoughts/activities, exercise, medications, complimentary therapies, seeking healthcare, and substance use. No changes were required to the symptom management scales as a result of the pilot study prior to using the scale in this study. Persons with MTBI for the pilot study were recruited from PAR Rehabilitation

Center, Lansing, MI. This was a convenience sample of the first 14 persons identified by the Neuropsychologist as having sustained a mild TBI, who were willing to participate in the study. The Neuropsychologist confirmed the diagnosis of MTBI and ruled out malingerers.. Informed consent was obtained and staff at PAR Rehabilitation administered the study scales. This study population was chosen due to the likelihood that they were symptomatic and thus be able to respond to more items on the questionnaires than those treated and released from Emergency Departments. Healthy controls will be persons without traumatic brain injury, with no prior TBI. Both the MTBI and control groups answered demographic questionnaires, the PCL, and the SSMQ-TBI.

Results of the pilot study support the use of the SSMQ-TBI for persons with MTBI (Bergman, Fabiano, & Blostein, 2011).

The original scale (www.ucsf.edu/aidsnursing) was evaluated for a psychometric validation by Holzemer and colleagues (1999, 2001) and included validation of the original Sign and Symptom Checklists for persons with HIV disease and the Revised Sign and Symptom Check-list for HIV.

Validity and reliability of the UCSF self-management questionnaire has been established through its use in studies with the HIV/AIDS population. Prior to development of the HIV/AIDS Symptom Management Manual, self-care strategies were researched using a database of 359 participants reporting 776 symptom self-care strategies. These strategies were categorized into eight categories of (1) medications, (2) self-comforting, (3) complementary treatments, (4) daily thoughts and activities, (5) diet changing, (6) help seeking, (7) spiritual care, and (8) exercise. These categories had interrater reliability of .49-1 (Chou, Holzemer, Portillo, & Slaughter, 2004). All categories are included on the version adapted for MTBI.

Wantland and colleagues (2008) performed a randomized controlled trial testing the efficacy of the HIV/AIDS Symptom Management Manual including 775 subjects. This study compared a symptom management using standard nutrition manual (control) versus the HIV/AIDS Symptom Management Manual (intervention). Results showed significantly greater decline in symptom frequency and intensity for the intervention group compared with the control group ($P = 0.018$). This study supports the use of the Symptom Management Manual, a portion of which is the Symptom Self-Management Questionnaire (Appendix C).

Questionnaires available from Holzemer and colleagues for the HIV/AIDS population include fatigue, depression, anxiety, neuropathy, and nausea. These symptoms are not exclusive for the HIV/AIDS population, and thus several of them should be adaptable for the TBI patient symptom self-management questionnaire. From the TBI literature, it is known that fatigue, depression, and anxiety are also common symptoms for that population. In addition, headache, dizziness, and memory difficulties are common complaints, and therefore should be added for the TBI population questionnaires.

In the questionnaires for anxiety, depression, and fatigue, the only changes made were substituting the words brain injury for HIV/AIDS and the addition of help seeking questions. Information is available to persons with MTBI, such as the CDC Heads Up about Concussion (CDC.gov); however, it is unknown whether persons seek out this or other information. The addition of a help-seeking question will be useful in identifying where persons look for information or help, such as from a healthcare provider, or the Internet. Items on the questionnaire are in the categories of activities/thoughts, exercise, medications, complementary therapy, substance use, healthcare seeking, and other.

The questionnaire for neuropathy was converted to a questionnaire for headache, a common symptom associated with TBI (Laansjo et al., 2009; Lundin et al., 2006; Yang et al., 2007). Activities/thoughts for the neuropathy questionnaire were somewhat specific to the feet; therefore, for headache the activities were changed to items appropriate for headache management, such as hot bath, close eyes, lay down, and hot/cold compress (Gurr & Coetzer, 2004; Lane & Arciniegas, 2002; Packard, 2008; Saper, 2000; Solomon, 2001). Exercise and medications (Solomon, 2001; Lane, 2002) were kept the same as for neuropathy. Supplements were made more general, to vitamins and herbs rather than specific items on neuropathy questions such as B-complex, calcium, and magnesium. Complimentary therapy (Gurr, 2004), substance use, and "other" were not changed.

There was not a dizziness questionnaire for the HIV/AIDS self-care version, and therefore one was created using the same format at the other symptom questionnaires. Dizziness has been shown to be a predictor of inability to return to work, and therefore management of dizziness is imperative for return to pre-injury status (Camelian & Feinstein, 2004). For activities/thoughts, diversion tactics such as talk with friends and not dwelling on dizziness are the options (Maskell, Chiarelli, & Isles, 2006). For medications, choices are for prescription or non-prescription medications for dizziness (Marzo et al., 2004). Supplements offer the choice of vitamins/herbs. Being prepared is a category unique to dizziness that includes "get up slowly, move slowly," and "hold on to things for support" (Marzo, 2004; Maskell, 2006). Substance use and "other" are the same as for other questionnaires.

A questionnaire was developed for memory difficulties, difficulty thinking. Items for activities and thoughts include make lists, keeping calendar, concentrating, resting, and talking with others (CDC.gov). Exercise choices are walking, exercising, and doing memory exercises

(Comper et al., 2005). Complementary therapies are meditation, prayer, and relaxation. Substance use choices are marijuana, cigarettes, alcohol, and street drugs. Healthcare includes see a doctor or other healthcare provider, and as with the other questionnaires, an “others you may wish to add category” is included.

A self-management strategy missing from all questionnaires is in regard to help seeking. It is hypothesized that if a person does not know how to self-manage or if their self-management techniques are not successful, that they might seek outside information for assistance (Bazarian et al., 2005). This could be in the form of doctor’s office visits or phone calls, ED visits or phone calls, internet information sources, friends or family, or other sources (Chou et al., 2004). A question about seeking help was therefore added to all symptom self-management forms.

The Symptom Self-Management adapted for TBI questionnaire (Appendix C) will be used to answer research questions 2, 3, and 4 and will be further described in the analysis section.

Data Collection Schedule and Procedures

Initial contact with potential study participants occurred in the emergency department (ED), prior to discharge, for those treated and released from the ED. In addition, persons with MTBI were recruited from PAR rehabilitation, an outpatient rehabilitation facility in the Lansing, MI area. Lastly, persons with self-reported concussion who do not seek healthcare for their injury were invited to join the study via communication in hospital flyers or word of mouth. Nurses caring for the patients in the ED presented them with a flyer that briefly described the study. If persons were interested in being contacted, they gave their contact information on the flyer that described the study. The study PI then contacted potential participants, further described the study, and asked if persons would like to participate. If they chose to participate, an appointment was made for the data collection time. This appointment was within 3 months of time since injury.

The PI or trained data collector performed the data collection. Participants were asked to meet for an interview at a hospital office setting or at PAR rehabilitation office. Time for this meeting is was approximately 30 minutes. Data collection included the PCL, the Symptom Self-Management Questionnaire for TBI, and demographic information. Participants were thanked for their participation in the study. No financial compensation was offered for participating.

Data Management

The PI or trained data collector for the study collected data on study questionnaire forms. Training is discussed below. Results from the data entered on the questionnaires were entered into a database in SPSS, designed for the study, protected by computer password. Data were entered by the PI. Data entered from the questionnaires were double checked by the PI for accuracy by running descriptive statistics of data entered, looking for outliers that could have been mis-entered, and by double checking data entry visually. In addition, for every 10 subjects entered into the database, one subject file was selected for an additional person to review the data entered. This reviewer was not able to identify subjects by name, only by study subject number. Questionnaires are stored in a locked file cabinet in a locked office for security. Study information will be saved for 2 years following completion of the study, or until all manuscripts are in press.

Training

Nurses that work in the emergency department and in the Trauma Care Unit were educated about the purpose of the study as well as what persons are appropriate for the study. They were educated by the PI regarding the use of the study flyer to approach person who may be able to participate. The nurses will have access to the study flyers for distribution to potential subjects. Nurses were allowed to ask questions at the initial education session, and have contact information for the PI for further questions. Education for the nurses responsible for distribution of the flyer was given as a presentation, with handouts, and with ongoing education via email and personal contact. Nurses were asked to complete a screening script identifying potential participants, explain the study flyer to the patients, and ask if persons are interested in participating. If they are interested, participants gave their name and phone numbers, sign the form, and were instructed that the PI or trained data collector would be calling to schedule an appointment for the meeting. One person was hired to perform data collection at Sparrow Hospital. This site enrolled one subject. PAR rehabilitation enrolled 7 subjects. The remaining 22 participants were enrolled by the PI. Funding to support hiring a data collector was from the Bronson Research Fund. The data collector was trained by the PI regarding the purpose of the study, recruitment process, data collection process, and security of data. The data collector has a certificate from the NIH Protection of Human Subjects online program. Ongoing quality of data collection was overseen by the study PI, monitoring data collection for 1 out of every 10 subjects. The PI was available to the data collectors via pager or cell phone for any questions or concerns. Data collectors were not responsible for data entry into the database. Data collectors maintained data protection by storing all completed study materials in a locked cabinet until collected by the PI.

Data Analysis

Data were analyzed to answer the research questions as described below. Statistic software was SPSS (16.0). Descriptive statistics were used to describe the study population in terms of age, race, sex, level of education, and living arrangements. Age was analyzed to find the mean age and range of the study population. Race and sex were tallied with frequency analysis. Level of education was categorized into less than high school, high school completed, attended some college, 2-year college degree, 4-year college degree, and advanced college degree. Living arrangements were categorized to living alone, live with family, live with friends, homeless, and incarcerated. Information about the injury was obtained such as mechanism of injury, date of injury (time since injury), and initial Glasgow Coma Scale score. Potential covariates such as social support, litigation status, medical history (comorbid conditions), and medications were collected. Demographic data were analyzed to compare MTBI and comparison group baseline data using *t*-tests for continuous variables and chi-square test for categorical variables.

Research Question 1

What symptoms are present and rated as most bothersome? How does bothersome rating compare to frequency or severity ratings? What symptoms are present (prevalence) as well as rated as most severe (those with highest severity scores) and most bothersome (those with highest bothersome scores) were answered with descriptive analysis of the PCL? How does the change of symptom severity result in change in the bothersome score in MTBI group, adjusting by patient's age and sex?

Spearman correlation was chosen to compare severity and bother due to small sample size of this study. Severity was rated from 0 (not severe) to 4 (very severe) and bothersome, rated as 0 (not at all bothersome) to 4 (very much bothersome) for each symptom, and were summed across all symptoms and treated as continuous interval variables. In addition, the univariate general linear model was used with bothersome as the outcome variable and severity as the independent variable with age, sex, and education as covariates to explore how a unit change of symptom severity could cause the change of bothersome ratings. Age, sex, education, and group were entered as covariates to identify if those variables have an independent effect on evaluating a symptom as more bothersome.

Research Question 2

What symptom self-management strategies are used?

Descriptive analysis was used to describe which symptom self-management strategies were used by persons with MTBI as well as the comparison group. The frequency and percent of each strategy used for each of the 6 symptoms of the symptom self-management questionnaire was calculated for the MTBI and comparison group. The most commonly used strategies per symptom and the most frequently used categories of strategies are listed in the results section. In addition, the number of strategies used per respondent was calculated and compared by group using general linear model adjusting for age, sex, and education.

Research Question 3

To what extent are bothersome symptoms the focus of self-management strategies? How does the bothersome score in each symptom (6 symptoms) affect whether persons are using any self-management strategies? How does total bothersome score relate to the usage of the symptom self-management strategies?

General linear model was used with the dependent variable as the sum of strategies used and the predictor will be the sum score of bothersome across all symptoms. Age, sex, education, and MTBI/comparison group will be entered into the model as covariates.

Research Question 4

What is the degree of effectiveness of self-management strategies on symptom relief after MTBI?

Degree of effectiveness of the strategies was calculated as the self-reported degree of symptom relief on the SSM-TBI. Self-management scores rated higher indicate higher perceived degree of effectiveness therefore self-management techniques will be compared to the effectiveness of techniques to determine those strategies deemed most effective by the study population. General linear model will be used to compare the overall sum of strategies used to the total score of self-reported effectiveness, with the covariates of age, sex, education, and group.

Power

Based on the means and standard deviation by group, the effect size is .21. Based on this effect size and 30 patient per group, the calculated power is greater than 0.999. This means that if a large difference in the population exists regarding the number of symptom differences, if you set that alpha = 0.05, then you will have over 99.9% chance to detect a significant difference.

Protection of Human Subjects

This study is approved (Appendix D) by the Michigan State University Institutional Review Board (IRB) as well as the IRBs specific for the data collection sites (Bronson Hospital IRB, Sparrow Hospital IRB). Participants were asked to sign informed consent, approved by all participating IRBs. At any time during the study, participants are allowed to withdraw from the study.

Participant’s identity is protected by assigning a study code number, and no names or identifying characteristics were used for data analysis. Data entered into the database for analysis is study code only, with no names are in the electronic file system. The list of study code numbers is kept in a locked file in the PI’s office, only available to the study PI.

This study does not include children. Women and minorities were included in this study. Women are estimated to reflect the national average of females who experience TBI and seek treatment in the ED, an estimated 30% (Langois, Rutland-Brown, & Thomas, 2006). Minorities were anticipated to reflect the community population, an estimated 15% of which are minorities (U.S. Census Bureau, 2008).

Data Security

Data were collected by the study PI as well as one or more persons trained to collect data for this study. Data were initially obtained on paper/form questionnaires, and was transferred by the study PI to an electronic database. Upon transferring data to the computer system, study code numbers were assigned by the PI, and identifying information other than the study number were not entered into the database. Identifying information is secured in a locked file in the study PI office. The study PI has completed the mandatory MSU IRB training related to patient consent, confidentiality, quality assurance, and data safety and security.

Recruitment

Participants were recruited from Bronson Hospital emergency department, PAR rehabilitation, Sparrow Hospital, and from communications sent within Bronson Hospital. Nurses caring for persons with MTBI, namely emergency department nurses and trauma care unit nurses were informed of the study and asked to identify potential participants. Potential participants were those diagnosed with MTBI or concussion, are over the age of 18, and speak English. Nurses approached potential participants for the study with a flyer designed by the PI to briefly explain the study and that asks if persons are willing to be contacted by the study PI. The nurses in the ED or trauma unit collected the flyers from the patient and gave them to the PI. Flyers were given to the PI in envelopes marked as confidential. When the patient indicated they were willing to speak to the study PI by giving their contact information on the flyer, the PI or trained data collector telephoned the potential subject. The study PI or data collector then explained the study including expected time commitments, and answered any questions. At that time, a date and time for the interview was set.

Facilities and Resources

Facilities for computer, telephone, data storage, and participant interviews were in office settings within each of the study sites. Rooms for the study interview were quiet, well lit and with comfortable seating for the study participant as well as for a significant other that may accompany the person. Parking was free for participants. Prior to the interviews, a meeting reminder along with room number and map was mailed to participants. Participants were given the phone number of the data collector for questions about location or time of meeting.

This chapter presents the design and methods used for this study as well as human subject protection and data safety. Chapters 5 and 6 present a discussion of the results of these findings as well as strengths and limitations of the study, and implications for practice and research.

CHAPTER 5

RESULTS

This study is cross sectional, observational survey of persons who are within 3 months of their mild traumatic brain injury with the aims to (1) identify symptoms that are bothersome, (2) determine what symptom self-management strategies are used, and (3) identify the extent to which self-management strategies are reported as effective. This study addresses characteristics of the symptom experience that are currently unknown, such as the bothersome nature of symptoms, symptom self-management strategies used, and their perceived effectiveness at symptom relief.

Thirty persons with mild traumatic brain injury and thirty persons without brain injury were recruited to participate in the study. A description of the groups and recruitment is provided below. Groups were matched on age, sex, and education level. All participants were asked to complete demographic questionnaires as well as The Problem Checklist (MTBI related symptoms questionnaire) and the symptom self-management questionnaire. Data collection was consistent with the plan described in Chapter 4.

Sample

Thirty persons with MTBI and 30 persons without brain injury were recruited to participate in the study. Persons with MTBI were within three months of their time since injury in order to capture a time-frame where symptoms and symptom management strategies are most likely to be present (Mean days 50.6, *SD* 37.27). The majority of the MTBI participants were recruited from Bronson Hospital (*n* = 23, 77%). One person was recruited from Sparrow Hospital (*n* = 1, 3%), and 6 were recruited from PAR rehabilitation (*n* = 6, 20%). Persons with MTBI were treated for their injury and were approached by staff at the respective facilities to obtain permission for the study PI or trained data collectors to contact them. If persons agreed to be contacted, the PI or data collector contacted those with MTBI either via phone or email and scheduled an appointment time to meet. Consent was obtained at the time of the meeting and then the questionnaires were answered. It is unknown how many persons were approached that chose not to be contacted regarding the study. Two persons (6.6%) from the MTBI group learned of the study through advertisement and contacted the PI to participate. These two persons also had been treated by healthcare providers for their injury supporting their self-report of obtaining a concussion.

The entire comparison group was recruited by the study PI. Persons that the PI knew who were similar in age, sex, and education to the MTBI group were approached to participate as the non-MTBI comparison group. This group was consented by the PI, and answered the demographic and study related questionnaires. All persons that were approached to be in the comparison group agreed to participate and gave consent.

The demographics of both the MTBI and comparison groups are shown in Table 2. The average age of persons in the MTBI group was 39.3 and the comparison group 40.7 years of age. There were 24 (80%) females and 6 (20%) males in the MTBI group, and 21 (70%) females and 9 (30%) males in the comparison group. The majority of both groups were non-Hispanic white (n = 23, 77% and n = 28, 93%), American Indian represented 2 (7%) of each group, and the MTBI group included 4 (13%) African American and 1 (3%) Asian respondent. Groups were not planned to be matched on race, and t-test for comparison of the groups by race revealed marginally significant results with p =.05. Groups were to be matched on age, sex, and education level with no statistically significant differences in those variables between groups (p = .673, .552, .738, respectively).

Table 2

Demographic Comparison of MTBI and Comparison Groups

	MTBI Group *N* = 30	Comparison Group *N* = 30	*p*-value
Age	39.27 Range (18–71)	40.70 Range (25–61)	.673
Sex			.552
Male	6 (20%)	9 (30%)	
Female	24 (80%)	21 (70%)	
Race			.050
Non-Hispanic White	23 (77%)	28 (93%)	
American Indian	2 (7 %)	2 (7%)	
African American	4 (13 %)	0	
Asian	1 (3 %)	0	
Employment			.110
Employed	23 (77%)	29 (97 %)	
Unemployed	3 (10%)	0	
Student	4 (13%)	0	
Homemaker	0	1 (3%)	
Education			.738
Less than high school	1 (3%)	0	
High school	4 (13%)	3 (10%)	
Some college	16 (53%)	13 (43 %)	
4 or more years college	9 (30%)	14 (47 %)	

The majority of both groups were employed, *n* = 23 (77%) of MTBI and *n* = 29 (97%) of comparison group. Three persons (10 %) of the MTBI group were unemployed, and *n* = 4 (13%) were students, and *n* = 1 (3 %) person from the comparison group was a homemaker. The MTBI group had education levels at *n* = 1 (3%) with less than high school education *n* = 4 (13%) completed high school, *n* = 16 (53 %) completed some college, and *n* = 9 (30%) had four or more years of college. The comparison group had *n* = 3 (10%) with high school education, *n* = 13 (43%) completed some college, and *n* = 14 (47%) completed four or more years of college. There was not a statistically significance for employment (*p* = .110) or education (*p* = .738) between the MTBI and comparison group.

Persons with MTBI sustained their injuries by falls (*n* =15, 50%), hit head on an object (*n* =8, 26.7%), hit by car (*n* =3, 10%), bike or all-terrain vehicle accident (*n* =2, 6.7%), motor vehicle crash (*n* = 1, 3.3%), and other (*n* = 1, 3.3%).

Eleven persons in the MTBI group were married (37%), 2 were widowed (7%), 12 (40%) never married, 4 (13%) divorced, and 1 (3%) separated. For the comparison group, the majority (20, 67%) were married, 1 (3%) was never married, 3 (10%) were in an unmarried couple relationship, and 6 (20%) were divorced. Living arrangements for the MTBI group were as follows, 18 (60%) lived with family/children, 4 (13%) lived with friends, and 8 (27%) lived alone. For the comparison group, 24 (80%) lived with family/children, 1 (3%) lived with friends, and 5 (17%) lived alone.

Medications were being used by members of both groups. The MTBI group report use of pain medication, heart medicine, and blood sugar medicine all at (*n* = 2, 7% each). Cholesterol medicine, blood thinners, and lung medicine were used each by 1 person (3%) in the MTBI group. For the comparison group, antidepressants were used by 4 (13%), 2 persons (7%) used pain medications, 1 person (3%) used heart medication, 3 (10%) used blood sugar medications, 2 (7%) used cholesterol medicine, and 1 (3%) used blood thinners.

The most common medical condition history for the MTBI group were depression (*n* = 7, 23%), and asthma (*n* = 3, 10%), while the comparison group also reports depression (*n* = 3, 10%) and diabetes (*n* = 3, 10%). One person (3%) of the MTBI group reports that they are seeking litigation, while 29 (97%) report they are not seeking legal action.

Glasgow Coma Scores were collected for those in the MTBI group to verify that they were indeed mild injuries as opposed to more complicated brain injury. There was data in medical records of the GCS in 15 (50%) of the records. For those 15, 14 (93%) had a GCS of 15 which is the highest score on the scale, indicating a mild injury. One person (7%) had a score of 14, which still indicates a mild brain injury, with scores of 13-15 being allowed to be classified as mild traumatic brain injury. Information was also collected about additional injuries sustained at the time of the MTBI. Fractures were reported by 6 (20%), chest injury by 1 (3%), facial injury by 5 (17%), extremity injury 4 (13%), and 7 (23%) report sustaining “other” injuries.

A description and psychometric properties of the measures for this study were presented in Chapter 4. A description of the scores of the measures used will be presented here. The Problem Checklist is a 43 item survey of MTBI related symptoms with the categories of frequency (how often ranging from 0 = never to 4 = most times), severity (0 = not severe to 4 = very severe), and bothersome (0 = not bothersome to 4 = very much bothersome). Number and percent from each group were used to calculate frequency scores for items in the PCL. Mean scores for each group were used to identify the most severe, and most bothersome reported symptoms. Note that although the comparison group did not have a brain injury, they are able to have some MTBI related symptoms (headache, for example). Findings from this study are similar to that of Paniak (1999) validity study of the PCL where persons with MTBI report significantly more symptoms than non-MTBI controls ($F = 14.07$, $p < .001$). For research question 3, the sum score for each respondent of severe and bother were used. For this calculation, the ratings for severe and for bothersome of each patient were summed across all symptoms to produce a sum score for each respondent. Sum scores were used to increase the power to predict significant differences because of the small number of subjects participating in the study and much smaller numbers of respondents for each of the 6 symptom management questionnaires.

The Symptom Self-Management for MTBI questionnaire (Appendix C) is a survey of self-management strategies that may be used for the symptoms of anxiety, depression, dizziness, fatigue, headache, and memory difficulties. These 6 symptoms were chosen for the self-management questionnaires based on their being commonly reported symptoms as previously described. Responses to the frequency of use for each self-management strategy ranged from 0 = not used to 5 = several times per day. Effectiveness of the strategy was self-reported with responses ranging from 0 = strategy never works to 4 = always works. Responses of 1 or greater for frequency support that the respondent used the strategy with higher scores meaning that they used it more often. The self-management questionnaires also include questions about how effective persons feel that their symptom management strategies are. Scores range from 0 = strategy never works to 4 = strategy always works. Scores of 1 or higher on the effectiveness portion of the measure indicate that the strategy was considered at least occasionally effective, with higher scores indicating that the strategy was deemed more effective. For research question 4, the sum scores of each participant’s responses for frequency and the sum score for effectiveness of symptom self-management strategies were calculated. Results from this study were similar to those obtained in a pilot study of this measure (Bergman, 2011) where 57-79% of persons in the MTBI group responded to the 6 symptoms within the symptom self-management measure, compared to 14-29% of those without MTBI. Also, Cronbach’s alpha for the pilot study ranged from .77-.97 and for this study ranged from .49-.84. The lowest score for scale reliability for this study was on the dizziness measure, which also has the fewest items within the scale, which could partially explain the lower score. Since Cronbach’s alpha is a measure of reliability of the scores in the scale, not the items themselves, sample differences in the two studies could explain the difference in reliabilities between the pilot and this study.

Groups

There were 30 persons in each of the MTBI and comparison group. This was a cross-sectional study and therefore there was no attrition. Groups were matched on age, sex, and education level. This study used group membership as a covariate in analysis, because as previously stated, persons in the comparison group also reported some of the symptoms and self-management strategies.

Results

SPSS version 16.0® was used for data analysis. Demographic data and scores on measures were entered into a password protected database. Methods for analysis will be described in detail for research questions one through four.

Research Question 1

There are several components to Research Question 1. (1) What symptoms are present and rated as most bothersome for persons with MTBI and the comparison group? (2) What symptoms are present (prevalence) as well as rated as more severe (those with highest severity scores) and more bothersome (those with highest bothersome scores)? In addition, (3) does the change of symptom severity result in change in the bothersome score in MTBI group, adjusting by patient's age, sex, and education?

Descriptive statistics were used to analyze responses to The Problem Checklist symptom endorsement by calculating mean scores for frequency, severity, and bothersome scores. Spearman correlation was used to explore the correlation between severity and bothersome scores because of the test's fit for the small sample size (as opposed to Pearson correlation).

Severity was rated from 0 (not severe) to 4 (very severe) and bothersome, rated as 0 (not at all bothersome) to 4 (very much bothersome) for each symptom, and was summed across all symptoms and be treated as continuous interval variables. In addition, the univariate general linear model was used with sum score of bothersome as the outcome variable and the sum score of severity as independent variable, with age, sex, education, and group as covariates to explore how a unit change of symptom severity could cause the change of bothersome. Age, sex, education, and group were entered into the model as covariates to identify if they have an independent effect on bothersome ratings of symptoms.

Table 3 below summarizes the responses for each group on The Problem Checklist. Items 1-43 in the rows of the table are the 43 symptoms that are available on the PCL, represented in the order on the PCL in which they occur. The MTBI and comparison group frequency of endorsement of having the symptom, along with percentages are represented. The most frequently reported symptoms from the MTBI group are headache (*n* = 25, 83%), feeling tired (*n* = 24, 80%), difficulty thinking and irritable (each *n* = 22, 73%), dizziness, trouble remembering, and forgetful (each 21, 70%).Most frequent symptoms reported by the MTBI group are also summarized in Table 4.

The most frequently reported symptoms for the non-MTBI comparison group were headache (*n* = 12, 40%), sleep disturbance (*n* = 8, 27%), distractible (*n* = 8, 27%), lose temper (*n* = 7, 23%), and forgetful (*n* = 7, 23%). Persons in the comparison group reported fewer symptoms (mean 5.83 symptoms per person) than those with MTBI (18.97 symptoms per person) on the 43 item symptom checklist (PCL).

Symptoms reported as most severe are not the same as those endorsed as most frequent. Symptoms endorsed as most severe by the MTBI group include headache with a means severity

Table 3

Summary for Frequency and Means for Severe and Bother Scores for MTBI and Comparison Group of the Problem Checklist (43-Item Symptom Scale for TBI)

The Problem Checklist PCL	MTBI Presence of symptom $N = 30$	%	Non-MTBI Presence of symptom $N = 30$	%	Severe Mean $N = 30$ MTBI Range (0–4)	Severe Mean $N = 30$ Non-MTBI	Bother Mean $N = 30$ MTBI Range (0–4)	Bother Mean $N = 30$ Non-MBI
1: vision	14	47	2	7	1.14	0.50	1.86	1.00
2: hearing	10	33	2	7	1.36	0.50	1.27	0.50
3: balance	15	50	1	3	1.27	1.00	1.33	1.00
4: slow	19	63	0		1.47	0.00	2.16	0.00
5: diff talk	13	43	1	3	1.08	0.00	1.85	1.00
6: coordination	14	47	0		0.93	0.00	1.36	0.00
7: tired	24	80	5	17	1.50	0.40	1.67	0.60
8: headache	25	83	12	40	2.04	1.73	2.52	1.82
9: dizzy	21	70	3	10	1.14	0.67	1.43	0.67
10: noise	11	37	2	7	1.17	0.50	1.33	1.00
11: light	16	53	3	10	1.06	0.67	1.29	1.67
12: taste	4	13	1	3	0.80	0.00	0.60	0.00
13: remember	21	70	5	17	1.33	0.60	1.81	0.60
14: wordy	16	53	6	20	1.13	0.33	1.25	0.50
15: distractible	16	53	8	27	1.87	0.75	2.12	1.25
16: poor concentrate	20	67	5	17	1.60	0.40	1.90	1.00
17: forgetful	21	70	7	23	1.90	0.14	2.55	0.57
18: diff thinking	22	73	5	17	1.50	0.20	2.00	0.40
19: diff planning	16	53	4	13	1.38	0.25	1.69	0.50
20: diff goal setting	6	20	4	13	1.00	0.00	1.17	0.25
21: diff finishing	11	37	6	20	1.64	0.67	1.91	1.00
22: apathetic	13	43	4	13	1.08	0.50	1.54	0.50
23: lack initiative	9	30	5	17	1.67	0.00	1.89	0.40
24: irritable	22	73	6	20	1.50	1.00	1.86	1.00
25: restlessness	15	50	6	20	1.80	0.67	1.87	0.83
26: lose temper	7	23	7	23	1.29	0.57	2.00	0.57
27: mood swings	12	40	5	17	1.33	0.20	1.33	0.40
28: diff emotions	7	23	5	17	0.43	0.40	0.29	0.80
29: arguments	9	30	5	17	0.67	0.60	0.89	0.80
30: violent	3	10	1	3	0.25	0.00	1.00	0.00
31: bored easily	12	40	3	10	0.92	0.67	1.36	0.67

Table 3 (cont'd)

The Problem Checklist PCL	MTBI Presence of symptom *N* = 30	%	Non-MTBI Presence of symptom *N* = 30	%	Severe Mean *N* = 30 MTBI Range (0–4)	Severe Mean *N* = 30 Non-MTBI	Bother Mean *N* = 30 MTBI Range (0–4)	Bother Mean *N* = 30 Non-MBI
32: complain a lot	11	37	6	20	1.00	0.00	1.18	0.00
33: depend on other	9	30	3	10	0.67	0.00	1.11	0.00
34: need supervision	3	10	1	3	0.67	0.00	0.67	0.00
35: anxiety	16	53	6	20	1.25	1.00	1.75	1.50
36: depression	13	43	4	13	1.38	0.25	1.62	0.25
37: loneliness	7	23	6	20	.86	1.40	0.86	1.40
38: loss confidence	12	40	4	13	1.67	0.75	2.08	1.25
39: change appetite	11	37	1	3	1.36	0.00	1.36	0.00
40: sleep disturb	19	63	8	27	1.84	1.00	2.26	1.38
41: low sex drive	8	27	3	10	1.75	1.00	1.62	1.33
42: high sex drive	5	17	4	13	0.80	1.25	0.80	1.00
43: personality change	11	37	0		1.00	0.00	1.00	0.00

Table 4

Top 5 Symptoms Endorsed by MTBI Group n = 30

Symptoms by Frequency	Number (%)
Headache	25 (83)
Tired	24 (80)
Difficulty thinking	22 (73)
Irritable	22 (73)
Dizzy	21 (70)

rating of 2.04, forgetful (mean 1.90), distractible (mean 1.87), sleep disturbance (mean 1.84), restless (mean 1.80), and low sex drive (mean 1.75). Note that headache is the only symptom endorsed both frequently and with higher severity scores. Symptoms rated with the highest severity ratings are also summarized in Table 5.

Table 5

Top 5 Symptoms Endorsed by MTBI Group as Most Severe n = 30

Symptoms by Severity	Mean Severity Rating Range (0–4)
Headache	2.04
Forgetful	1.90
Distractible	1.87
Sleep disturbance	1.84
Restlessness	1.80

Symptoms endorsed as more severe for the comparison group are headache (mean 1.73), loneliness (mean 1.40), high sex drive (mean 1.25), and balance difficulty, irritability, sleep difficulty, and low sex drive all with mean scores of 1 for severity.

Symptoms reported as most bothersome by those with MTBI are not always also rated as more severe. The symptoms rated as most bothersome by the MTBI group include forgetful (mean 2.55), headache (mean 2.52), sleep disturbance (mean 2.26), doing things slowly (mean 2.16), being distractible (mean 2.12), and loss of confidence (mean 2.08). Comparing bothersome to frequency, headache was the only symptom that was rated both as frequent and highly bothersome by the MTBI group. Comparing severe and bother, headache, distractible, forgetful, and sleep disturbance were all endorsed as more severe and more bothersome by persons with MTBI. Symptoms reported with the highest bothersome ratings for the MTBI group are summarized in Table 6.

Table 6

Top 5 Symptoms Endorsed by MTBI Group as Most Bothersome n = 30

Symptoms by Bother	Mean Bother Rating Range (0–4)
Forgetful	2.55
Headache	2.52
Sleep disturbance	2.26
Slow	2.16
Distractible	2.12

Symptoms reported as most bothersome for the non-MTBI comparison group include headache (mean 1.82), light sensitivity (mean 1.67), loneliness (mean 1.40), sleep disturbance (mean 1.38), and low sex drive (1.33).

For ease of reading, summary tables are provided below identifying the most frequent symptoms for the MTBI group, as well as the symptoms with highest severity and bothersome ratings.

Spearman correlation was used to compare the sum scores of severe and bother of the MTBI group to identify if they are correlated. Spearman rho (28) = .960, p = .000, n = 30, indicating that for this group, severe and bother are significantly correlated. Spearman correlation for the comparison group produced similar results with Spearman's rho (14) =.899, p = .000, n = 16 (only 16 persons in the comparison group reported symptoms). The combined groups Spearman rho (44) = .961, p = .000, n = 46 also produced results similar to the separate groups, indicating that severe and bother are significantly correlated.

Results of the general linear model with the sum score of bothersome as the dependent variable, the sum score of severe as the independent variable, and the covariates entered of age, sex, education, and group. These results indicate that there is a significant relationship between severity and bother, with severity explaining 91%, (r^2 (1, 21) = 91, p = .000) the variance of the bothersome score in the model. There is not a significant effect from age (F(1,21) = .636, p = .432), sex (F(1, 21) = .088, p = .769), education (F(5, 21) = .145, p = .980), or group (F(1, 21) = .141, p = .732). Parameter estimates show the Beta of 1.015 (p = .000) indicating that for each change in one unit on the severity score there would be a 1.015 change on the bothersome score.

From the descriptive analysis we have identified that those symptoms rated most frequently, are not those that are necessarily rated as most severe or bothersome. For this reason, when assessing symptoms either in clinical settings or in research it may be best to include other measures of symptoms beyond having the symptom, such as severe or bothersome ratings as well. There are several ways to evaluate symptoms, with severity and bothersome being 2. Severity and bothersome are ways to evaluate a symptom, thus it is reasonable that they are correlated. Those symptoms rated as most severe are not always the most bothersome, although some are. Evaluating symptoms with multiple questions such as frequency, severity, and bothersome provides more information about the presence and evaluation of symptoms and may be helpful in making clinical decisions about symptom management as well as in research studies.

Research Question 2

What symptom self-management strategies are used?

Descriptive analysis was used to describe which symptom self-management strategies were used by persons with MTBI as well as the comparison group. The frequency and percent of each strategy used for each of the 6 symptoms of the symptom self-management questionnaire will be calculated for the MTBI and comparison group. The most commonly used strategies per symptom and the most frequently used categories of strategies will be listed in the table below. In addition, the number of strategies used per respondent will be calculated and compared by group using general linear model adjusting for age, sex, group, and education.

The Table 7 below reports the most frequently used symptom management strategies used by each group for each of the 6 symptoms of the Symptom Self-Management Questionnaire. The second and fourth columns are the 5 most commonly reported strategies used per symptom for the MTBI group and comparison group. The third and fifth columns are the categories of strategies used for each group. Persons were allowed to respond to as many symptom management strategies and categories of strategies that they used. For the MTBI group persons used an average of 10.14 strategies for anxiety, 10.5 for depression, 5.19 for dizziness, 8.48 for fatigue, 6.08 for headache, and 8.44 for memory. For the comparison group, the average number of strategies used was 9 for anxiety, 10.5 for depression, 4 for dizziness, 5.67 for fatigue, 6.57 for headache, and 10.4 strategies per person for memory. There were no statistically significant differences in number of strategies used by group.

For the symptom of anxiety, 7 persons (23%) in the MTBI group and 4 persons (13%) in the comparison group responded to the questionnaire about symptom management strategies. The most commonly reported symptom management strategies for the MTBI group are talk through it (n = 7, 100%), talking with friends (n = 6, 86%), walk (n = 6, 86%), read (n = 5,

Table 7

Most Commonly Reported Symptom Management Strategies and Categories of Strategies for the MTBI and Comparison Groups

Symptom	Most Commonly Reported Strategies	Most Commonly Reported Categories of Strategies	Most Commonly Reported Strategies	Most Commonly Reported Categories of Strategies
	MTBI Group		Comparison Group	
Anxiety	Talk with family and friends Walking Talk through it Read Watch TV	Activities/ thoughts Exercise Complementary therapy	Talk with family and friends Exercise Prayer Read Cook	Activities/ thoughts Exercise Complementary therapy
Depression	Keep busy Talk with family/friends Do things I enjoy Listen to music Prayer	Activities/ thoughts Exercise Complementary therapy	Talk with family/friends Do things I enjoy Keep busy Read Walk	Activities/ thoughts Exercise
Dizziness	Get up slowly Hold onto things Move slowly Talk with friends Don't dwell on it	Activities/ thoughts Being prepared	Get up slowly Move slowly See doctor Hold onto things Practice balancing	Activities/ thoughts Being prepared Healthcare
Fatigue	Enough sleep at night Eating well Take breaks Avoid stress Nap	Activities/ thoughts Nutrition	Prayer Eating well Exercise Enough sleep at night	Complementary therapy Nutrition Activities/ thoughts
Headache	Over the counter medication Close eyes Lay down Relaxation	Medications Activities/ thoughts	Lay down Over the counter medication Relaxation	Activities/ thoughts Medications
Memory	Take breaks Talk with others Practice remembering Use calendar Get enough sleep	Activities/ thoughts Exercise	Enough sleep Use calendar Walking Prayer Make lists	Activities/ thoughts Exercise

71%) and watch television (*n* = 5, 71%). These strategies are from the symptom management categories of activities and thoughts, exercise, and complementary therapies.

For the comparison group responding to the anxiety questionnaire, the most commonly endorsed symptom management strategies were talking with friends (*n* = 4, 100%), exercise (*n* = 3, 75%), prayer (*n* = 3, 75%), read (*n* = 2, 50%), and cook (*n* = 2, 50%). These symptom management strategies are from the categories of activities and thoughts, exercise, and complementary therapies.

Ten persons (33%) from the MTBI group and 3 (10%) from the comparison group responded to the depression symptom self-management questionnaire. The most commonly endorsed symptom management strategies for the MTBI group were keep busy (*n* = 9, 90%), talk with friends (*n* = 8, 80%), do things I enjoy (*n* = 8, 80%), listen to music (*n* = 8, 80%), and prayer (*n* = 8, 80%). These strategies are from the symptom management categories of activities and thoughts, exercise, and complimentary therapies.

The three persons in the comparison group endorsed the symptom management strategies for depression of talk with friends (*n* = 2, 67%), do things I enjoy (*n* = 2, 67%), keep busy (*n* = 2, 67%), read (*n* = 2, 67%), and walk (*n* = 2, 67%). These strategies are from the symptom management categories of activities/thoughts, and exercise.

For the symptom of dizziness, 16 persons (53%) from the MTBI and 2 persons (7%) from the comparison group responded to the symptom self-management questionnaire. Strategies most commonly used by the MTBI group include getting up slowly (*n* = 15, 94%), hold on to things for support (*n* = 13, 81%), move slowly (*n* = 11, 69%), talk with friends (*n* = 7, 44%), and don’t dwell on it (*n* = 7, 44%). These strategies are from the categories of activities/thoughts, and being prepared.

The comparison group reported use of get up slowly and move slowly (both *n* = 2, 100%), and see the doctor, hold onto things, and practice balancing (each *n* = 1, 50%). These strategies are from the categories of symptom management of activities/thoughts, being prepared, and seeking healthcare.

For the symptom of fatigue, 21 persons (70%) from the MTBI group and 2 persons (7%) from the comparison group report using fatigue symptom management strategies. For the MTBI group, the most common strategies used were get enough sleep at night (*n* = 16, 76%), eat well (*n* = 14, 67%), take frequent brakes (*n* = 14, 67%), avoid stress (*n* = 14, 67%), napping (*n* = 14, 67%). These strategies are from the categories of activities/thoughts and nutrition.

The comparison group reported using prayer, getting enough sleep at night, exercising, and eating well (all *n* = 2, 100%) as their most commonly used strategies. These strategies are from the categories of complementary therapy, nutrition, and activities/thoughts.

Twenty-six (87%) of the MTBI group and 7 (23%) of the comparison group reported using headache symptom management strategies. Use of over the counter medication was the most commonly used strategy for the MTBI group (*n* = 22, 85%). Other strategies commonly used by persons with MTBI include closing eyes (*n* = 19, 73%), laying down (*n* = 18, 69%), and use of relaxation techniques (*n* = 11, 42%). These commonly used strategies are from the categories of medications and activities/thoughts.

The comparison group reported use of over the counter medications and lying down (both *n* = 7, 100%), and use of relaxation techniques (*n* = 5, 71%). These commonly used strategies are from the categories of medications and activities/thoughts.

For the symptom of memory difficulties the MTBI group (*n* = 18, 60%) reports using the self-management strategies of taking frequent break and talking with others (both *n* = 14, 78%).

In addition, using a calendar (*n* = 13, 72%) and getting enough sleep at night (*n* = 12, 67%) were frequently used strategies. These strategies are from the categories of activities/thoughts and exercise.

Persons in the comparison group (*n* = 5, 17%) answering the memory difficulties questionnaire reported using the strategies of getting enough sleep at night, walking, prayer, and using a calendar (all *n* = 5, 100%). Making lists was also a commonly reported strategy for the comparison group (*n* = 4, 80%).

Knowing what persons do to self-manage symptoms that are commonly associated with MTBI can be helpful in developing tools or discharge instructions about symptom self-management for future patients that sustain this injury.

For the second part of Research Question 2, general linear model was used to evaluate the effect of age, sex, education level and group on symptom management strategies used for each of the 6 symptoms in the self-management questionnaire. The sums of strategies used by patient for each symptom were entered as the dependent variable, with age, sex, education, and group entered as covariates. Results are summarized in Table 8.

Results of the general linear model analysis indicate that for this study there was not a significant effect of age (*F*(1, 5) = 1.75, *p* = .808), sex (*F*(1, 5) = .17, *p* = .413), education (*F*(3, 5) = .334, *p* = .804), or group (*F*(1, 5) = 20.64, *p* = .732) on the use of symptom management strategies for anxiety. For the symptom of depression there is a significant effect of age (*F*(1, 7) = 15.45, *p* = .029) and sex (*F*(1, 7) = 18.21, *p* = .024) on use of symptom management strategies, where older persons and females used more symptom management strategies. Group (*F*(1, 7) = 1.76, *p* = .276) and education (*F*(3, 7) = 6.26, *p* = .083) did not have a significant impact on use of symptom management strategies. For the symptom of fatigue,

Table 8

General Linear Model Comparison of Effects of Age, Sex, Education, and Group on Symptom Strategies Used for Each Symptom

Variable	Symptom	SS	*DF*	*F*	Beta	*p-v*alue
	Anxiety					
Age		16.9	1	1.75	–.329	.808
Sex		216	1	0.17	–3.829	.413
Group		34	1	1.57	20.640	.732
Education		241	3	.334	4.3	.804
	Depression					
Age		946	1	15.45	.824	.029*
Sex		1115	1	18.21	26.78	.024*
Group		108	1	1.76	19.74	.276
Education		1150	3	6.26	–15.38	.083
	Fatigue					
Age		9.39	1	.031	.054	.864
Sex		439	1	1.43	–40.38	.253
Group		.053	1	0.0	–28.67	.990
Education		1368	4	1.12	19.05	.392
	Headache					
Age		175	1	1.082	.254	.311
Sex		1.35	1	.008	–42.21	.928
Group		763	1	4.70	18.07	.043*
Education		1127	5	1.40	16.43	.273
	Dizziness					
Age		53.98	1	0.69	.147	.430
Sex		227	1	2.91	5.85	.126
Group		92.96	1	1.19	14.37	.307
Education		425	4	1.36	–6.33	.328
	Memory					
Age		103	1	.251	.198	.626
Sex		669	1	1.63	26.79	.228
Group		6.92	1	.017	28.38	.899
Education		1311	4	.798	25.62	.551

none of the variables of age ($F(1,16) = .031$, $p = .864$), sex ($F(1, 16) = 1.43$, $p = .253$), education ($F(4, 16) = 1.12$, $p = .392$), or group ($F(1, 16) = 0$, $p = .990$) had a significant effect on use of symptom management strategies. Group membership ($F(1, 25) = 4.70$, $p = .043$) had a significant effect on the use of symptom management strategies for headache symptoms. Variables of age ($F(1, 25) = 1.08$, $p = .331$), sex ($F(1, 25) = .008$, $p = .928$), and education ($F(5, 25) = 1.40$, $p = .273$) did not have a significant effect on headache symptom strategy use. None of the variables of age ($F(1, 11) = .69$, $p = .430$), sex ($F(1, 11) = 2.91$, $p = .126$), education ($F(4, 11) = 1.36$, $p = .328$), or group ($F(1, 11) = 1.19$, $p = .307$) had a significant effect on the use of symptom management strategies for dizziness. For the symptom of memory difficulties, again, none of the variables of age ($F(1, 15) = .251$, $p = .626$), sex ($F(1, 15) = 1.63$, $p = .228$), education ($F(4, 15) = .798$, $p = .551$), or group ($F(1, 15) = .017$, $p = .899$) had a significant effect on the use of symptom management strategies.

Overall, for the 6 symptoms of the symptom self-management questionnaire, age, sex, education, and group did not have significant effects on the sum score of symptom management strategies used. Although the MTBI group symptom management sum scores were higher than the comparison groups scores, the only symptom management that group had a statistically significant effect on was headache. These findings may be due to the small sample size, for example, the headache symptom had the most responses from both groups (26 MTBI and 7 comparison) and achieved statistically significant group differences, whereas the symptom of anxiety had much smaller groups (7 MTBI and 4 comparison group members).

Research Question 3

To what extent are bothersome symptoms the focus of self-management strategies? How does the bothersome score in each symptom (6 symptoms) affect whether persons are using any self-management strategies. (1) How does bothersome score relate to the usage of the symptom self-management strategies for each symptom? General linear regression of each symptom was used to test how bothersome ratings (from 0-4 rated on PCL) of symptoms are associated with use of self-management strategies, adjusting for age, sex, and education. (2) General linear model was used with the dependent variable as the sum score of strategies used per person and the predictor will be the sum score of bothersome across all symptoms. Age, sex, education, and MTBI/comparison group were entered into the model as covariates. Results are shown in Table 9.

The second part of Research Question 3 addresses whether there is a relationship between bother and the use of symptom management strategies overall. For this analysis the sum score of symptom strategies used for all 6 symptoms was entered into general linear model analysis as the dependent variable, and the independent variable was the sum score of bother across all 6 symptoms. The covariates of age, sex, education, and group were also entered into the model.

Results of this analysis show that there is a significant relationship between overall reports of being bothered by symptoms and the use of symptom management strategies ($F(1, 51) = 8.322$, $p = .008$). There were no significant relationships among the covariates of age ($F(1, 51) = .398$, $p = .534$), sex ($F(1, 51) = .030$, $p = .864$), education ($F(5, 51) = .539$, $p = .745$), or group ($F(1, 51) = .095$, $p = .761$).

The small *N* in each group for the individual 6 symptoms (for example 7 in the MTBI group and 4 in the comparison group for anxiety) may explain the non-significant results when comparing bother and use of symptom management strategies for each symptom. When combining the symptom to produce a total bother score across all 6 symptoms as well as a total sum of strategies used, there is a significant relationship.

Table 9

Relationship Between the Bothersome Nature of Symptoms and the Use of Symptom Management Strategies

Symptom	Variable	Beta	Std.Error	Significance
Anxiety symptom management strategies	Age	–.551	.399	.239
	Sex	–11.76	15.07	.479
	Education	5.44	6.153	.427
	Group	–14.32	11.29	.270
	Bother	2.56	5.39	.659
Depression symptom management strategies	Age	.221	.380	.635
	Sex	–37.35	.380	.187
	Education	1.99	5.516	.753
	Group	0	0	
	Bother	–1.43	5.516	.897
Dizziness symptom management strategies	Age	.070	.180	.706
	Sex	–12.82	7.67	.129
	Education	1.86	2.72	.511
	Group	–5.12	9.22	.592
	Bother	4.282	2.686	.145
Fatigue symptom management strategies	Age	–.138	.314	.665
	Sex	2.76	13.14	.835
	Education	.289	3.204	.929
	Group	–.054	17.658	.998
	Bother	2.063	5.063	.689
Headache symptom management strategies	Age	.019	.245	.940
	Sex	–1.407	7.196	.847
	Education	.442	2.494	.861
	Group	–2.748	6.259	.664
	Bother	2.826	2.606	.288
Memory symptom management strategies	Age	.022	.362	.953
	Sex	–.499	12.54	.969
	Education	–2.357	3.827	.547
	Group	7.231	16.636	.670
	Bother	3.960	4.898	.431

Research Question 4

What is the degree of effectiveness of self-management strategies on symptom relief? Degree of effectiveness of the strategies, or symptom relief, was scored by respondents from 0 (never works) to 4 (always works). Higher scores therefor reflect higher self-reported degree of effectiveness of the management strategy on symptom relief. (1) Descriptive statistics (frequency and percent) were used to identify which strategies are deemed most effective by persons using the symptom management strategy. (2) General linear model was be used to compare the overall the sum score of symptom strategies used to sum score for effectiveness of techniques, adjusting for age, sex, education, and group.

For all six symptoms in Table 10, the most frequently used symptom management strategies were not necessarily the ones endorsed as providing symptom relief. For the symptom of anxiety, the strategy of talking through it was endorsed by 7 persons with MTBI and 2 persons in the comparison group, with the mean score for effectiveness of that strategy of 2.33 (range 0-4) for the MTBI and 4.0 (4.0 = always works at symptom relief) for the comparison group. The MTBI group reported watching television to be a more effective symptom management strategy with a mean score of 3.25, where the comparison group scored the effectiveness of this strategy at 3.0.

For the symptom of depression, 9 out of 10 persons with MTBI report keeping busy as a strategy they use for symptom management and rate the effectiveness of that strategy at 2.88. The comparison group used this strategy in 2 out of 3 persons with this symptom and rated it as 3.0 in effectiveness indicating that it often works. The MTBI group rated listening to music as more effective with a mean score of 3.29 and this strategy was endorsed by 8/10 persons in that

Table 10

Symptom Management Strategies Rated as Most Effective at Symptom Relief

	Number (%) of MTBI persons using strategy	Mean effectiveness score Range 0–4	Number (%) of comparison group using strategy	Mean effective score Range 0–4
Anxiety Self-Management *N* =11 respondents	*N* = 7		*N* = 4	
Talk through it	7 (100)	2.33	2 (50)	4.00
Walking	6 (91)	2.00	2 (50)	3.00
Talk with family and friends	6 (91)	2.80	4 (100)	2.75
Read	5 (71)	3.20	2 (50)	3.00
Watch TV	5 (71)	3.25	2 (50)	3.00
Depression Self-Management *N* =13 respondents	*N* = 10		*N* = 3	
Keep busy	9 (90)	2.88	2 (67)	3.00
Talk with friends and family	8 (80)	2.86	2 (67)	3.00
Do things I enjoy	8 (80)	3.12	3 (100)	3.00
Listen to music	8 (80)	3.29	1 (33)	4.00
Prayer	8 (80)	3.00	1 (33)	4.00
Dizziness Self-Management *N* =18 respondents	*N* = 16		*N* = 2	
Get up slowly	15 (94)	3.18	2 (100)	3.50
Hold onto things for support	13 (81)	3.08	1 (50)	3.00
Move slowly	11 (69)	3.30	2 (100)	3.50
Don’t dwell on it	7 (44)	2.20	0	0
Talk with friends	7 (44)	2.50	0	0

Table 10 (cont'd)

	Number (%) of MTBI persons using strategy	Mean effectiveness score Range 0–4	Number (%) of comparison group using strategy	Mean effective score Range 0–4
Fatigue Self-Management *N* =23 respondents	*N* = 21		*N* = 2	
Get enough sleep at night	16 (76)	2.79	2 (100)	3.00
Take frequent breaks	14 (67)	2.62	1 (50)	2.00
Not get stressed out	14 (67)	2.62	1 (50)	2.00
Nap during the day	14 (67)	3.00	1 (50)	4.00
Eating well	14 (67)	2.15	2 (100)	3.00
Headache Self-Management *N* =33 respondents	*N* = 26		*N* = 7	
Over counter medications	22 (85)	2.95	7 (100)	2.71
Close eyes	19 (73)	2.17	4 (57)	2.00
Lay down	18 (69)	2.24	7 (100)	2.57
Relaxation techniques	11 (42)	2.09	5 (71)	2.40
See doctor	9 (35)	2.00	3 (43)	1.67
Memory Difficulties Self-Management *N* =23 respondents	*N* = 18		*N* = 5	
Take frequent breaks	14 (78)	2.15	3 (60)	2.00
Talk with others	14 (78)	2.69	3 (60)	2.00
Practice remembering	14 (78)	2.43	2 (40)	1.33
Use calendar	13 (72)	3.42	5 (100)	3.00
Enough sleep at night	12 (67)	2.27	5 (100)	3.20

group. One person in the comparison group indicated that they use the listening to music strategy, and they rated it as always working with a score of 4.

Most of the respondents for the dizziness symptom self- management questionnaire were from the MTBI group (16 persons) and only 2 were from the comparison group. Getting up slowly was used by 15/16 of the MTBI group and the mean rating for effectiveness was 3.18. Both of the persons in the comparison group used this strategy and gave it a mean rating of 3.5. Moving slowly had a slightly higher effectiveness rating for the MTBI group with a 3.3, and again, both persons in the comparison group endorsed this strategy and rated it as 3.5 for effectiveness.

The vast majority of respondents to the fatigue questionnaire were also from the MTBI group with 21(70% of MTBI group) persons while only 2 (7%) persons were from the comparison group. Sixteen (76%) of the 21 persons in the MTBI group and both of the comparison group members reported use of getting enough sleep at night as a self-management technique. The MTBI mean rating for effectiveness was 2.79 and slightly higher at 3.0 for the comparison group. The MTBI group rated napping during the day as slightly higher in effectiveness with a mean score of 3.0 and one person from the comparison group used napping as a strategy and rated that as always effective with score of 4.0.

There were 26 (87%) persons with MTBI and 7 (23%) from the comparison group that responded to the headache symptom self-management questionnaire. Twenty-two (85%) persons with MTBI and all 7 from the comparison group reported use of over the counter medication as a headache management technique with effectiveness rated at 2.95 for MTBI and 2.71 for comparison group members. In this case, the most frequently used technique was also the one rated as most effective compared to other strategies such as close eyes, lie down, relax, and see doctor. None of the mean scores for effectiveness for either group scored above 3.0, which would indicate that although many strategies were used, persons did not find them highly effective.

For the symptom of memory difficulties, 18 (60%) persons with MTBI and 5 (17%) from the comparison group responded to the symptom self-management questionnaire. Taking frequent breaks was endorsed by 14 (78%) of 18 persons with MTBI and 3(60%) of 5 in the comparison group. Effectiveness was rated as 2.15 and 2.0, respectively. Use of a calendar was a self-management strategy for 13(72%) persons with MTBI and all 5 of persons in the comparison group, and had higher mean effectiveness scores of 3.42 and 3.0 respectively.

The above tables and summary describe the use of strategies and effectiveness of those strategies for each of the six symptoms within the symptom self-management questionnaire. The second part of research question 4 asks a broader question about the overall relationship between symptom management strategies and effectiveness, and these procedures and results are described below.

For the second part of Research Question 4, general linear model was used to identify the relationship between symptom strategies used and the effectiveness of those strategies which were self-rated as to whether the strategy worked or not at symptom relief. The sum score responses to the effectiveness question were summed for all participants and compared to the sum score of symptom self-management strategies used for all participants. Age, sex, education, and group were entered as covariates. There was a significant relationship between strategies used and effectiveness of symptom relief ($F(1, 51) = 34.63$, $p = .000$) and sex ($F(1, 51) = 4.77$, $p = .04$). The parameter estimates show Beta = .469 ($p = .000$) indicating that for each increase of approximately .5 unit for use of symptom strategies there is one unit increase in effectiveness rating. There were not significant relationships among the covariates of age ($F(1, 51) = .938$, $p = .343$), education ($F(5, 51) = .882$, $p = .509$), and group ($F(1, 51) = .707$, $p = .409$).

These results support that the use of symptom management strategies results in symptom relief overall within this sample population. In addition, there is an effect of sex on symptom relief for this sample, in that men are more likely to report symptom relief from symptom management strategies than women.

CHAPTER 6

DISCUSSION

The purpose of this study was to describe the symptom experience for persons with mild TBI in terms of presence of symptoms and bothersome nature of symptoms and identify what persons do to manage those symptoms. This study also describes how well persons report their symptom self-management strategy as being effective. A better understanding of these concepts by healthcare providers may improve the discharge process of what information is given to persons with MTBI and guide the follow up management for this population. This study was guided by the conceptual framework of the UCSF Symptom Management Model.

Results of this study indicate that persons with MTBI experience symptoms following their injury and those symptoms that are the most frequent are not always those that are most severe or bothersome. Persons use symptom self-management techniques to try to relieve their symptoms, and the strategies used are frequently from the categories of activities/thoughts, complementary therapies, medications, and exercise. Persons rate these strategies as at least being somewhat effective at symptom relief. Since it is known that persons experience symptoms after MTBI and those simple self-management strategies can be effective at symptom relief, use of this study's findings to create a symptom self-management toolkit may provide a means to improve person's ability to self-management post MTBI symptoms and improve outcomes.

A group of persons without MTBI was used as a comparison group for this study. Persons in the comparison group reported fewer symptoms than those in the MTBI group. The use of symptom management strategies was not significantly different between groups. In other words, when persons without MTBI had symptoms, they did use symptom management strategies to attempt to relieve the symptoms, and they reported similar levels of symptom relief.

These findings make intuitive sense, that persons with an injury such as MTBI would have more symptoms, and that persons regardless of group would attempt to manage their symptoms. This study adds to the science of symptom self-management for persons with MTBI by describing the bothersome nature of symptoms and identifying self-management strategies used as well as the self-reported effectiveness of those strategies. Results of this study can be used to guide further research in the area of symptoms, self-management, and symptom relief for the MTBI population.

Symptoms

For this study of persons who were within 3 months of their MTBI and the non-MTBI comparison group, persons with MTBI reported an average of 19 symptoms (out of 43 listed in the PCL) while persons in the comparison group reported an average of 6 symptoms. It is known that symptoms are not unique to the MTBI population so that the non-MTBI population can experience similar symptoms, such as headaches. The five most frequently reported symptoms for persons with MTBI for this study were headache, being tired, being irritable, dizziness, and memory difficulties. These findings are consistent with most commonly reported in the MTBI literature of headache, dizziness, anxiety, memory difficulties, depression, and fatigue (Lannsjo 2009; Lundin et al., 2006; Yang et al., 2007). These symptoms for most will resolve slowly over a period of weeks to months following injury (Ponsford et al., 2011). Lundin et al. (2006) report that for their population of 122 persons with MTBI they found symptom complaints decreased from 86% of persons reporting one or more symptom on day one to 48% by 3 months post injury without any specific intervention.

The comparison group for this study reported headache, sleep disturbance, being distractible, lose temper, and being forgetful as being the most common symptoms. These findings are similar to results of Ponsford's (2011) study, where the control group reported headache, fatigue, being slow, difficulty with sleep, and irritability as their most common symptoms. Findings of this study are consistent with other studies in the MTBI literature (Krauss et al., 2009; Ponsford et al., 2011) where comparison groups were used, and the comparison groups also endorse having symptoms, but somewhat different symptoms than the MTBI group, and less symptoms than the MTBI group. Further discussion of the most frequent MTBI group symptoms are provided below.

For this study, headache was the most frequently endorsed symptom, with 25 (83%) of the 30 persons with MTBI reporting headaches while 12 (40%) of those in the comparison group also reported having headaches. Ponsford (2011) performed a longitudinal study of 123 persons with MTBI and 100 non MTBI controls and found that headache was the number one complaint at baseline, with 78% of persons reporting that symptom complaint. This group reported a decrease in headache over time, so that 25% of the MTBI group endorsed this symptom complaint at 3 months post injury. The comparison group had 35% of the group complain of headache on their baseline evaluation, and 28% at three months. Headache being a symptom frequently reported by persons with MTBI in this and other studies should be included in symptom management education for this population.

For this study, 21 (70%) of persons with MTBI report the symptom of dizziness, while only 3 (10%) of the comparison group have dizziness. Dizziness is also a frequently reported symptom for persons with MTBI as reported in current literature. Ponsford (2011) report 68% of their 123 persons with MTBI complain of dizziness at baseline, reduced to 31% at 1 week, and 8% at three months post injury. Forty-one percent of the control group in the Ponsford study report dizziness, decreasing to 14% at the time of their 3-month evaluation. Lannsjo et al.,

(2009) performed a large cohort study of persons with MTBI evaluating their symptoms at 3 months post injury and found dizziness to be the second most commonly reported symptom, with 333 (13%) of their 2,523 participants reporting that they had the symptom but it has resolved by three months, and 398 (16%) continue to experience the symptom at three months.

Anxiety is a frequently reported symptom following MTBI both for this study and for other MTBI literature. For this study, anxiety is reported by 16 (53%) of persons with MTBI and 6 (20%) of the non-MTBI comparison group. Dischinger et al. (2009) evaluated 180 persons with MTBI at 3 to 10 days post injury, and again at 3 months post injury and report that anxiety was reported by 49% of their sample at 10 days, and 27% at 3 months post injury. For this study, 21 (70%) of persons with MTBI and 5 (17%) persons from the comparison group report problems with memory. Memory difficulties are also reported in the MTBI literature, with the Lannsjo (2009) study reporting memory difficulties in 563 (22%) of the persons with MTBI. Ponsford et al. report higher frequencies in their sample with 47% reporting memory difficulties after their injury, decreasing to 16% having trouble remembering at 3 months. Only 7.5 % of the control group in the Ponsford study report memory difficulties, with a slight increase to 11% at 3 months.

Depression is a common symptom reported by both MTBI and non-MTBI groups in this study and in the literature. For this study, 13 (43%) of persons with MTBI and 4 (13%) of persons without MTBI report the symptom of depression. Dischinger et al. (2009) found that 38% of their 180 persons with MTBI had depression as a symptom complaint early after their injury (3-10 days post injury) which decreased slightly to 26% at 3 months post injury. Lannsjo’s sample of 2523 persons with MTBI report 13% of their study population to have symptom complaints of depression at 3 months post injury.

Fatigue is a common symptom complaint after MTBI. For this study, 24 (80%) of persons with MTBI and 5 (17%) of persons in the comparison group had the symptom complaint of fatigue. In the Ponsford study, 73% of persons with MTBI and 47% of non-MTBI control group report the symptom of fatigue following their injury. Within 3 months of injury, fatigue rates for their sample decreased to 37% for MTBI and 22% for the control group. Fatigue could impact person's ability to self-manage symptoms or to adhere to self-management strategies.

Findings of the most frequently reported symptoms for this study are consistent with those of other studies of persons with MTBI and also for the comparison group (Kraus et al., 2009; Ponsford et al., 2011). Based on the findings of this study and others, when developing symptom management education for persons with MTBI, inclusion of the symptoms of headache, being tired or fatigue, being irritable, dizziness, and memory difficulties would be appropriate. In addition to the results from this study, the literature also supports depression and anxiety (Ponsford, 2011) as common MTBI symptoms and therefore those would be useful to include in symptom management education such as development of a symptom management toolkit.

The frequency of reporting symptoms in the MTBI literature varies from study to study, most likely because the time points for assessment of symptoms is inconsistent. For this study, persons were asked to participate within three months of their injury. The average time since injury was 51 days, which makes comparing this study results to studies that had 7-day follow up or 90-day follow up more difficult. In addition, definitions among studies for MTBI vary, with some using the full range of Glasgow Coma Scale scores of 13-15, while others focus more on just those with GCS 15. Lange (2011) also reports that depression can impact symptom reporting for persons with MTBI, such that persons with depression endorse more symptoms than those without depression. For this reason, this study excluded persons with known psychiatric history or major depression. Litigation status can also impact persons reporting more symptoms and thus was a consideration for this study. Only 1 person from the MTBI group was seeking litigation/workman's compensation, and therefore litigation status was not problematic for this study.

It is known that the presence of symptoms following MTBI impacts person's ability to return to normal role functions such as work or school (Lundin et al., 2006; Yang et al., 2007), and therefore a better understanding of symptoms following MTBI will assist clinicians and researchers in ways to help manage those symptoms. In addition to knowing the presence of symptoms following MTBI, it may be useful to better understand the symptom experience by identifying additional characteristics of the symptoms, such as how much persons are bothered by post-MTBI symptoms.

Bothersome

Bothersome refers to how much a symptom is evaluated as being disruptive to person's daily life (Kay et al., 1995; O'Leary 2005). Knowing how much persons are bothered by symptoms may add depth to our current knowledge of MTBI symptoms, which is largely about what symptoms are experienced. Severity or intensity of symptoms are sometimes reported (Lannsjo et al., 2009); however, it is unknown what the relationship between severity and bothersome is. Are symptoms that are severe also bothersome? This study sought to describe what symptoms are present, severe, and bothersome in order to add to the knowledge about post MTBI symptoms.

For this study, the Problem Checklist (PCL) was used as the measurement tool to ask if persons had the symptom (43 symptoms common to MTBI), and if they had the symptom, how severe was it and how bothersome was it. Although there was some overlap between symptom frequency, severity, and bother, there were also differences that should be noted.

Headache was endorsed as the most frequent symptom among persons with MTBI and was also the most severe (mean severity rating 2.04, range 0-4), and had a high bothersome rating of 2.52. Although this was not the highest bothersome rating, it is among the top 2 in the bothersome category and one can see the trend across frequency, severity, and bothersome for this symptom.

Twenty-four out of 30 persons with MTBI reported being tired; however, they did not rate the symptom as severe or as bothersome as other symptoms. Being tired had a mean severity score of 1.5 and mean bother score of 1.67. Forgetful is a symptom that was endorsed as both severe and bothersome with mean ratings of 1.90 and 2.55, respectively. In this situation, being forgetful was not the most commonly endorsed symptom, but for those that had it, they felt it was both severe and bothersome, or disruptive to their daily life. Feeling like they are doing things more slowly (mean bothersome rating 2.16) and loss of confidence (mean bothersome rating 2.08) were endorsed in the top 5 items most bothersome to those with MTBI that were not endorsed as a frequent symptom nor a severe symptom.

Correlation analysis was done to determine if severe and bother ratings of symptoms are associated. For this sample population, severe and bother are significantly correlated. Frequency, severity, and bothersomeness are different ways of evaluating symptoms. Evaluating a symptom using different dimensions such as severe and bother, or as others have used, interference with daily life, broadens our knowledge about the overall interpretation of the symptom and how it may impact persons desire to manage symptoms. In healthcare, assessing symptoms of patients by more than just the presence of the symptom can be useful in identifying symptoms that may be most important for each patient to address with symptom management strategies. For instance, if a person reports their dizziness to be present only once per week, and states that it is not severe, however it is highly bothersome because they cannot drive or work while dizzy, then for that patient it may be best to target that symptom for management so that they can return to their normal roles.

Bothersome has been used as a component of symptom evaluation in the chronic illness populations. O'Leary (2005) describes the use of a "bother score" to evaluate symptoms for benign prostatic hyperplasia and supports the importance of bother as playing a central role in decision making for persons to seek treatment of their symptoms. The O'Leary study was a multinational survey of aging male (MSAM-7) study and reports that 90% of the respondents had lower urinary tract symptoms, while only 19% sought medical care, and only 11% were medically treated (Rosen et al., 2003) thus supporting the importance of assessing bothersome symptoms with the findings that the (1) most common symptoms are not necessarily the most bothersome, (2) symptoms that are the most disruptive to daily life are those rated as most bothersome, and (3) persons reported significant differences in the degree that they are bothered by symptoms. This MTBI study results indicating that the most frequent symptoms are not always being endorsed as the most bothersome supports the findings of the O'Leary (2005) study and that the additional questioning of persons about their symptoms being bothersome can be beneficial.

Being bothered by a symptom may lead persons to want to manage that symptom. As in the previous example of dizziness, if a person is bothered by a symptom and it is disruptive to their daily life, they may be more motivated to try to have symptom relief through the use of symptom self-management.

Bother and Symptom Management

Does being bothered by a symptom make persons more likely to self-manage that symptom? As previously mentioned, the O'Leary study on benign prostatic hypertrophy showed that being bothered by a symptom made men more likely to seek treatment for their symptoms. Seeking treatment or managing symptoms on your own when persons are sufficiently bothered by the symptom makes good intuitive sense; however, this has not been explored in the MTBI literature.

For this study, general linear model was used to identify the relationship between bother and use of symptom management strategies for each of the symptoms in the Symptom Self-Management Questionnaire. When each of the 6 symptoms were entered into general linear model separately with the independent variable of the bother score for that symptom, there was not a significant relationship between bother and the use of symptom management strategies. In addition, there were no significant relationships of the covariates of age, sex, education, or group. This may be due to the small number of respondents to each of the symptom management questionnaires. For example, for the anxiety questionnaire there were 7 respondents from the MTBI and 4 from the comparison group, which may be too few responses to detect a significant association. When combining the bothersome scores across symptoms and using that sum score as the independent variable and the sum of symptom management scores for all 6 symptoms, and entering the sum scores into general linear model with the same covariates, there is a significant association between bother and use of symptom management strategies. In this model, there were no significant relationships between the covariates and symptom management.

The way persons evaluate symptoms, such as frequency, severity, and bother are a part of the symptom experience component of the UCSF Symptom Management Model that guides this research. In the model, the symptom experience is related to symptom management strategies such that the ways that persons evaluate their symptoms is associated with their use of symptom management strategies. This relationship is supported by the results of this research where the overall evaluation of symptoms as bothersome is associated with use of symptom management strategies. Using this knowledge, healthcare providers can ask about symptoms from different perspectives, such as frequency, severity, or bother to better understand the symptom experience, and then either assist with symptom management or guide symptom self-management based on what persons are experiencing.

Rosenberg et al. (2009) use the amount that men are bothered by enlarged prostate as trigger to offer symptom management strategies. For example, if persons have symptoms that they do not rate as bothersome, then watchful waiting is done. If symptoms are bothersome, then medications are used with re-evaluation for symptom relief. Evaluating how much persons are bothered by symptoms in this way is useful to offer the appropriate symptom management options, providing more management as the symptoms are more bothersome. This example is similar to the MTBI population in that enlarged prostate symptoms are largely self-managed at home which is also the case with MTBI symptom management. Healthcare providers assisting persons with MTBI to self-manage their symptoms can use bothersome as a guide to help persons know when to try self-management strategies. For instance, if someone is having a headache but it is not bothersome to them, but fatigue is bothering them very much, then target the fatigue symptom so that they can better return to their daily activities. Healthcare providers would require education based on current evidence to support a change in practice to include questioning persons about being bothered by symptoms. Publication of studies such as this one is a beginning step to change the practice. Beyond that, updating the clinical practice guideline (AANN.org) and public speaking about the importance of bother would be next steps to educate healthcare providers on the importance and the difference between assessing frequency and bother of a symptom.

Symptom Management Strategies

Persons with MTBI are typically treated and released from emergency departments, or do not seek treatment for their injury (Bazarian et al., 2005). Once they leave the emergency department, persons are expected to manage the symptoms associated with MTBI on their own, or self-manage. Management of an acute and often time limited diagnosis such as MTBI is different from symptom self-management for persons with chronic illness, as they are typically being followed by healthcare providers who at least initially assist with the symptom management process. It was previously unknown what persons with MTBI were doing to self-manage their symptoms, and this study sought to describe the strategies used.

For this study, persons who were within 3 months of their time since injury were asked to complete a questionnaire about what symptom management strategies they used to manage 6 of the most common symptoms for this population. Symptom management strategies available on the questionnaire were based on the prior work of Chou et al. (2004) researching the HIV population.

Anxiety was one of the six symptoms that persons were asked to complete the questionnaire if they had the symptom. Seven persons from the MTBI and four persons from the comparison group answered this questionnaire. The most commonly reported symptom management strategies for the MTBI group are talk through it (n = 7, 100%), talking with friends (*n* = 6, 86%), walk (*n* = 6, 86%), read (*n* = 5, 71%) and watch television (*n* = 5, 71%). These strategies are from the symptom management categories of activities and thoughts, exercise, and complementary therapies. For the comparison group responding to the anxiety questionnaire, the most commonly endorsed symptom management strategies were talking with friends (*n* = 4, 100%), exercise (*n* = 3, 75%), prayer (*n* = 3, 75%), read (*n* = 2, 50%), and cook (*n* = 2, 50%). These symptom management strategies are from the categories of activities and thoughts, exercise, and complementary therapy. The strategies used by persons with MTBI and persons in the comparison group that also experienced the symptom of anxiety were similar, especially when considering the categories of strategies used, such as activities and thoughts being the most common category of strategies for both groups. This finding makes intuitive sense in that when persons are trying to manage a symptom, regardless of the reason that they have the symptom, they are going to try strategies that are not specific to any one diagnosis. They will try strategies that they believe to be helpful for that particular symptom, regardless of the cause of the symptom. If the strategies persons try are not effective for symptom relief, they will attempt additional strategies. For this study, persons attempted multiple strategies to self-manage symptoms, and the use of more strategies was related to increased self-report of symptom relief.

Ten persons (33%) from the MTBI group and 3 (10%) from the comparison group responded to the depression symptom self-management questionnaire. The most commonly endorsed symptom management strategies for the MTBI group were keep busy (*n* = 9, 90%), talk with friends (*n* = 8, 80%), do things I enjoy (*n* = 8, 80%), listen to music (*n* = 8, 80%), and prayer (*n* = 8, 80%). These strategies are from the symptom management categories of activities and thoughts, exercise, and complimentary therapies. The three persons in the comparison group endorsed the symptom management strategies of talk with friends (*n* = 2, 67%), do things I enjoy (*n* = 2, 67%), keep busy (*n* = 2, 67%), read (*n* = 2, 67%), and walk (*n* = 2, 67%). These strategies are from the symptom management categories of activities/thoughts, and exercise. As above, the symptom management strategies are from the same categories of activities/thoughts and exercise for both groups. Persons from both groups are attempting to self-manage a symptom, not specific strategies for the reason that they have the depression. For persons with MTBI, the injury occurred and persons cannot reverse the occurrence of that event, they can only manage the symptoms that result from the injury. Persons who do not have symptom relief are less likely to be able to return to work or normal role functions (Lundin et al., 2006, Yang et al., 2007) therefore self-management of their MTBI symptoms soon after their injury is important.

For the symptom of dizziness, 16 persons (53%) from the MTBI and 2 persons (7%) from the comparison group responded to the symptom self-management questionnaire. Strategies most commonly used by the MTBI group include getting up slowly (*n* = 15, 94%), hold on to things for support (*n* = 13, 81%), move slowly (*n* = 11, 69%), talk with friends (*n* = 7, 44%), and don’t dwell on it (*n* = 7, 44%). These strategies are from the categories of activities/thoughts, and being prepared. The comparison group reported use of get up slowly and move slowly (both *n* = 2, 100%), and see the doctor, hold onto things, and practice balancing (each *n* = 1, 50%). These strategies are from the categories of symptom management of activities/thoughts, being prepared, and seeking healthcare. Again, the categories of strategies are similar between groups as would be expected for management of the symptom and not the illness.

For the symptom of fatigue, 21 persons (70%) from the MTBI group and 2 persons (7%) from the comparison group report using fatigue symptom management strategies. For the MTBI group, the most common strategies used were get enough sleep at night (*n* = 16, 76%), eat well (*n* = 14, 67%), take frequent breaks (*n* = 14, 67%), avoid stress (*n* = 14, 67%), napping (*n* = 14, 67%). These strategies are from the categories of activities/thoughts and nutrition. The comparison group reported using prayer, getting enough sleep at night, exercising, and eating well (all *n* = 2, 100%) as their most commonly used strategies. These strategies are from the categories of complementary therapy, nutrition, and activities/thoughts.

Twenty six (87%) of the MTBI group and 7 (23%) of the comparison group reported using headache symptom management strategies. Use of over the counter medication was the most commonly used strategy for the MTBI group (*n* = 22, 85%). Other strategies commonly used by persons with MTBI include closing eyes (*n* = 19, 73%), laying down (*n* = 18, 69%), and use of relaxation techniques (*n* = 11, 42%). These commonly used strategies are from the categories of medications and activities/thoughts. The comparison group reported use of over the counter medications and lying down (both *n* = 7, 100%), and use of relaxation techniques (*n* = 5, 71%). These commonly used strategies are from the categories of medications and activities/thoughts.

For the symptom of memory difficulties the MTBI group (*n* = 18, 60%) reports using the self-management strategies of taking frequent break and talking with others (both *n* = 14, 78%). In addition, using a calendar (*n* = 13, 72%) and getting enough sleep at night (*n* = 12, 67%) were frequently used strategies. These strategies are from the categories of activities/thoughts and exercise. Persons in the comparison group (*n* = 5, 17%) answering the memory difficulties questionnaire reported using the strategies of getting enough sleep at night, walking, prayer, and using a calendar (all *n* = 5, 100%). Making lists was also a commonly reported strategy for the comparison group (*n* = 4, 80%).

Management strategies from the activities/thoughts categories were most commonly used across all 6 symptoms and both groups. Exercise was among the top categories used for three of the symptoms, anxiety, depression, and memory difficulties. Strategies from the category of complimentary therapies were commonly used for the symptoms of anxiety and depression. Items from the category of seeking healthcare were not commonly used, which could imply that persons feel they are able to manage their symptoms on their own or that they did not know who to seek healthcare from. The lack of use of healthcare seeking may require further research to identify if there is a service gap in persons not knowing how to get access back into the healthcare system once they leave the emergency department, or if they did not seek treatment that they do not know where to go for assistance.

As previously described, symptom management strategies used to manage MTBI symptoms are not highly sophisticated or complicated things for persons to do, but are very simple and most would require little if any guidance to implement them. What is lacking is a mechanism to help raise awareness of these strategies. One way to raise awareness about strategies that are helpful at symptom management would be development of a toolkit, so that for instance if someone has the symptom of dizziness they could go to the toolkit and see what simple self-management strategies might be helpful. In order to develop a toolkit for MTBI symptoms, it is important to know how effective persons feel that symptom self-management strategies are. Those strategies that are deemed helpful could be supported by other literature and evidence (Bell et al., 2008; Sayegh et al., 2010), and added to the symptom self-management toolkit for MTBI. After MTBI, persons may have difficulty making decisions or concentrating enough to find solutions for managing their symptoms, so the symptom management toolkit can be used as a quick guide to simple strategies that can be used to help relieve the symptoms. The toolkit would also give suggestions for seeking healthcare in situations where symptoms cannot be sufficiently relieved by the strategies suggested which would fill the service gap that currently exists where persons do not seek healthcare many times for their injury.

Symptom Management and Effectiveness of Strategies

The goal of any symptom management strategy, including self-management, would be to have symptom relief. For this study, symptom relief or effectiveness of symptom management strategies was measured as person's responses to the question "Does the strategy work?" with responses ranging from never to always. Knowing what strategies are considered by this sample to be most effective will be used to guide further studies as well as to create the symptom management toolkit.

The most frequently used strategies for symptom self-management were not always rated as most effective. General linear model was used to compare the symptom management strategies used to self-rated effectiveness of symptom strategies. Covariates of age, sex, education, and group were entered into the model. Results show that there is a significant relationship between the use of symptom management strategies and the effectiveness of symptom management strategies ($F = 34.63$, $p = .000$). In addition, with this model, sex had a significant relationship with effectiveness ratings such that males rated their symptom management strategies to be more effective than the females did ($F = 4.77$, $p = .04$).

It makes intuitive sense that the use of symptom management strategies would have a positive association with strategies being rated as effective. Bazarian et al. (2009) found sex differences in outcome of their large study of 1425 subjects with MTBI. When looking at outcomes they found no significant sex differences in the time to return to normal activities, but did find males to have lower odds (OR 0.62, CI: 0.5-.78) of having a large number of postconcussion symptoms at three months post injury. These findings could represent similar sex differences, in that this study evaluated symptom relief and the Bazarian (2009) study evaluated the presence of symptoms, with females having more prolonged symptoms and reporting less symptom relief.

Research in the area of symptom management for persons with MTBI is limited. Bell et al. (2008) performed a randomized trial evaluating the effect of telephone counseling on symptom reduction following MTBI. Subjects were randomized to standard of care or the treatment group that included received telephone contact aimed at symptom reduction and resumption of normal activities. The phone calls were scheduled at 2 days, and 2, 4, 8, and 12 weeks post injury. Persons assigned to the treatment group had significantly improved symptom resolution compared to control group (p = 0.016) at the 6-month follow up.

Sayegh et al. (2010) performed a systematic review of studies describing treatment of post-concussion syndrome, which are symptoms after MTBI lasting longer than 3 months. Many of the trials summarized indicated no significant effect in treatment, acknowledging that the science behind post-MTBI symptom management is still not fully understood. Cognitive behavioral therapy, reassurance and education, and rehabilitation programs including psychotherapy may have a role in MTBI symptom management. Of these, education is likely to be the source that can be delivered either in the emergency department when persons seek treatment, or via other mechanisms such as websites for those who don’t seek treatment, in order for persons to self-manage their symptoms.

The studies described above by Bell and Sayegh involve healthcare providers using an intervention such as education to improve the outcomes of persons with MTBI. Many persons with MTBI do not seek healthcare for their injury, and for this population, access to the symptom management toolkit may provide them with valuable information to improve their symptom management. In addition to those that do not seek healthcare, there are persons that are treated and released from the emergency department following MTBI. These patients are often symptomatic while in the emergency department, and attempts to educate in the often chaotic setting of an ED can be difficult. Persons often do not understand or remember their discharge instructions, and therefore the toolkit would provide them with information that they and their family members can refer to once they have left the hospital.

Management of persons with MTBI who seek treatment often involves discharge instructions that focus on the warning signs that the brain injury could be getting worse. Discharge instructions usually do not include symptom management education despite the studies that have shown that education may be effective at symptom reduction (Bell, 2008; Sayegh, 2010). Use of results of this study and others to produce a symptom management toolkit could provide a simple and effective way to reduce symptoms following MTBI and improve outcomes.

Limitations

The sample size for this study was 30 persons with MTBI and 30 persons to serve as a comparison group, so the small sample size limits the generalizability of the results to the overall MTBI population. This study design was a cross-sectional study interviewing persons within three months of their time since injury. This provides a single time point for evaluation of symptoms, self-management, and effectiveness. It is known that symptoms following MTBI decrease with time, even without specific intervention. It is possible that when persons were reporting their symptom management strategies to be effective at symptom relief, that the natural course of symptom resolution over time was actually why they felt the strategies were effective.

An intervention study would better answer the question about the effectiveness of certain strategies while having a control group to compare natural symptom resolution.

Further studies with a longitudinal design would be helpful to follow symptom resolution over time. Since this study was cross-sectional it is unknown what the effect of adherence to symptom management strategies is on the symptom management process. As shown in the UCSF Symptom Management Model, adherence is important between the use of symptom management strategies and outcomes. A longitudinal study would better identify the importance of adherence of strategies to symptom relief.

This study relied on self-report of symptoms, symptom management strategies, and effectiveness of strategies. There is not an objective way to measure these variables, and therefore the study relies on self-report. The self-management questionnaires for this study included the 6 most commonly reported symptoms from the current MTBI literature, so we now have information regarding symptom management strategies for those symptoms, however further studies would be useful to identify symptom management strategies for additional symptoms. For this study, the symptom management questionnaires were limited to those six for ease of use in the case where persons had multiple symptoms to respond to. For example, there are between 17-27 strategies to select from for each of the questionnaires, so if someone had 3 symptoms to answer the self-management strategies questionnaires for they could have fatigue or response burden from this. Future studies could be tailored to physical symptoms, or affective symptoms, where the researcher could limit the self-care measure to those specific to that set of symptoms.

There is a discrepancy between the report of the symptom of headache on the Problem Checklist, and the number of persons in the MTBI group who completed the self-management questionnaire for headache. Twenty-five persons with MTBI reported headache on the symptom checklist, while 26 completed the self-management questionnaire. Persons were first asked to complete the symptom checklist, and then were asked later in the interview if they had the symptom and if they said yes, then they were asked to complete the self-management questionnaire. The data collectors did not monitor responses on the Problem Checklist prior to having persons complete the self-management questionnaire. For future studies using these measures, it may be best to first see what symptoms were reported on the symptom checklist and then give the self-management questionnaires based on those responses.

Litigation was collected as a potential covariate because if there were many persons in the MTBI sample that were in litigation, it could be a limitation of the study because persons may endorse more symptoms in order to embellish their litigation status. Only one person in the MTBI group was seeking litigation, workman's compensation, for their injury, and so for this study it was not felt that litigation would contribute as a significant variable.

Implications for Clinical Practice

Persons with Mild Traumatic Brain Injury (MTBI)/concussion are typically treated and released from the emergency department (ED) (Bazarian et al., 2005). In many cases, persons are not promptly directed for follow up care (Blostein & Jones 2003; Bazarian et al., 2005) and are thus left to manage their symptoms without professional oversight. Up to 62% of persons report at least one symptom following their MTBI with 44% reporting one or more symptom at 3 months post-injury (Lannsjo et al., 2009). It is important to achieve symptom relief because symptoms that are not alleviated, or persistent symptoms, can lead to disability in terms of return to work or school (Lundin et al., 2006; Yang et al., 2007).

Results from this study can be used to develop the symptom management toolkit. From this study we know that there are simple strategies that persons with MTBI have used that they consider to be effective at symptom relief. Using this information, we can create a toolkit for the most frequent MTBI symptom as well as the most bothersome symptoms, and list the strategies that others have found to be helpful for each symptom.

There are inconsistencies in the management and follow up of persons with MTBI. In some cases, persons do not seek treatment for their MTBI and are left to manage symptoms on their own. Development of the symptom management toolkit that could be advertised and available to the public would allow those that do not seek treatment to have access to the education about symptom management. This toolkit would also have suggestions for seeking healthcare if/when symptoms do not improve.

Development of a symptom management toolkit that persons could use to self-manage symptoms would likely help reduce the number and duration of symptoms. We know from previous studies that education provided by healthcare providers (Bell et al., 2008) was beneficial at reducing symptoms, so in the case of a toolkit, persons are able to self-educate at the time that they need the help with symptom management.

From this study, we found that symptoms that occur most frequently are not always the same as those that are most severe or most bothersome following MTBI. For healthcare providers this knowledge could enhance the way that we ask persons about their post-MTBI symptoms. Current concussion evaluation tools such as the Acute Concussion Evaluation offered by the CDC (cdc.gov, 2005) include a symptom checklist that asks about the presence of the symptom but no other characteristics such as severity or bother. Perhaps adding to that or other patient instructions that management of symptoms that are most bothersome would be a good way to prioritize symptom self-management.

There has been an increase interest in the mild brain injury population in recent years, due to increasing suspicions about the long term effects of concussion on NFL players, to the possibility of a fatal second impact syndrome that impacts adolescents in sports, and the increasing awareness of military personnel sustaining brain injuries in blast and non-blast related incidents. Through this increase awareness, several groups have worked to develop guidelines for the management of MTBI/concussion. The American Association of Pediatrics (Halstead et al., 2010), The Veterans Administration (Department of Veterans Affairs, 2009), and the American Association of Neuroscience Nurses (American Association of Neuroscience Nurses, 2011, available at AANN.org) have all developed guidelines. In addition, the International Symposia on Concussion in Sports has established guidelines for the sports injury population (McRory et al., 2009). These guidelines can be very helpful to healthcare providers in development of management guidelines within institutions, and will ideally help to limit the variation in care and management of MTBI that has existed in the past (Blostein & Jones, 2003). The guidelines are written to assist healthcare professionals and are not written at a literacy level appropriate for the general public. The symptom management toolkit would use information from the guidelines that are supported by levels of evidence, along with the results of this study, to create helpful symptom self-management strategies that are easily understood by the majority of the population.

Implications for Future Research

This study produced new information about the bothersome nature of symptoms following MTBI as well as new knowledge about symptom management strategies and effectiveness of those strategies. One of the limitations of this study was the small sample size of 30 persons in the MTBI and comparison groups, and further studies with larger sample sizes might be helpful to better detect significant relationships.

The role of bother in the symptom management process requires further investigation. In this study, overall, there was a relationship between being bothered by symptoms and the use of symptom management strategies. The use of larger sample size would help to better understand this relationship. If it is further supported that being bothered by symptoms is the driving force behind attempting to manage symptoms, then asking that question of persons during assessment of MTBI would be useful. In addition, when educating persons about symptom management strategies, healthcare providers could discuss with persons with MTBI that they may be more bothered by some symptoms than others, and that focusing their self-management strategies on those symptoms that are most bothersome may be beneficial.

The symptom self-management questionnaire used for this study was adapted from the HIV literature, and then pilot tested with the MTBI sample. Further refinement of this measure for use with the MTBI and other populations may be useful. The measures for each symptom contain between 17-28 self-management strategies. For this study, the self-management questionnaires were limited to the 6 most commonly reported MTBI symptoms to limit the response burden. It may be possible in future studies to combine the self-management strategies into one single measure that could be used for all symptoms, provided that a space for persons to write in their own strategies was available. Use of a single measure would reduce the response burden but may not be appropriate for all research questions. For example, if a researcher wanted to know specifically about symptom management for a specific symptom, then the respondent would need to answer the questionnaire for each symptom that they have, whereas if the researched wanted to know overall what persons are doing to manage symptoms (not any one specific symptom), then the more general questionnaire would be useful.

Based on the results of this study as well as supporting literature, a symptom toolkit will be developed. Pilot testing of the symptom management toolkit will be necessary for ease of use, for content validity, and for effectiveness of symptom relief. After the pilot test and any necessary changes to the tool, it would be ideal to perform a randomized trial to compare use of the toolkit to current standard of care for MTBI.

Because not all persons with MTBI seek treatment, another area of research would be to explore ways to make information such as the symptom management toolkit available to persons outside of the healthcare setting. Various sources of advertisement about how persons can locate the toolkit would be necessary to spread the word of its availability. There also could be a link to the toolkit from common MTBI sites such as the CDC's Heads Up on Concussion site. Monitoring of the website hits could be done to determine the amount of visits to the website, and a survey about the use of the toolkit could be offered on the website as well. The toolkit could be made available in paper copies available at healthcare settings and available to download to computers or smartphones. Larger sites such as the CDC or the American Association of Neuroscience Nurses could sponsor the toolkit and advertise and distribute them to a wide population. Ongoing research regarding the use of and helpfulness of the toolkit would be warranted.

Policy Implications

Recently, there has been increased awareness regarding the long term consequences of mild traumatic brain injury/concussion. The NFL has undergone public scrutiny about knowing that players are sustaining multiple concussions and returning them to play. There has been a trickle-down effect of this public awareness to the college and high school athletic organizations. As a result, several states have supported policies regarding reporting and follow up of athletes with concussion. Many states adhere to the National Federation of State High School Association guidelines which can be found at NFHS.org. While there has been improvement in awareness of concussion due to the NFL, NCAA, and NFHS, the adherence to the guidelines is not monitored or reported.

Although there are guidelines for the management of MTBI as previously discussed, the use of the guidelines is unknown and healthcare providers at this time are not mandated to follow these guidelines. There are known inconsistencies in the management of MTBI (Blostein & Jones, 2003) and the consistent use of guidelines would reduce the inconsistency and improve care for persons with MTBI. Ideally, large groups and organizations such as American Association of Neurology, Academy of Emergency Department Physicians, American Association of Neuroscience Nurses, Trauma Nurses Society, and others can continue to endorse the use of guidelines and improve the outcomes of persons with MTBI. One way to streamline the care of persons with MTBI would be to offer healthcare services through concussion clinics. These clinics could utilize the current guidelines for management and continue to research the symptom experience and outcomes for person with MTBI.

Summary

This study described the bothersome nature of symptoms, explored what symptom management strategies are used by persons with MTBI, and evaluated the self-reported effectiveness of symptom management strategies. Results from this study can be used to improve our understanding of the symptom experience for persons with MTBI. In addition, this study was the first to ask persons with MTBI what they were doing on their own to self-manage their symptoms, and discover how effective they report those strategies to be. These results can be used to create improved patient education regarding MTBI related symptoms and how to manage symptoms once they leave the healthcare setting. Improving the ability for persons to manage symptoms on their own may improve person's ability to return to their roles and improve outcomes for this population.

APPENDICES

Appendix A

Demographic Questionnaire

Name______________________

Address_____________________

City________________________

State_______________________

Zip Code____________________

Phone______________________

Cell phone__________________

Date of injury:__________

Age_____

Sex _____Male ____Female

Race:
___Non-Hispanic White ___African American
___Hispanic ___Asian or Asian American
___American Indian or Alaskan Native
___Hawaiian or other Pacific Islander

Marital Status:
___Married ___Divorced
___Widowed ___Separated
___Never Married
___A member of an unmarried couple

Living Arrangements:
___Live alone ___Live with family/children(___# children)
___Live with Friends ___Homeless ___Incarcerated
Do you have support of friends/family for dealing with this injury____yes____no

Employment Status
___Employed
___Homemaker
___Student
___Unemployed since injury
___Unemployed prior to injury
___Self-employed
___Student
___Retired

Education Level
___Less than high school
___Some college
___4 year college degree
___Completed high school
___2 year college degree
___Advanced degree (Masters, PhD)

How were you injured:

___fall

___assault

___hit by car

___other

___car accident

___hit head on object

___bike/ATV

Medications:

Antidepressant___________

Pain medication__________

Heart medicine___________

Lung medicine___________

Blood sugar medicine___________

Arthritis medicine______________

Cholesterol medicine____________

Blood thinners_________________

Past Medical History:
___Depression
___Asthma

___Diabetes ___Problems with heart

___Lung problems ___Previous brain injury

___MS, Parkinson’s, or other neurologic conditions

___Stroke ___Chronic pain (location_______)

___Psychiatric illness (severe depression, psychosis, bipolar disease)

___Regular use (abuse) of alcohol or other substances

Litigation Status:

____Seeking legal compensation for injury

____Not seeking legal compensation

Injury Variables:

Initial Glasgow Coma Score (GCS) _____

Self-reported Presentation and Symptoms at time of injury:

confusion or disorientation_____ loss of consciousness for 30 minutes or less____

post traumatic amnesia for less than 24 hours____

other transient neurological abnormalities______Describe______________________

____

Verified with ED documentation ____yes _____no
(explain)____

Other injuries sustained at the time of this injury:

Fractures_____________describe_____________

Abdominal injury____________

Chest Injury________________

Facial Injury________________

Extremity Injury_____________

Other (describe)___________________________

Appendix B

The Problem Checklist (PCL)

PROBLEM CHECKLIST ITEMS—Adapted from Kay

The following is a list of symptoms that you may have experienced. For each symptoms or problem that you experienced in the **present or past 1 week**, please identify **how often** you experience the symptom, **how severe** it was and **how bothersome** the symptom was.

****

Bothersome=disruptive to daily activities	**How often?**	**How severe?**	**How bothersome?**
	0= never	0=not severe	0= not at all bothersome
	1= rarely	1= slightly severe	1= a little bothersome
	2= a little (1-2days/week)	2= moderately severe	2= somewhat bothersome
	3= occasionally (3-4 days/week)	3= severe	3= bothersome quite often
	4= most times (5-7 days/week)	4 = very severe	4= very much bothersome
Symptom or problem	**How often?**	**How severe?**	**How bothersome?**
1. Do you have visual problems; difficulty seeing?			
2. Do you have hearing difficulties?			
3. Do you have poor balance?			
4. Do you do things slowly?			
5. Do you have difficulty pronouncing words clearly (dysarthria)?			
6. Do you have problems with coordination?			
7. Do you fatigue quickly or get tired easily?			
8. Do you get headaches?			

Appendix B (cont’d)

	How often?	**How severe?**	**How bothersome?**
	0= never	0=not severe	0= not at all bothersome
	1= rarely	1= slightly severe	1= a little bothersome
	2= a little (1-2days/week)	2= moderately severe	2= somewhat bothersome
	3= occasionally (3-4 days/week)	3= severe	3= bothersome quite often
	4= most times (5-7 days/week)	4 = very severe	4= very much bothersome
Symptom or problem			
9. Do you have dizziness/vertigo?			
10. Do you have sensitivity to noise?			
11. Do you have sensitivity to light?			
12. Do you have problems with taste or smell?			
13. Do you have difficulty remembering the right word (word finding)?			
14. Do you express yourself in a wordy, roundabout way?			
15. Are you easily distractible (e.g., in a noisy room)?			
16. Do you have poor concentration for extended periods of time?			
17. Are you forgetful or have difficulty remembering things?			

Appendix B (cont'd)

	How often?	**How severe?**	**How bothersome?**
	0= never	0=not severe	0= not at all bothersome
	1= rarely	1= slightly severe	1= a little bothersome
	2= a little (1-2days/week)	2= moderately severe	2= somewhat bothersome
	3= occasionally (3-4 days/week)	3= severe	3= bothersome quite often
	4= most times (5-7 days/week)	4 = very severe	4= very much bothersome
Symptom or problem			
18. Do you have difficulty thinking clearly and efficiently?			
19. Do you have difficulty planning and organizing things?			
20. Do you have difficulty in setting realistic goals?			
21. Do you have difficulty following through or finishing things?			
22. Do you feel apathetic, or a lack of interest in things?			
23. Do you lack initiative and can't start things up?			
24. Do you feel irritable?			
25. Do you feel restlessness?			
26. Do you lose your temper or have outbursts?			
27. Do you have mood swings, and quick emotional shifts?			
28. Do you have difficulty bringing your emotions under control once you've expressed them?			

Appendix B (cont’d)

	How often?	**How severe?**	**How bothersome?**
	0= never	0=not severe	0= not at all bothersome
	1= rarely	1= slightly severe	1= a little bothersome
	2= a little (1-2days/week)	2= moderately severe	2= somewhat bothersome
	3= occasionally (3-4 days/week)	3= severe	3= bothersome quite often
	4= most times (5-7 days/week)	4 = very severe	4= very much bothersome
29. Do you get into arguments with others?			
30. Do you get physically violent?			
31. Do you get bored easily?			
32. Do you complain about things?			
33. Are you dependent on others?			
34. Do you need supervision?			
35. Do you have anxiety/tension?			
36. Do you have depression?			
37. Do you feel loneliness?			
38. Do you feel a loss of confidence?			
39. Do you have changes in appetite?			
40. Do you have sleep disturbance?			

Appendix B (cont'd)

	How often?	**How severe?**	**How bothersome?**
	0= never	0=not severe	0= not at all bothersome
	1= rarely	1= slightly severe	1= a little bothersome
	2= a little (1-2days/week)	2= moderately severe	2= somewhat bothersome
	3= occasionally (3-4 days/week)	3= severe	3= bothersome quite often
	4= most times (5-7 days/week)	4 = very severe	4= very much bothersome
41. Do you have a low sexual drive?			
42. Do you have a high sexual drive?			
43. Has your personality changed?			

Appendix C Symptom Self-Management Questionnaire

Anxiety - worrisome thoughts or feelings of panic

Self-Care for Anxiety Here are some things people may do for anxiety. Please review the list and:

1) Circle how often you use this strategy
2) If you use the strategy, circle the number to rate how well it works for you.

	How often used						Does it work?				
	Not used	Rarely used	Monthly	Weekly	Daily	Several times Per day	Never	Rarely	Some times	Often	Always
	0	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**	**4**
ACTIVITIES/THOUGHTS											
Talk with family & friends	0	1	2	3	4	5	0	1	2	3	4
Talk with health care provider	0	1	2	3	4	5	0	1	2	3	4
Talk with others with brain injury	0	1	2	3	4	5	0	1	2	3	4
Denial or try not to think	0	1	2	3	4	5	0	1	2	3	4
Cry	0	1	2	3	4	5	0	1	2	3	4
Stay alone	0	1	2	3	4	5	0	1	2	3	4
Talk myself through it	0	1	2	3	4	5	0	1	2	3	4
Watch TV	0	1	2	3	4	5	0	1	2	3	4
Playing cards	0	1	2	3	4	5	0	1	2	3	4
Read	0	1	2	3	4	5	0	1	2	3	4
Cook	0	1	2	3	4	5	0	1	2	3	4
EXERCISE											
Walking	0	1	2	3	4	5	0	1	2	3	4
Exercising	0	1	2	3	4	5	0	1	2	3	4
MEDICATIONS											
Prescription anti-anxiety agent (such as Ativan^{TM} Xanax^{TM})	0	1	2	3	4	5	0	1	2	3	4

	How often used						**Does it work?**				
	Not used **0**	Rarely used **1**	Monthly **2**	Weekly **3**	Daily **4**	Several times Per day **5**	Never **0**	Rarely **1**	Some times **2**	Often **3**	Always **4**
Other Medications for anxiety List______________	0	1	2	3	4	5	0	1	2	3	4
COMPLEMENTARY THERAPIES											
Meditation	0	1	2	3	4	5	0	1	2	3	4
Prayer	0	1	2	3	4	5	0	1	2	3	4
Relaxation techniques	0	1	2	3	4	5	0	1	2	3	4
SUBSTANCE USE											
Marijuana	0	1	2	3	4	5	0	1	2	3	4
Cigarettes	0	1	2	3	4	5	0	1	2	3	4
Alcohol	0	1	2	3	4	5	0	1	2	3	4
Street Drugs	0	1	2	3	4	5	0	1	2	3	4
Healthcare											
See Doctor	0	1	2	3	4	5	0	1	2	3	4
See other healthcare provider List: _________________	0	1	2	3	4	5	0	1	2	3	4
Seek information/education about this symptom Where:________________	0	1	2	3	4	5	0	1	2	3	4
OTHERS YOU MAY WISH TO ADD											
_________________	0	1	2	3	4	5	0	1	2	3	4
_________________	0	1	2	3	4	5	0	1	2	3	4

Depression - feeling blue, low, depressed or sad.

Self-Care for Depression Here are some things people may do for depression. Please review the list and:
1) Circle how often you use this strategy
2) If you use the strategy, circle the number to rate how well it works for you.

	How often used						Does it work?				
	Not used **0**	Rarely used **1**	Monthly **2**	Weekly **3**	Daily **4**	Several times Per day **5**	Never **0**	Rarely **1**	Some times **2**	Often **3**	Always **4**
ACTIVITIES/THOUGHTS											
Talk with family & friends	0	1	2	3	4	5	0	1	2	3	4
Talk with health care provider	0	1	2	3	4	5	0	1	2	3	4
Talk with others with brain injury	0	1	2	3	4	5	0	1	2	3	4
Avoid negative or annoying things	0	1	2	3	4	5	0	1	2	3	4
Go to work	0	1	2	3	4	5	0	1	2	3	4
Do things I enjoy	0	1	2	3	4	5	0	1	2	3	4
Keep busy	0	1	2	3	4	5	0	1	2	3	4
Draw	0	1	2	3	4	5	0	1	2	3	4
Read	0	1	2	3	4	5	0	1	2	3	4
Listen to music	0	1	2	3	4	5	0	1	2	3	4
EXERCISE											
Walking	0	1	2	3	4	5	0	1	2	3	4
Exercising	0	1	2	3	4	5	0	1	2	3	4
MEDICATIONS											
Prescription anti-depressant (such as Prozac^{TM}, Zoloft^{TM})	0	1	2	3	4	5	0	1	2	3	4

	How often used						Does it work?				
	Not used 0	**Rarely used 1**	**Monthly 2**	**Weekly 3**	**Dailv 4**	**Several times Per day 5**	**Never 0**	**Rarely 1**	**Some times 2**	**Often 3**	**Always 4**
COMPLEMENTARY THERAPIES											
Meditation	0	1	2	3	4	5	0	1	2	3	4
Prayer	0	1	2	3	4	5	0	1	2	3	4
SUBSTANCE USE											
Marijuana	0	1	2	3	4	5	0	1	2	3	4
Cigarettes	0	1	2	3	4	5	0	1	2	3	4
Alcohol	0	1	2	3	4	5	0	1	2	3	4
Street drugs	0	1	2	3	4	5	0	1	2	3	4
Healthcare											
See Doctor	0	1	2	3	4	5	0	1	2	3	4
See other healthcare provider List: __________________	0	1	2	3	4	5	0	1	2	3	4
Seek information/education about this symptom Where:_________________	0	1	2	3	4	5	0	1	2	3	4
OTHERS YOU MAY WISH TO ADD											
_______________	0	1	2	3	4	5	0	1	2	3	4
_______________	0	1	2	3	4	5	0	1	2	3	4

Dizziness- a feeling as if the room is spinning, or that you are losing your balance. This is sometimes called vertigo by healthcare providers.

Self-Care for Dizziness: Here are some things people may do for Dizziness. Please review the list and:
1) Circle how often you use this strategy
2) If you use the strategy, circle the number to rate how well it works for you

	How often used						**Does it work?**				
	Not used	Rarely used	Monthly	Weekly	Daily	Several times Per day	Never	Rarely	Some times	Often	Always
	0	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**	**4**
ACTIVITIES/THOUGHTS											
Talk with friends	0	1	2	3	4	5	0	1	2	3	4
Don’t dwell on it	0	1	2	3	4	5	0	1	2	3	4
Practice balancing	0	1	2	3	4	5	0	1	2	3	4
MEDICATIONS											
Prescription medicine for dizziness List_____________	0	1	2	3	4	5	0	1	2	3	4
Over the Counter medicine	0	1	2	3	4	5	0	1	2	3	4
Nutrition/Supplements											
Vitamins/herbs	0	1	2	3	4	5	0	1	2	3	4
Low Salt Diet	0	1	2	3	4	5	0	1	2	3	4
BEING PREPARED											
Get up slowly	0	1	2	3	4	5	0	1	2	3	4
Move slowly	0	1	2	3	4	5	0	1	2	3	4
Hold on to things for support	0	1	2	3	4	5	0	1	2	3	4

	How often used						**Does it work?**				
	Not used **0**	Rarely used **1**	Monthly **2**	Weekly **3**	Daily **4**	Several times Per day **5**	Never **0**	Rarely **1**	Some times **2**	Often **3**	Always **4**
SUBSTANCE USE											
Marijuana	0	1	2	3	4	5	0	1	2	3	4
Cigarettes	0	1	2	3	4	5	0	1	2	3	4
Alcohol	0	1	2	3	4	5	0	1	2	3	4
Street drugs	0	1	2	3	4	5	0	1	2	3	4
Healthcare											
See Doctor	0	1	2	3	4	5	0	1	2	3	4
See other healthcare provider List: ________________	0	1	2	3	4	5	0	1	2	3	4
Seek information/education about this symptom Where:________________	0	1	2	3	4	5	0	1	2	3	4
OTHERS YOU MAY WISH TO ADD											
______________	0	1	2	3	4	5	0	1	2	3	4
______________	0	1	2	3	4	5	0	1	2	3	4

Fatigue - feeling tired, weary, or exhausted.

Self-Care for Fatigue Here are some things people may do for fatigue. Please review the list and:

1) Circle how often you use this strategy
2) If you use the strategy, circle the number to rate how well it works for you

	How often used						**Does it work?**				
	Not used	Rarely used	Monthly	Weekly	Daily	Several times Per day	Never	Rarely	Some times	Often	Always
	0	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**	**4**
ACTIVITIES/THOUGHTS											
Get Enough sleep	0	1	2	3	4	5	0	1	2	3	4
Take frequent breaks	0	1	2	3	4	5	0	1	2	3	4
Adjust social activities	0	1	2	3	4	5	0	1	2	3	4
Not get stressed out	0	1	2	3	4	5	0	1	2	3	4
Nap during the day	0	1	2	3	4	5	0	1	2	3	4
EXERCISE											
Walking	0	1	2	3	4	5	0	1	2	3	4
Other Exercising	0	1	2	3	4	5	0	1	2	3	4
COMPLEMENTARY THERAPIES											
Acupuncture	0	1	2	3	4	5	0	1	2	3	4
Prayer	0	1	2	3	4	5	0	1	2	3	4
Massage	0	1	2	3	4	5	0	1	2	3	4
SUPPLEMENTS/VITAMINS/NUTRITION											
Vitamins	0	1	2	3	4	5	0	1	2	3	4
Minerals	0	1	2	3	4	5	0	1	2	3	4

	How often used						Does it work?				
	Not used **0**	Rarely used **1**	Monthly **2**	Weekly **3**	Daily **4**	Several times Per day **5**	Never **0**	Rarely **1**	Some times **2**	Often **3**	Always **4**
Amino acids	0	1	2	3	4	5	0	1	2	3	4
Herbs	0	1	2	3	4	5	0	1	2	3	4
Eating well	0	1	2	3	4	5	0	1	2	3	4
MEDICATIONS											
Prescription Medications	0	1	2	3	4	5	0	1	2	3	4
Over the counter sleep aids	0	1	2	3	4	5	0	1	2	3	4
SUBSTANCE USE											
Marijuana	0	1	2	3	4	5	0	1	2	3	4
Cigarettes	0	1	2	3	4	5	0	1	2	3	4
Alcohol	0	1	2	3	4	5	0	1	2	3	4
Street Drugs	0	1	2	3	4	5	0	1	2	3	4
Healthcare											
See Doctor	0	1	2	3	4	5	0	1	2	3	4
See other healthcare provider List: ________________	0	1	2	3	4	5	0	1	2	3	4
Seek information/education about this symptom Where:_______________	0	1	2	3	4	5	0	1	2	3	4
OTHERS YOU MAY WISH YOU ADD											
_____________	0	1	2	3	4	5	0	1	2	3	4
_____________	0	1	2	3	4	5	0	1	2	3	4

Headache : pain or tension in the head

Self-Care for Headache: Here are some things people may do for Headache. Please review the list and:

1) Circle how often you use this strategy

2) If you use the strategy, circle the number to rate how well it works for you

	How often used						**Does it work?**				
	Not used	Rarely used	Monthly	Weekly	Daily	Several times Per day	Never	Rarely	Some times	Often	Always
	0	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**	**4**
ACTIVITIES/THOUGHTS											
Relaxation techniques	0	1	2	3	4	5	0	1	2	3	4
Close eyes	0	1	2	3	4	5	0	1	2	3	4
Lay down	0	1	2	3	4	5	0	1	2	3	4
Hot/Cold compresses	0	1	2	3	4	5	0	1	2	3	4
Think reassuring thoughts	0	1	2	3	4	5	0	1	2	3	4
EXERCISE											
Walking	0	1	2	3	4	5	0	1	2	3	4
Other Exercising	0	1	2	3	4	5	0	1	2	3	4
MEDICATIONS											
Prescribed anti-epileptic agent (Neurontin^{TM} Klonopin^{TM})	0	1	2	3	4	5	0	1	2	3	4
Prescribed pain medicine	0	1	2	3	4	5	0	1	2	3	4
Over-the-counter medications (Tylenol^{TM}, Motrin^{TM}, Advil^{TM})	0	1	2	3	4	5	0	1	2	3	4
SUPPLEMENTS/VITAMINS											
Vitamins	0	1	2	3	4	5	0	1	2	3	4
Herbal supplements	0	1	2	3	4	5	0	1	2	3	4
COMPLEMENTARY THERAPIES											
Massage	0	1	2	3	4	5	0	1	2	3	4

	How often used						Does it work?				
	Not used	Rarely used	Monthly	Weekly	Daily	Several times Per day	Never	Rarely	Some times	Often	Always
	0	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**	**4**
Acupuncture	0	1	2	3	4	5	0	1	2	3	4
Reflexology therapy	0	1	2	3	4	5	0	1	2	3	4
Meditation	0	1	2	3	4	5	0	1	2	3	4
SUBSTANCE USE											
Marijuana	0	1	2	3	4	5	0	1	2	3	4
Cigarettes	0	1	2	3	4	5	0	1	2	3	4
Alcohol	0	1	2	3	4	5	0	1	2	3	4
Street Drugs	0	1	2	3	4	5	0	1	2	3	4
Healthcare											
See Doctor	0	1	2	3	4	5	0	1	2	3	4
See other healthcare provider List: __________________	0	1	2	3	4	5	0	1	2	3	4
Seek information/education about this symptom Where:_________________	0	1	2	3	4	5	0	1	2	3	4
OTHERS YOU MAY WISH TO ADD											
_________________________	0	1	2	3	4	5	0	1	2	3	4
__________________________	0	1	2	3	4	5	0	1	2	3	4

Difficulty thinking, memory Difficulties - problems remembering things, problems concentrating, feeling mentally foggy, thinking slowly.

Self-Care for memory difficulties: Here are some things people may do for problems with memory or concentration. Please review the list and:

1) Circle how often you use this strategy
2) If you use the strategy, circle the number to rate how well it works for you

	How often used						**Does it work?**				
	Not used	Rarely used	Monthly	Weekly	Daily	Several times Per day	Never	Rarely	Some times	Often	Always
	0	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**	**4**
ACTIVITIES/THOUGHTS											
Get Enough sleep	0	1	2	3	4	5	0	1	2	3	4
Take frequent breaks	0	1	2	3	4	5	0	1	2	3	4
Talk with others	0	1	2	3	4	5	0	1	2	3	4
Adjust work/school activities	0	1	2	3	4	5	0	1	2	3	4
Make lists	0	1	2	3	4	5	0	1	2	3	4
Use calendar	0	1	2	3	4	5	0	1	2	3	4
Practice remembering	0	1	2	3	4	5	0	1	2	3	4
EXERCISE											
Walking	0	1	2	3	4	5	0	1	2	3	4
Other Exercising	0	1	2	3	4	5	0	1	2	3	4
COMPLEMENTARY THERAPIES											
Acupuncture	0	1	2	3	4	5	0	1	2	3	4
Prayer	0	1	2	3	4	5	0	1	2	3	4
Massage	0	1	2	3	4	5	0	1	2	3	4

	How often used						Does it work?				
	Not used **0**	Rarely used **1**	Monthly **2**	Weekly **3**	Daily **4**	Several times Per day **5**	Never **0**	Rarely **1**	Some times **2**	Often **3**	Always **4**
SUPPLEMENTS/VITAMINS/NUTRITION											
Vitamins	0	1	2	3	4	5	0	1	2	3	4
Herbs	0	1	2	3	4	5	0	1	2	3	4
Eating well	0	1	2	3	4	5	0	1	2	3	4
MEDICATIONS											
Prescription Medications	0	1	2	3	4	5	0	1	2	3	4
Over the counter medicine	0	1	2	3	4	5	0	1	2	3	4
SUBSTANCE USE											
Marijuana	0	1	2	3	4	5	0	1	2	3	4
Cigarettes	0	1	2	3	4	5	0	1	2	3	4
Alcohol	0	1	2	3	4	5	0	1	2	3	4
Street Drugs	0	1	2	3	4	5	0	1	2	3	4
Healthcare											
See Doctor	0	1	2	3	4	5	0	1	2	3	4
See other healthcare provider	0	1	2	3	4	5	0	1	2	3	4
Seek information/education about this symptom Where:_________________	0	1	2	3	4	5	0	1	2	3	4
OTHERS YOU MAY WISH YOU ADD											
_______________	0	1	2	3	4	5	0	1	2	3	4
_______________	0	1	2	3	4	5	0	1	2	3	4

Appendix D

Research Participant Information and Consent Form

You are being asked to participate in a research project. Researchers are required to provide a consent form to inform you about the study, to convey that participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Study Title: Symptom Self-Management for Mild Traumatic Brain Injury

Researcher and Title:	Karen Bergman, Doctoral Student in College of Nursing, Michigan State University
Department and Institution:	Neuroscience Coordinator, Bronson Hospital
Address and Contact Information:	601 John St, Kalamazoo MI, 49007 269-341-7587 office 269-993-6153 cell 269-341-8244 fax
Researcher and Title:	Barbara Given RN PhD
Department and Institution:	MSU College of Nursing
Address and Contact Information:	B515C West Fee East Lansing MI 48824 517-432-9159 phone 517-353-8536 fax

Sponsor: Dr Barbara Given

1. PURPOSE OF RESEARCH:

- You are being asked to participate in a research study of the self-management of symptoms after mild brain injury. This study may be done with Bronson Hospital, Sparrow Hospital, and PAR rehabilitation.
- You have been asked to join this study because you recently had a mild traumatic brain injury or concussion
- From this study, the investigators hope to learn what persons with mild brain injury do to manage their symptoms once they leave the emergency department
- In the entire study, 105 people are being asked to join.
- The time needed for you to be in this study is about 30 minutes.
- If you are under 18, you cannot be in this study.

2. ALTERNATIVE OPTIONS

- If you decide not to take part in this study, you should know that there are other treatments that may be helpful in treating your condition. They include discussing your symptoms and any problems you are having with your healthcare provider.

3. WHAT YOU WILL DO:

If you agree to participate in this study you will be asked to:

- *Return to the hospital to an office setting within three months of your injury.*
- *Answer 2 questionnaires, one about what symptoms you have and one about what you have been doing to manage the symptoms.*
- *Answer basic questions about your age, employment status, how you got injured, ect.*

4. POTENTIAL BENEFITS:

- You will not directly benefit from being in this study. However, your being in this study may help us better understand brain injury and this may help others in the future.

5. POTENTIAL RISKS:

- The potential risks of being in this study are fatigue (being tired) and possibly frustration with answering several questions
- There are no known risks associated with participation in this study.

6. PRIVACY AND CONFIDENTIALITY:

- Information that you give will not be linked to your personal information. Only the person collecting your data and the study investigator will have access to your personal information. Your name will be removed from forms. A study number will be used in place of your name.
- Information for the questionnaires will obtained in a private location. Questionnaires once completed will be placed in locked files.
    - Protected health information will be kept in a secure location (locked cabinet in locked office) for 3 years, and then will be destroyed

- Information about you will be kept confidential to the maximum extent allowable by law.
    - People who will have access to your data may include
        - Researchers and Research Staff.
        - Institutional Review Board (IRB).[MSU, Bronson Hospital, Sparrow Hospital]

- The results of this study may be published or presented at professional meetings, but the identities of all research participants will remain anonymous.

7. YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW

- Participation in this research project is completely voluntary. You have the right to say no.
- You may change your mind at any time and withdraw.
    - *There are no consequences to you if you decide not to participate or to withdraw*
- You may choose not to answer specific questions or to stop participating at any time.
- Choosing not to participate or withdrawing from this study will not make any difference in
    - the quality of any treatment you may receive.
    - benefits to which you are otherwise entitled.
- Whether you choose to participate or not will have no affect on your care.

8. COSTS AND COMPENSATION FOR BEING IN THE STUDY:

- *There is no costs or compensation for being in the study*.

9. CONFLICT OF INTEREST

- *The researcher and research team have no conflicts of interest with this study.*

10. Release of Protected Health Information for Research Purposes:

This section explains how your personal health information that is collected for this study may be used. The law lets us use and share health information for research, if you agree to let us do this. If you let us use and share information about you, we will protect it as required by law.

What information are you asking me to release?
The health information that may be used or disclosed (released) for this study includes

Health information related to your brain injury, health history, information such as age, gender, education level.

What will be done with this information?

Your information may be used and shared with others:

- To carry out and to evaluate the results of this study
- To make sure the study is correctly performed
- To meet the reporting requirements of government agencies or for legal actions

WHO MAY USE OR SHARE YOUR PROTECTED HEALTH INFORMATION FOR THIS RESEARCH STUDY?

By signing this document you are giving permission to Bronson Hospital to use and share your health information for this research.

This information may be shared with:

- *The Research team including the Principal Investigators, Karen Bergman and Dr Barbara Given and all other research staff*
  - *Contact information: Karen Bergman 269-341-7587; Dr Barbara Given 517-432-9159*

Others who may see your health information during this study include:

- The Michigan State Institutional Review Board; The Bronson Methodist Hospital Institutional Review Board and their staff
- Agencies of the federal, state, or local government. This includes the Food and Drug Administration (FDA), Department of Health and Human Services (DHHS) and the Office for Human Research Protection.

If the information is shared with others and leaves Bronson Hospital, we cannot promise that others will keep it private. The information will be shared only if necessary.

If the results of this study are published, or presented at medical meetings, you will not be identified in any way.

How long will this authorization last?

Protected health information will be kept in a secure location (locked cabinet in locked office) for 3 years, and then will be destroyed.
Permission to view your protected health information will expire at the end of this study.

What happens if I do not give authorization or want to stop a previous authorization?

You can refuse to release your personal health information for this study. If you decide not to permit the release of your information:

- You will not be able to take part in the study.
- Your medical care outside of this study will not change
- Your medical care benefits will not change

You can change your mind and decide to withdraw your consent for the release of this information. You can stop collection of the information for study purposes by sending a letter to Karen Bergman, 601 John St, Kalamazoo MI, 49007. If you decide to withdraw your consent for the release of this information:

- We will stop collecting your medical information, and
- Any information that was collected before you withdrew your consent will be used and seen as described above.

11. CONTACT INFORMATION FOR QUESTIONS AND CONCERNS

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researcher Karen Bergman 601 John Street, Kalamazoo MI, 49007. 269-341-7587, email bergmank@bronsonhg.org. In addition, you may contact Dr Barbara Given at B515C West Fee, Michigan State University, East Lansing MI, 48824. Barbara Given phone is 517-432-9159.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 207 Olds Hall, MSU, East Lansing, MI 48824.

12. DOCUMENTATION OF INFORMED CONSENT.

Your signature below means that you voluntarily agree to participate in this research study.

______________________________________ ______________________________
Signature Date

Principal Investigator (or Designee):

Name (Print legal name): ____________________________ Title: _________________________

Signature of Primary Investigator or Designee: _____________________ Date: _____________

You will be given a copy of this form to keep.

This consent form was approved by the Community research Institutional Review Board (CRIRB) at Michigan State University. Approved 3/1/11-valid through 2/28/12. This version supersedes all previous versions. IRB # C09-178

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