Informatics Intervention for Self-Management of Pain after TBI

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Abstract

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The occurrence of traumatic brain injury (TBI) and post injury recovery are major public health concerns in the United States (Taylor et al., 2017). The number of TBI related emergency department visits, hospitalizations and deaths has increased over time and is currently about 2.8 million each year (Taylor et al., 2017). A prevalent and troublesome symptom following TBI is persistent pain, defined here as pain due to a health condition, disease process, injury or surgery that lasts beyond the normal period of healing, is resistant to treatment, includes physiological maladaptation, continues for at least 3 months, and is moderate or severe in intensity. More than three-quarters (75.3%) of those with mTBI report pain following injury (Nampiaparampil, 2008). Despite the prevalence and daily impact of persistent pain in persons with TBI, examination of contributing factors is a notable gap in this field of research. To promote optimal recovery and quality of life, there is a need to detect at-risk patients for persistent pain following TBI. This would enable development of interventions and rehabilitation services to ensure maximum post-injury recovery (Selassie, 2008). The purpose of this study is to fill a knowledge gap by first identifying patient risk factors for persistent pain, and then using

that information to create a prototype for a personalized informatics intervention for symptom self-management.

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Dedication

To Dr. Peter L. Portanova

Chapter 1

Introduction

Dissertation Abstract

Background

Traumatic brain injury (TBI)-related emergency department visits, hospitalizations and deaths are increasing, and currently number 2.8 million in the U.S. each year (Taylor et al., 2017). Approximately three-fourths of TBIs in the U.S. are classified as mild TBIs (mTBI) (Kobeissy et al., 2015). A mTBI is defined by having a Glasgow Coma Scale score of 13-15. Persistent pain after mTBI is common, with 75% of those with mTBI reporting post-injury pain (Nampiaparampil, 2008)**.** Persistent pain is associated with other negative outcomes including poor mental and physical health as well as social and financial consequences (Somers et al., 2015; Castillo et al., 2013; Honerlaw et al., 2016; Makris et al., 2014; Soh et al., 2017). To promote optimal recovery and quality of life, there is a need to detect at-risk patients for persistent pain following mTBI as well as develop interventions and rehabilitation services.

Purpose/Aims

The purpose of this study is to fill a gap in knowledge by first identifying risk factors for development of persistent pain following mTBI, and then using that information to create a prototype for a personalized informatics intervention for symptom self-management. This study has three aims. **The first study aim is to examine baseline characteristics, symptoms, injury related variables and demographic factors associated with the endorsement of persistent pain among those with mTBI from baseline to 6 months post injury**. To meet Aim 1, we will: a) describe the prevalence of persistent pain endorsement in a sample of adults following mTBI; b) identify pre-injury/injury-related factors associated with the development of persistent pain following mTBI including demographic variables, injury-related variables, and baseline characteristics; and c) describe differences in other symptoms endorsed between those with persistent pain and those who do not from baseline to 6 months post-injury. **Aim 2 is to determine if there are symptom clusters in those who have persistent pain following TBI**. **Aim 3 is to design a prototype of a mHealth intervention for self-management of**

pain after TBI. To meet this aim, we use data obtained from Aims 1 and 2 as well as participant feedback to inform the design of an informatics intervention to aid symptom detection, tracking and self-management.

Methods

The dissertation is organized into two phases. Phase 1 is a secondary data analysis that addresses Aims 1 and 2, and Phase 2 utilizes qualitative methods to address Aim 3. This study is guided by the Persistent Pain Model, which is constructed from the concept analysis of persistent pain where antecedents, attributes and consequences as well as other important variables are described.

Results/Implications

In the secondary analyses of persons with mTBI (n=183), we found that persistent pain was prevalent in those who had experienced a mTBI with 78% reporting persistent pain. Better quality of life at 7 days as well as 1 month after injury was a predictor for lower odds of experiencing persistent pain at 6 months. Findings from factor analysis indicated that persistent pain was strongly associated with other symptoms including anxiety, depression, dizziness, nausea and vomiting, sleep disturbance, poor memory, poor concentration, requiring longer to think and light sensitivity. Interviews of those who experienced pain after mTBI (n=7) indicated the desire for an app that could support self-management of pain and symptoms as well as enable sharing of recovery details with selected individuals.

Introduction

Significance

The occurrence of traumatic brain injury (TBI) and post injury recovery are major public health concerns in the United States (Taylor et al., 2017). The number of TBI-related emergency department visits, hospitalizations and deaths has increased over time and is currently about 2.8 million each year (Taylor et al., 2017). Approximately three-fourths of TBIs in the US are classified as mTBI (Kobeissy et al., 2015). A prevalent and troublesome symptom following TBI is persistent pain. More than three-quarters (75.3%) of those with mTBI report pain following injury (Nampiaparampil, 2008). Certain pain locations, such as neck and back, are associated with prolonged recovery time (Mollayeva et al., 2015). Experiencing a TBI is associated with having headaches and other poor outcomes such as depression (Lucas et al., 2016). Despite the prevalence and daily impact of persistent pain in persons with TBI, examination of contributing factors is a notable gap in this field of research.

Persistent Pain

After reviewing the literature (Portanova & Thompson, 2019), we define persistent pain as: “Pain due to a health condition, disease process, injury or surgery that lasts beyond the normal period of healing, is resistant to treatment, includes physiological maladaptation, continues for at least 3 months, and is moderate or severe in intensity.” Further discussion of development of a model for persistent pain can be found in Chapter 2. Persistent pain is widely known to be pain that lasts for an extended period. However, the antecedents and consequences as well as the way that patients’ own characteristics and health behaviors interact with their persistent pain experience are not clearly defined.

Persistent pain and symptoms.

Persistent pain is a major issue among persons following TBI and should be addressed early in the symptom trajectory (Prince & Bruhns, 2017). The goal of this line of inquiry is to enable healthcare professionals to be able to identify patients at risk for persistent pain first, understand their likely symptom clusters, and address their pain and other symptoms by implementing an informatics intervention that promotes self-management. This tool could improve self-efficacy in patients with TBI pain and reduce the burden on the healthcare system and reach underserved communities.

Patients who experience TBI and pain present a unique challenge for healthcare professionals to address (Sherman, Goldberg, & Bell, 2006). TBI and secondary symptoms such as pain have long-term consequences for patients in terms of job loss, difficulty returning to pre-injury activities and reduced life satisfaction (Centers for Disease Control and Prevention [CDC], 2015). Identifying which patients are at risk for persistent pain as early as possible is key to treating their pain and symptoms. This study seeks to identify characteristics of patients at-risk for persistent pain so they can be treated early on in their pain and symptom trajectory. Multiple constructs such as anxiety, depression, poor self-reported health, that impact quality of life, disability, and decreased socialization are measured from baseline to six months after injury. These constructs align with the variables in the Persistent Pain Model that guides this study. Pre-injury or injury variables might be indicators of which patients are more likely to have pain and symptoms throughout their recovery. These variables are often collected in the healthcare setting following injury and could be useful in identifying patients at risk for persistent pain after mTBI and allow for early intervention. We also examine symptoms co-occurring with persistent pain due to the increased burden multiple symptoms present to patients and the potential to alleviate more than one symptom.

Certain symptoms are commonly reported by those who have experienced mTBI. This study examines whether there are symptom clusters among those with mTBI to determine if patients experience interrelated, co-occurring symptoms after their injury. Information about symptom clusters after mTBI could lead to the creation of more effective symptom management interventions in the future. Symptom clusters have not been widely examined in the mTBI population. As an example of potential imact, those who experience the highest level of pain after mTBI often have co-occurring health conditions such as PTSD (Stojanovic et al., 2016). Furthermore, Lucas and colleagues (2016) suggest that those who present with headache after mTBI should also be evaluated for depression. Pain measures can help demonstrate the overall symptom burden in patients following mTBI (Schwab et al., 2017).

The focus of this study is exclusively on mTBI and not all TBI. The majority of those who suffer from TBI are classified as having mTBI and pain is often experienced during the recovery process among patients with mTBI (Nampiaparampil, 2008). The prevalence of mTBI, as well as the need for improvement in pain outcomes in this group make those with mTBI the ideal population to study for pain outcomes and to target for intervention. The neurological impact of mTBI is long term in nature (Webb et al., 2015). Gaps in the literature include: how special populations such as older adults or those from minority race/ethnic groups are impacted by pain after mTBI; what types of pain management techniques can be used together to reduce persistent pain; and how those with additional diagnoses can better self-manage their pain after injury.

Self-management.

Self-management strategies that have been successfully implemented for pain after mTBI include exercise and antidepressant use (King et al., 2015). Other self-management strategies for pain such as complementary and alternative medicine may improve outcomes but have not been studied in persons with mTBI (King et al., 2015). King and colleagues (2015) suggest that self-management for pain after mTBI might benefit from concurrent mental health interventions. Self-management of pain among those experiencing chronic pain has been effective in reducing pain and improving mental health (Mann et al., 2013). Common formats for delivery of self-management interventions for pain include group and individual sessions, telephone calls and/or study toolkits, online websites and delivering an intervention using more than one method (Mann et al., 2013). Facilitators to self-management for pain include support from family, friends and healthcare professionals, flexible self-management strategies and scheduling and treated mental health conditions (Mann et al., 2013).

Current self-management strategies for mTBI are important to learn from and to integrate into future interventions. A study of a self-management program of symptoms following TBI had promising results and demonstrated improvement in daily functioning (Kendrick et al., 2012). The supported self-management program approach was based in the community for a limited duration consisting of 8 sessions with an occupational therapist and psychologist (Kendrick et al., 2012). The program consisted of various coaching strategies including cognitive reframing and collaborative problem solving to help participants reduce their limitations in daily functioning after their injury (Kendrick et al., 2012). Multidisciplinary coaching to compensate for challenges has been favored over traditional rehabilitation in this population (Kendrick et al., 2012) and would be important to include in any self-management program. Therefore, prior programs support use of coaching and therapeutic techniques to support patient self-management.

Demographic and cultural factors are also imperative to consider when designing an intervention for those vulnerable to pain after mTBI and are understudied. Including aspects of education for the patient or family/caregiver could be a key element to making a self-management intervention successful in populations at an increased risk for poor pain management. Given the likely need for a tailored approach to pain management in this diverse population, an informatics tool may be highly beneficial. This is reinforced by Sawyer and colleagues’ (2015) recommendation to target interventions in order to improve early detection and secondary prevention of headaches in those with mTBI.

Current Informatics tools to support pain self-management.

Several informatics tools for pain tracking are currently available as mobile phone applications and computerized questionnaires. These tools allow patients to manage their pain from home with varied features and levels of usability. Tools that are easy for the end-user to use and that can be used remotely are good approaches to persistent pain management. Some of the current tools used to record, track, manage, and report pain are PainCompanion (2018), CatchMyPain (2018), PainScale (2018) and PainTracker (2017). Using Nielsen's (1995) 10 Usability Heuristics for User Interface Design we evaluated these currently available tools (see Appendix A). The range of criteria met these four tools was between two and nine out of ten. On average, tools met 60% of the criteria. Only two of the four tools met criteria for consistency and standards, recognition rather than recall, and help and documentation which would be critical features for persons following brain injury. Just one of the four tools met criteria for error prevention and flexibility and efficiency of use. No informatics intervention currently exists for patients with TBI who are at risk for persistent pain. Knowledge about the pain experiences of those with mTBI can be used to create more relevant and effective tools targeted at this population.

Some features that have been used in other pain applications might be successful with an informatics tool for those who have TBI. For example, ranking items of importance, as seen in the PainTracker computerized questionnaire, might be beneficial for those with TBI who have multiple issues to address when they meet with their healthcare providers. Suggestions from Valenti's (2016) study about increasing font size and working around scrolling capacity might make the application more usable for those with sensory issues as well as those who are older adults. The 2-way messaging capabilities explored by Jamison and colleagues (2017) might be able to increase use of the application in some participants. Pairing what we know from the evidence about pain in those with TBI with what we ask users to input on the application should increase the usefulness of the tool and reduce the burden on the user (Reynoldson et al., 2014).

Currently informatics interventions to address pain following traumatic brain injury are not widely used. This project challenges current clinical practice paradigms by developing an early intervention for those at risk of persistent pain and tailoring it to specific patient needs. The intervention could be adapted for those with cognitive issues (e.g., memory impairment) and may be useful in other populations with cognitive impairment in the future. The informatics intervention will be guided by the model of persistent pain which outlines the way the individual interacts with antecedents, attributes, and consequences of persistent pain. Understanding who is at risk for developing which co-occurring symptoms could lead to interventions addressing prevention and tailored treatment.

Given the potential impact of pain on the lives of those with TBI, there is a need for research to address how early intervention can improve patient outcomes. There are likely signs that someone is at risk for persistent pain, and that the risk for persistent pain can be identified and addressed early. Currently there are no known early interventions that address self-management of pain after a TBI. A novel informatics approach to address pain can assist in tracking pain and response to treatment. Given memory impairments commonly experienced following a TBI, this type of tool may play a particularly important role in self-management; however, little research is published that addresses the effectiveness of such interventions for persistent pain. This study is the first step in a trajectory to develop scalable tools to improve pain self-management. This area of research is important as it can improve the reach of interventions. This could particularly benefit rural living individuals and those in medically underserved areas, who often lack access to adequate pain management post TBI in order to reduce symptom burden and improve quality of life (Harrison et al., 2016).

Statement of Purpose

To promote optimal recovery and quality of life, there is a need to detect at-risk patients for persistent pain following TBI. This would enable development of interventions and rehabilitation services to ensure maximum post-injury recovery (Selassie, 2008). The purpose of this study is to fill a knowledge gap by first identifying patient risk factors for persistent pain, and then using that information to create a prototype for a personalized informatics intervention for symptom self-management.

Contents of Dissertation

Chapter 2:

A Concept Analysis of Persistent Pain is presented using Walker and Avant's (1988) approach as a guide in order to develop a testable model of persistent pain to undergird the dissertation work. This analysis included: uses of the concept; definitions; defining attributes; antecedents; consequences; a model case; a contrary case; a borderline case; empirical referents; and a conclusion. Data for this concept analysis was gathered systematically from PubMed by searching for "persistent pain" among adults. Articles published within the previous five years were included in this analysis to capture the most recent meaning of persistent pain in the literature to move forward with a current premise for future research in this area. Attributes, antecedents and consequences in the final model are described in the context of other important variables.

Chapter 3:

Results from secondary data analyses that were conducted to learn more about pain after traumatic brain injury are presented. Data was utilized from a separate NIH-funded longitudinal study, "Impact of Aging on the Immune Response to Traumatic Brain Injury." This parent study was a prospective cohort study of adults following mTBI. The analysis of this data addresses Specific Aims 1 and 2. Differences in persistent pain after mTBI were found between men and women. Significant differences in endorsement of persistent pain after mTBI are discussed.

Chapter 4:

Qualitative methods were utilized to address Aim 3 to design a prototype of a mHealth intervention for self-management of pain after TBI. The interview questions and data analysis were based on a design approach to examine the needs, preferences and features that the end-user wants from such a tool. In this study, we sought to understand the experiences of those who have pain after mTBI in order to try to create an informatics tool that alleviates pain and symptoms. Feedback from participants who have been individually interviewed after experiencing pain after mTBI are presented. This chapter discusses the needs of this patient population in terms of self-management of pain and symptoms and the ways that informatics tools would or would not be helpful to meet their needs.

Chapter 5:

This chapter is a summarization of the background described in Chapter 1 and the results of Aims 1-3 found in Chapters 3 and 4. The Persistent Pain Model described in Chapter 2 is revisited to discuss how results from the aims of this dissertation contribute to a better understanding of the concept of persistent pain and the needs of those with persistent pain. New findings are compared to current literature on persistent pain to discuss where the field is now. Future directions for research and practice in this area are suggested.

References

Castillo, R.C., Wegener, S.T., Heins, S.E., Haythornthwaite, J.A., Mackenzie, E.J., & Bosse, M.J. (2013). Longitudinal relationships between anxiety, depression, and pain: Results from a two-year cohort study of lower extremity trauma patients. *Pain*, 154, 2860-2866.

CatchMyPain. (2018). Retrieved from https://www.catchmypain.com/

Centers for Disease Control and Prevention. (2015). Report to congress on traumatic brain injury in the united states: epidemiology and rehabilitation. National Center for Injury Prevention and Control; Division of Unintentional Injury Prevention. Atlanta, GA.

Honerlaw, K.R., Rumble, M.E., Rose, S.L., Coe, C.L., Costanzo, E.S. (2016). Biopsychosocial predictors of pain among women recovering from surgery for endometrial cancer. *Gynecologic Oncology*, 140, 301-306.

Jamison, R. N., Jurcik, D.C., Edwards, R.R., Huang, C.C. & Roos, E.L. (2017). A pilot comparison of a smartphone app with or without 2-Way messaging among chronic pain patients: who benefits from a pain app? *Clinical Journal of Pain*, 33(8), 676-687.

Kendrick, D., Silverberg, N.D., Barlow, S., Miller, W.C., Moffat, J. (2012). Acquired brain injury self-management programme: a pilot study. *Brain Injury*, 26(10), 1243-9.

King, P.R., Beehler, G.P., Wade, M.J. (2015). Self-reported pain and pain management strategies among veterans with traumatic brain injury: A pilot study. *Military Medicine*, 180(8), 863.

Kobeissy, F.H., editor. Brain Neurotrauma: Molecular, Neuropsychological, and Rehabilitation Aspects. Boca Raton (FL): CRC Press/Taylor & Francis; 2015.

Lucas, S., Smith, B.M., Temkin, N., Bell. K.R., Dikmen, S., Hoffman, J.M. (2016). Comorbidity of headache and depression after mild traumatic brain injury. *Headache*, 56, 323-330.

Makris, U.E., Abrams, R.C., Gurland, B., Carrington Reid, M. (2014). Management of persistent pain in the older patient a clinical review. *Journal of the American Medical Association*, 312(8), 825-836.

Mann, T., De Ridder, D., Fujita, K. (2013). Self-regulation of health behavior: Social psychological approaches to goal setting and goal striving. *Health Psychology*, 32(5), 487-498.

Mollayeva, T., Shapiro, C.M., Mollayeva., David Cassidy, J., Colantonio, A. (2015). Modeling community integration in workers with delayed recovery from mild traumatic brain injury. *BioMed Central Neurology*, 15,194.

Nampiaparampil, D. E. (2008). Prevalence of chronic pain after traumatic brain injury: A systematic review. *Journal of the American Medical Association*, 300 (6), 711–719.

Nielsen, J. (1995). 10 Usability Heuristics for User Interface Design. Retrieved from https://www.nngroup.com/articles/ten-usability-heuristics/

PainCompanion. (2018). Retrieved from https://itunes.apple.com/us/app/pain-companion/id985521736?mt=8

PainTracker. (2017). Retrieved from https://paintracker.cirg.washington.edu/demo/users/index

PainScale. (2018). Retrieved from https://itunes.apple.com/us/app/painscale-pain-diary-and-coach/id1240897273?mt=8

Portanova, J. & Thompson, H. (2019). Persistent Pain: A Concept Analysis. WIN Conference, San Diego, CA.

Prince, C. & Bruhns, M.E. (2017). Evaluation and treatment of mild traumatic brain injury: the role of neuropsychology. *Brain Science*, 7(8).

Reynoldson, C., Stones, C., Allsop, M., Gardner, P., Bennett, M.I, Closs, S.J., Jones, R., & Knapp, P. (2014). Assessing the quality and usability of smartphone apps for pain self-management. *Pain Medicine*, 15, 989-909.

Sawyer, K., Bell, K.R., Ehde, D.M., Temkin, N., Dikmen, S., Williams, R.M., Dillworth, T., & Hoffman, J.M. (2015). Longitudinal study of headache trajectories in the year after mild traumatic brain injury: relation to posttraumatic stress disorder symptoms. Archives of Physical Medicine and Rehabilitation, 96,2000-6.

Schwab, K., Terrio, H.P., Brenner, L.A., Pazdan, R.M., McMillan, H.P., MacDonald, M., Hinds, S.R., & Scher, A.I. (2017). Epidemiology and prognosis of mild traumatic brain injury in returning soldiers. *Neurobiology BB*, 88,1571-1579.

Selassie, A.W., Zaloshnja, E., Langolis, J.A., Miller, T., Jones, P., and Steiner, C. (2008). Incidence of long-term disability following traumatic brain injury hospitalization, United States, 2003. Journal of Head Trauma Rehabilitation, 23(2), 123–131.

Sherman, K.B., Goldberg, M., Bell, K.R. (2006). TBI and pain. *Physical Medicine & Rehabilitation Clinics of NorthAmerica*,17(2),473-490.

Soh, E.D. & Portanova, J. (2017). Chronic noncancer pain management: systemic inequities in access. *Journal of Gerontological Nursing*, 43(10), 4-6.

Somers, T.J., Abernethy, A.P., Edmond, S.N., Kelleher, S.A., Wren, A.A., Samsa, G.P., & Keefe, F.J. (2015). A Study of a Mobile Health Pain Coping Skills Training Protocol for Patients with Persistent Cancer Pain. *Journal of Pain and Symptom Management*, 50(4), 553-558.

Stojanovic, M.P., Fonda, J., Brawn Fortier, C. B., Higgins, D.M., Rudolph, J.L., Milberg, W.P., McGlinchey, R.E. (2016). Influence of mild traumatic brain injury and posttraumatic stress disorder on pain intensity levels in OEF/OIF/OND veterans. *Pain Medicine*, 17, 2017-2025.

Taylor, C.A., Bell, J.M., Breiging, M.J., Xu, L. (2017). Traumatic brain injury-related emergency department visits, hospitalizations, and deaths- united states, 2007 and 2013). *Surveillance Summaries*, 66(9), 1-16.

Valenti, K.G., Portanova, J., Laguna, J., Wu, S., Ell, K., Stone, S., & Enguidanos, S. (2016). Feasibility of smartphone use in monitoring pain and symptoms among patients with serious illness. *Clinical Nursing Studies*, 4(3).

Walker, L. & Avant, K. (1988). *Strategies for Theory Construction in Nursing*, 2nd ed. Norwalk, Appleton: Century Crofts.

Webb, T.S., Whitehead, C.R., Wells, T.S., Gore, R.K., & Otte, C.N. (2015). Neurologically-related sequelae associated with mild traumatic brain injury. Brain Injury, 29(4), 430-437.

Appendix

Appendix A.

Nielsen’s 10 Usability Heuristics for User Interface

1. Visibility of system status
2. Match between system and the real world
3. User control and freedom
4. Consistency and standards
5. Error prevention
6. Recognition rather than recall
7. Flexibility and efficiency of use
8. Aesthetic and minimalist design
9. Help user recognize, diagnose, and recover from errors
10. Help and documentation

Chapter 2

Persistent Pain: A Concept Analysis

Abstract

The purpose of this paper is to analyze the concept of persistent pain by using Walker and Avant's approach as a guide. This analysis includes: uses of the concept, definitions, defining attributes, antecedents, consequences, a model case, a contrary case, a borderline case, empirical referents, and conclusions. Data for this concept analysis was gathered systematically from PubMed by searching for "persistent pain" and related phrases among adults. Articles published within the previous five years were included in this analysis to capture the most recent meaning of persistent pain in the literature to move forward with a current premise for future research in this area. In the final model, attributes included physiological response, occurring over a long period, and resistant to treatment. Antecedents include surgery as well as injury, health condition or disease process. Consequences include anxiety, poor self-reported health, impact on quality of life, disability, decreased socialization and economic costs. Since persistent pain can negatively impact one's quality of life and has physical, psychological and financial consequences, it is important to address pain early in the trajectory to prevent or reduce incidence and severity of persistent pain. Special ethical considerations should be made due to the impact that persistent pain can have specifically on those identifying as race/ethnic minorities, older adults and those from low socioeconomic status.

Introduction

The purpose of this paper is to analyze the concept of persistent pain by using Walker and Avant's approach as a guide.[1] The lack of consensus about the meaning of persistent pain merits such an analysis in order to better understand the current literature in this area and to inform future persistent pain research. A gap in the understanding of persistent pain limits the development of approaches that can interfere with the onset and continuation of persistent pain. By understanding the concept, new approaches can be developed to better target those at risk for future persistent pain.

Methods

The Walker and Avant framework was chosen for a concept analysis to create an understanding about what is currently meant by "persistent pain" in the literature. Data for this concept analysis was gathered systematically from PubMed. The key term "persistent pain" was searched, additional search terms including "perception of pain," "pain measures," "pain," "cancer pain," "chronic pain," and "acute pain," were utilized to find literature to support a better understanding of the concept. Filters were set to search for articles available in English that included adults aged 19 and older. Articles published within the previous five years (02/20/2013-2/20/2018) were included in this analysis to capture the most recent meaning of persistent pain in the literature to move forward with a current premise for future research in this area. This search returned 583 articles. The search was narrowed to include available full text articles published in English, those with human subjects, and excluded subject areas of AIDS, dietary supplements, toxicology and veterinary sciences. There were 166 articles that were considered following title screening. After reading abstracts, a total of 30 full-length articles were selected for this analysis. Articles stopped being included from the initial literature search when saturation was reached as seen in other concept analyses using Walker and Avant's method.[2,] Walker and Avant's steps for a concept analysis include: uses of the concept, definitions, defining attributes, antecedents, consequences, a model case, a contrary case, a borderline case, empirical referents, and conclusion.

Uses of the Concept

Persistent pain is a concept that is used both inside and outside of the professional setting. The concept of persistent pain is often discussed within the fields of palliative care, both in research as well as the clinical setting.[4,5] Persistent pain is also commonly referred to in the cancer research literature.[6-8] In the 30 articles reviewed, all 30 used the term "persistent pain" and 16 of these articles included the word "persistent" in the title of the article. Among the articles, 16 included the term chronic pain as well and one used the term "chronic" in the title.

The MeSH term search for persistent pain in PubMed returns results for "pain, intractable" which was introduced to PubMed in 1974. The definition of intractable pain is "persistent pain that is refractory to some or all forms of treatment."[9] This type of pain is subcategory of "pain" in the PubMed database. Other subcategories of pain found include pain described by location (abdominal pain, chest pain), event (labor pain, procedural pain), body system (musculoskeletal pain), and length of pain duration (chronic pain, acute pain).

There were 30 articles that were reviewed to determine the meaning and use of the term "persistent pain" in the research literature. Types of pain and the definition used to define persistent pain in each article reviewed is described in Table 1. According to Weiner and Herr,[10] the term persistent pain is another word for chronic pain. Persistent pain is a term that can be used to describe chronic pain without attaching the negative stigma that chronic pain has for some patients who seek treatment for their pain.[10,11] While patients with chronic pain can face a negative stigma of abusing opioid pain medications,[49] those who use the term persistent pain might change the focus to the length of time their pain has been experienced. Some authors use these two terms interchangeably.[10,12,13]

Definitions of Pain

Pain can be defined in various ways. Pain is defined by PubMed as “An unpleasant sensation induced by noxious stimuli which are detected by nerve endings of nociceptive neurons.”[17] Merriam-Webster defines pain as “usually localized physical suffering associated with bodily disorder (such as a disease or an injury).”[18] In the nursing literature, McCaffrey’s definition of pain, “whatever the experiencing person says it is, existing whenever the experiencing person says it does,”[19] is often used.[20] Another definition used in the literature is from the International Association for the Study of Pain that defines pain as, “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of tissue damage, or both.”[21,22] Based on the findings in this concept analysis, persistent pain will be defined in the conclusion. The word persistent is defined in the Mirriam-Webster Dictionary as, “existing for a long or longer than usual time or continuously.”[23] Specific types of pain such as chronic pain, acute pain and cancer pain are defined below.

Persistent Pain

Consistent with the dictionary definition of "persistent" stated above, Castillo and colleagues defined persistent pain as, “pain beyond the period of healing after an injury or surgery.”[14] Persistent pain and chronic pain were both described as, “complex physical and psychological phenomenon lasting longer than 3 months."[13] Other definitions of persistent pain that were used in the examined literature include “more than six months of continual pain,”[15] and “moderate to severe intensity (pain) at 1 year postoperatively.”[16] Baird and colleagues define both persistent and chronic pain as, “pain that is present for more than three months, assuming the initial injury to have healed in that time.”[12] There is not consistency among the definitions of persistent pain which can hinder the identification and treatment of persistent pain.

Chronic pain.

Merriam-Webster defines the word chronic as, “continuing or occurring again and again for a long time.”[24] PubMed defines chronic pain as, “Aching sensation that persists for more than a few months. It may or may not be associated with trauma or disease and may persist after the initial injury has healed. Its localization, character, and timing are more vague than with acute pain."[25] Chronic pain is classified by the World Health Organization (WHO) by its duration, which often is described as lasting more than three months.[26]

Acute pain.

Merriam-Webster defines the word acute as, "characterized by sharpness or severity," and defines acute pain as, "having sudden onset, sharp rise, and short course."[27] Acute pain is defined by PubMed as, "Intensely discomforting, distressful, or agonizing sensation associated with trauma or disease, with well-defined location, character, and timing."[28] According to WHO, acute pain is often classified based on having a duration of less than 30 days.[26]

Cancer pain.

Cancer pain is related to the pain experience of those who have cancer or had cancer. PubMed defines cancer pain as, "Pain that may be caused by or related to cellular, tissue, and systemic changes that occur during neoplasm growth, tissue invasion and metastasis."[29] The medical definition of cancer according to Merriam-Webster is, "a malignant tumor of potentially unlimited growth that expands locally by invasion and systemically by metastasis."[30] It is important to note that those with cancer pain can also experience pain that is grouped into other categories such as persistent pain, chronic pain and acute pain.[26] The term cancer pain refers to the pain that results from the disease process of cancer, regardless of the characteristics or duration of that pain.

Attributes of Persistent Pain

From the literature review, three attributes of persistent pain were identified: 1) occurring over a long period of time, 2) resistant to treatment, and 3) having a sustained physiological response. Attributes of persistent pain are presented in Figure 1.

Occurring over a Long Period

One of the hallmarks of persistent pain is that it occurs over a long period of time.[4] Some define persistent pain as pain that is sustained for three months or longer.[7,11-13,31-34] Others define persistent pain as pain that is sustained for a longer period, such as six months,[15,35] or 12 months.[16,36] Some studies included those who had experienced persistent pain for three to ten years.[37-39]

Resistant to Treatment

One attribute of persistent pain is that it is resistant to treatment.[6,33,38] Those who had had persistent pain were more likely to have hyperalgesia to pressure during the post-operative phase and were more resistant to therapeutic interventions than those who did not experience widespread hyperalgesia.[6] In one study of those with persistent musculoskeletal pain, 10-year follow-up with two different types of treatment interventions showed that 56% of participants reported a pain score of five or higher, indicating moderate pain on the Numeric Rating Scale-11, which has patients rate their pain from 0-10 with 10 being the worst pain.[38, 40]

Physiological Response

A physiological response is one of the attributes of persistent pain. When those with persistent pain are studied on the physiological level, changes are often found in the brain and blood including differences in intracortical networks and increases in inflammatory markers such as interlukin-6 (IL-6).[41-43] In those who have chronic lateral epicondylalgia, a musculoskeletal condition often characterized by persistent pain, intracortical networks may be a target for future therapies.[43] Compared to controls in this study, those with chronic lateral epicondylalgia have less intracortical inhibition and facilitation.[43] The cerebellar and frontal cortical brain regions may change as a result from pain.[41] There is also an association between persistent pain and higher levels of interleukin 6 (IL-6) in the blood.[42] IL-6 is a proinflammatory cytokine, indicative of inflammation.[63] Vital sign changes associated with persistent pain were not found in the literature. Symptoms of co-occurring depression and anxiety might also be observable in those experiencing persistent pain.[13-15, 39]

Model Case

Walker and Avant suggest that a model case be included as one of the steps of the concept analysis.[1] The following model case contains all the attributes of persistent pain and is constructed from a real patient example. A pseudonym has been used to protect the privacy of the patient and family.

A model case of persistent pain is described:

Mary is an 89-year-old woman residing in an assisted living facility in Seattle, WA. Mary suffers from Trigeminal Neuralgia. Her facial pain has lasted for several years and the doctors cannot find any way for her to control it through medication. Since her pain began many years ago, Mary and her healthcare team have noted that markers of inflammation such as IL-6 were elevated in her last blood test. She is also experiencing symptoms of anxiety. She does not go out with her friends anymore because it is too overwhelming. Her activity level has decreased, and she knows her health is not as good as it used to be. Mary continues to see specialists in hopes of getting her pain under control.

This model case with Mary demonstrates pain occurring over a long period, pain resistant to treatment and sustained physiological response. Mary's story exemplifies all three of the key identified antecedents of persistent pain.

Contrary Case

A contrary case to persistent pain might be one of acute pain. This contrary case would lack the attributes or essential properties of persistent pain. The following contrary case contains none of the attributes of persistent pain and is constructed in contrast to the model case. A pseudonym has been used to protect the privacy of the patient and family.

A contrary case is described:

Alex is a 60-year-old man who lives in an assisted living facility due to his sensory disabilities. He is legally blind and deaf and has challenges with ambulation due to deficiencies in balance and coordination. Alex loses his balance and falls face first into a drawer, cutting his head open. He experiences headache and wound pain from the cut and accompanying stiches for one week after injury. During that week he is prescribed pain medication to take every 4 hours. In the first few nights after his injury, he was occasionally awakened from his sleep with pain if his medication wore off. Now that weeks have passed, Alex has a small scar on his forehead, but his head pain has been eliminated completely.

Alex does not demonstrate any of the identified key attributes of persistent pain. His pain only occurred for one week after his injury and did not last for a prolonged amount of time. His pain responded well to his treatment. No sustained physiological responses were demonstrated during or after his incident.

Borderline Case

A borderline case to persistent pain might be one of chronic pain. This borderline case includes some attributes or essential properties of persistent pain but is distinguishable as its own concept of chronic pain. The following borderline case contains some of the attributes of persistent pain. A pseudonym has been used to protect the privacy of the patient and family.
A borderline case is described:

Bonnie is a 60-year-old woman who lives at home with her adult children and her husband. Bonnie started reporting back pain to her primary care physician many years ago. She sometimes experiences “flare ups” of back pain and seeks out pain management medications from her provider. The cause of this back pain is unknown and sometimes Bonnie experiences anticipatory anxiety for future “flare ups.” The medication she is prescribed helps her pain most of the time, however, if she uses it too often, she develops a tolerance and needs a higher dose.

Some of the key attributes of persistent pain are present in this story, but Bonnie’s pain is distinguishable as chronic pain and not persistent pain. Bonnie experiences her pain over a long period of time however, there are gaps in the “flare ups.” Her pain is responsive to treatment sometimes, but not all the time. There are no known antecedents to her pain. Anxiety is a consequence of her pain experience.

Antecedents

Two antecedents to persistent pain were able to be identified from the literature: 1) injury, health condition or disease process and 2) surgery. Antecedents of persistent pain are presented in Figure 1.

Injury, Health Condition or Disease Process

One antecedent to persistent pain is injury, or disease process. Often persistent pain occurs after one sustains injury or another health condition.[7,8] Persistent pain is not a "normal" part of aging or an inherent condition. Those with persistent pain may have a health condition that physiologically causes pain that is not treatable. This antecedent is important to consider in the overall context of pain/health, as those with persistent pain are also facing other major health challenges besides their pain.

Surgery

Persistent pain often occurs following a surgery.[7,31,35] Nerve damage from an operation or other therapy can cause persistent pain and be present throughout one's experience of persistent pain.[31] Those who underwent repeated reoperations for their groin hernias were more likely to report "residual pain" than those who only had a single operation.[35] Persistent pain prevalence in women who had surgery for breast cancer was 11.3%.[7]

Consequences

Six consequences of persistent pain were identified in the literature. The consequences of persistent pain are: anxiety, poor self-reported health, impact on quality of life, disability, decreased socialization and economic costs. Consequences of a persistent pain are presented in Figure 1.

Anxiety

Those with persistent pain often have mental health concerns.[13,39,44] While it is somewhat challenging to determine the relationship between persistent pain and the timing of psychological changes, some studies have demonstrated that premorbid and comorbid anxiety is associated with persistent pain.[14,42] Veterans with persistent pain were more likely to have anxiety disorders than veterans who did not have persistent pain.[39] One study suggests that pain can be a predictor for anxiety within the first year after a trauma.[14] Some evidence suggests that anxiety also may be a predictor for pain, especially beyond the first year of trauma.[14]

Depression

Those who experience persistent pain such as headache pain after mild traumatic brain injury (mTBI) are at-risk for experiencing depression.[45] Lucas and colleagues suggest that those who present with headache after mTBI should also be evaluated for depression.[45] In a study of veterans with mild-moderate TBI, nonopioid medications, exercise, rest, heat therapy, antidepressants, opioids, topical analgesics, biofeedback and corticosteroids were used as pain management strategies.[46] Antidepressants and exercise were found to be the most effective pain management strategies for participants with headache pain.[46]

Poor Self-Reported Health

Reduced physical function is one of the consequences of persistent pain and can often be exacerbated by other health conditions.[5, 47] Self-rated health was measured by asking participants whether their health was excellent, very good, good, fair or poor.[47] In older adults with persistent pain, self-rated health was fair-poor in 17% of the overall sample.[47] One study that targeted older adults with persistent pain found that those who received massage therapy had improved their self-reported health more than those who did not receive massage therapy.[64]

Impact on Quality of Life

Persistent pain can reduce quality of life by limiting one’s ability to engage in activities and by increasing physical challenges. Those with persistent pain after breast cancer can have reduced quality of life more than one year after their initial surgery.[16] In a study with adolescents who had experienced TBI, those with pain at 3 months after injury had poorer health related quality of life at future time points.[37] Makris and colleagues suggest that persistent pain can result in decreased quality of life and quality of life should be assessed in older adults who present with persistent pain.[44]

While decreased quality life is often a consequence of persistent pain, there are ways that this consequence can be mitigated. In Stewart and colleagues' figure of "Older Adults' Persistent Pain Self-management," increased quality of life is a consequence of the pain being managed well by the older adult.[13] In women with persistent pain after breast cancer treatment, fat grafting was associated with improved quality of life and alleviation of persistent pain.[31]

Disability

Disability in persons with persistent pain has been seen across multiple patient populations including those with cancer, musculoskeletal and post-surgical liver donation. Disability is acknowledged as one of the consequences for those with persistent cancer pain and some interventions aim to address this patient concern.[5] Somers and colleagues used activities of daily living (ADL) and instrumental ADL (IADL) questionnaires to measure disability among those with cancer. [5] Disability was defined in another study by a score greater than 4 on the Pain Disability Index, a 7-item (0-10) questionnaire that measures, "self-reported disability and the impact of pain on activities of daily living and social role functioning."[38, 48] In a study testing two different therapies in response to persistent musculoskeletal pain, there was no difference in pain-related disability between the behavioral treatment group and the exercise-based physiotherapy group.[38] In Emilson's sample that had completed the 10-year follow-up, only 30% reported low levels of pain-related disability.[38] Persistent pain after live donor liver donation is associated with future disability.[36]

Decreased Socialization

Engaging in a social life can be a challenge among those with persistent pain.[15] These social challenges can lead to negative emotional and social consequences including, "less ability to respond emotionally to their friends, family and partners."[15] Since social support and social interaction is important to managing pain, those who struggle with isolation following persistent pain may need to be connected to resources such as support groups or group-based therapies.[13,44] Makris and colleagues report that decreased socialization and isolation can be a result of persistent pain.[44] Addressing mental health issues such as depression may enable increased socialization in those with persistent pain.[44] Seeking and using social support from family and friends was associated with successful self-management of persistent pain in older adults.[13]

Economic Costs

The possible economic consequences of persistent pain include job loss and health expenses for individuals, families, and institutions. Lack of pain management is associated with loss of work productivity and increased health expenses.[49] These economic stresses may be in addition to others since those who have lower income, education and net worth are more likely to report persistent pain than those with higher levels of socioeconomic status.[50]

Empirical Referents

The concept of persistent pain has been measured in several ways. The Brief Pain Inventory-Short Form, McGill Pain Questionnaire Short Form, Numeric Rating Scale, and Short Form-36 are frequently used measures of persistent pain.

Brief Pain Inventory-Short Form

The Brief Pain Inventory Short Form (BPI-SF) is made up of nine questions that measure how pain interferes with one’s life and measures the intensity level of pain experienced.[51] Though this measure was originally for those with cancer pain, Tan and colleagues have also validated it for non-malignant pain.[52] This measure was used in several studies to measure persistent pain in those with cancer, surgery due to cancer, and fibromyalgia.[5,41,42,47] According to Stewart, [47] the BPI has been validated in older adult populations with nonmalignant pain.[65,66] The BPI was shown to be reliable in women who had persistent pain after their surgery for endometrial cancer.[42]

McGill Pain Questionnaire Short Form

The McGill Pain Questionnaire Short Form measure is used by Henne and colleagues in a study investigating relationships between persistent pain, psychological distress and emotional connectedness.[15] This measure focuses on various aspects of pain such as sensory qualities, affect and intensity.[53] The first 15 questions are graded with a Likert scale from 0-3 which indicate the choices of none, mild, moderate and severe.[53] Eleven of these first 15 descriptors are about sensory aspects of pain and four of the questions relate to affect.[53] Present pain intensity is measured on a 0-5 scale with 5 representing excruciating pain. [53] This questionnaire produces four different results. [53] Each of the three aspects of pain measured (sensory, affect and intensity) receive a score and the overall score is given after adding the first three scores together. [53] The McGill Pain Questionnaire has been used to measure persistent pain in several studies including those examining women in persistent pain and their psychological distress as well as those with musculoskeletal injury.[15, 54,] The McGill Pain Questionnaire is valid and reliable in those with musculoskeletal pain.[67,68] This measure is recommended in those with multimorbidity and specifically, neuropathic pain.[40]

Numeric Rating Scale

In the Numeric Rating Scale (NRS-11), 0 indicates no pain and 10 indicates the highest pain intensity.[40] One of the benefits of this scale is that it takes less than one minute to administer to a patient.[40] In a study of adolescents after TBI, Tham and colleagues defined persistent pain over three years as experiencing 3/10 pain on the NRS-11 at every follow-up time point.[37] Pain was measured at three months, one year, two years and three years after injury. [37] The NRS-11 was used in multiple research studies to measure persistent pain.[8,16,31,38,39,43,50] Some studies included participants who had persistent pain following breast cancer surgery or who were military veterans with persistent pain. [8,39] In these populations, researchers used a score of four or higher out of ten on the NRS-11 as a qualifier to classify pain as “persistent pain.”[8,39] The Numeric Rating Scale is a valid and reliable measure for those with pain.[40] This measure has only one-item, can be administered in person or remotely, is unidimensional for pain intensity and has low respondent burden.[40]

Short Form-36

The Short From-36 (SF-36) is a quality of life measure that has been used in studies to measure persistent pain.[35] Magnusson and colleagues used the 36-item self-report form to measure eight domains of quality of life, including pain. [35] The pain section of the SF-36 consists of two items and is called the bodily pain scale.[40] The two pain questions address pain intensity and interference with daily activities. [40] Since the SF-36 covers multiple aspects of health, it is widely used as a measure in persistent pain research of samples including older adults as well as post-op groin hernia and liver donor patients.[13,35,36,40] The SF-36 bodily pain scale is valid and reliable in diverse populations.[40]

Summary of Empirical Referents

While the Brief Pain Inventory-Short Form, McGill Pain Questionnaire Short Form, Numeric Rating Scale, and Short Form-36 are all frequently used measures of persistent pain, there are advantages and disadvantages to each measure. The SF-36 has some distinct advantages over the other measures due to its high reliability and validity in diverse populations.[40] Measuring persistent pain with the SF-36 is expedient with only two questions in the bodily pain scale section. Additionally, the ability to measure other variables that might interact with persistent pain including other types of quality of life indicators is possible and convenient through the remaining 34 questions of the SF-36.

Discussion

Persistent Pain Definition as Framework for Future Work

Based on findings from the 30 articles reviewed, the definition of persistent pain that best integrates the literature about the concept of persistent pain is: Persistent Pain is pain due to a injury, health condition, disease process, or surgery that lasts beyond the normal period of healing, continues for at least 3 months without remission, is resistant to treatment, and is moderate or severe in intensity.

Persistent pain has similarities and differences with other pain types such as chronic pain, acute pain, and cancer pain. Chronic pain is like the above definition of persistent pain in terms of possible causes and possibly unexpected nature. However, the severity and duration of chronic pain is less defined than persistent pain. The well-defined location, character and timing of acute pain is not required to be considered as characteristics of persistent pain. Further differing the two concepts, acute pain is not defined by pain that is unexpected or persists beyond a time of expected healing. Most notably, the three-month duration required for pain to be classified as persistent is not present in the definition of acute pain. There is some overlap between cancer and persistent pain as some people with cancer pain have persistent pain but not all people with persistent pain have cancer pain. Cancer pain differs from persistent pain because it lacks the parameters of intensity and duration of persistent pain. The concept of persistent pain includes the cause of pain, the unexpected nature of the pain, as well as the duration and intensity, but does not include pain location or disease-specific differentiation of pain. The three-month mark was chosen because this was the most specified time parameter for persistent pain in the literature. [7,11-13,31-34]

Persistent pain model.

The persistent pain model (Figure 1) describes the antecedents, attributes and consequences of persistent pain in the context of a larger system with additional important variables. The model illustrates how perception of pain by others can influence the individual and must consider demographic, cultural and contextual factors. One’s overall demographic, cultural and contextual factors can influence health behaviors, which impact their interaction with the antecedents, attributes and consequences of persistent pain in a bidirectional manner. Those with advantageous demographic, cultural or contextual factors are less likely to advance from antecedents to attributes and attributes to consequences than individuals with disadvantageous factors.

Health behaviors.

Health behaviors are included in the persistent pain model to indicate how one's positive and negative health behaviors can influence experience with the antecedents, attributes and consequences of persistent pain in a bidirectional manner. Health behaviors include, but are not limited to, behaviors such as diet, physical activity and smoking. One study with an all-female sample indicated that smoking was associated with persistent back pain.[69] Another study that examined smoking among persistent pain patients indicated that pain triggers smoking behavior but does not reduce pain in patients.[70] Persistent pain has a complicated relationship with physical activity. Patients with persistent lower back pain have been able to significantly reduce their pain by engaging in physical activities such as yoga and tai chi exercise.[71,72] However, some patients who experience persistent pain face significant activity limitations which limits their physical activity level.[73] Diet can also influence persistent pain. In a sample of patients who were undergoing detoxification, persistent pain at the end of treatment was associated with heavy use of alcohol at a follow-up visit two years later.[74] In a longitudinal study, women who had a poor diet consisting of few fruits and vegetables were more likely to report persistent pain at future visits.[75] The directionality of health behaviors and the antecedents, attributes and consequences is likely bidirectional.

Ethical Considerations

Special ethical issues should be considered due to determinants of health that may influence one's experience with persistent pain, such as those from race/ethnic minority groups, older adults and those with low socioeconomic status. Differences in pain management have been found between those from White, Black, and Hispanic ethnic backgrounds.[56] Edwards and colleagues report that there are differences between race/ethnic groups in the experience of persistent pain.[57] In Edwards' review, higher levels of persistent pain were often reported by non-White ethnic groups compared to White ethnic groups. [57]

The older adult population has a high prevalence of persistent pain and pain is undertreated in this population.[13,58] The way that others and older adults themselves perceive pain in the context of aging can be a barrier to older adults receiving adequate pain management.[59] The perception that pain is a natural occurrence that comes with age, it worsens over time, being tough will make it better, and pain medication is addictive can perpetuate poor treatment of pain.[59] Healthcare providers, caregivers and patients may have different understandings about what constitutes well-managed pain in older adults.[59]

Those with low socioeconomic status are more likely to have poor health outcomes that result in pain and may lack resources to seek out adequate pain management.[49] Individuals from lower socioeconomic backgrounds may face barriers at the societal level when trying to find ways to alleviate their pain.[49] They may be impacted more by provider stigma and institutional attitudes that group those seeking chronic pain management care with those who engage with opioid misuse.[49] When pain clinics close, those who access healthcare through Medicaid are often left without resources to buffer the negative impact of services becoming limited.[49] A holistic view by clinicians of the many ways vulnerable groups are impacted by persistent pain may improve pain outcomes in these populations.

Conclusion

Attributes, antecedents and consequences of persistent pain were found by reviewing the literature. In the final model (see Figure 1), attributes include physiological response, occurring over a long period, and resistant to treatment. Antecedents included surgery as well as injury, health condition or disease process. Consequences included anxiety, poor self-reported health, impact on quality of life, disability, decreased socialization and economic costs. Demographic and cultural variables contribute to one's incidence of health conditions, pain treatment effectiveness and ability to mitigate consequences of persistent pain. These variables can influence whether one is likely to advance from the antecedents to the attributes and consequences of persistent pain. Additionally, perception of pain by the individual and by others can influence one's experience with persistent pain.

Future persistent pain research should consider the impact that persistent pain can have on one's life. Those with persistent pain often have health challenges that they face simultaneously such as cancer, injury or other health conditions. Since persistent pain can negatively impact one's quality of life and has physical, psychological and financial consequences, it is important to address pain early in the trajectory to prevent or reduce incidence and severity of persistent pain.

References

1. Walker L and Avant K. Strategies for Theory Construction in Nursing. 2nd ed. Norwalk: Appleton Century Crofts, 1988.
2. Brüggemann AJ, Wijma B, Swahnberg K. Abuse in health care: a concept analysis. Scandinavian Journal of Caring Sciences 2012; 26: 123–132.
3. Chabeli MM, Malesela JML, Nolte AGW. Best practice during intrapartum care: A concept analysis. *Health SA Gesondheid 2017;* 22: 9-19.
4. Galicia-Castillo, M. Opioids for persistent pain in older adults. *Clevland Clinic Journal of Medicine 2016;* 83(6):443-451.
5. Somers TJ, Abernethy AP, Edmond SN, et al. A Study of a Mobile Health Pain Coping Skills Training Protocol for Patients with Persistent Cancer Pain. *JPSM 2015; 50(4): 553-558.*
6. van Helmond N, Steegers MA, Filippini-de Moor, GP, et al. Hyperalgesia and Persistent Pain after Breast Cancer Surgery: A Prospective Randomized Controlled Trial with Perioperative COX-2 Inhibition. *PLoS ONE 2016*; 11(12): e0166601.
7. Romero A, Tora-Rocamora I, Bare,M, et al. Prevalence of persistent pain after breast cancer treatment by detection mode among participants in population-based screening programs. *BMC Cancer 2016;* 16:735.
8. Wijayasinghe N, Andersen KG, Kehlet H. Analgesic and Sensory Effects of the Pecs Local Anesthetic Block in Patients with Persistent Pain after Breast Cancer Surgery: A Pilot Study. *Pain Practice 2017;* 17(2):185-191.
9. PubMed. (1974). “Pain, intractable.” Retrieved from: https://www.ncbi.nlm.nih.gov/mesh/68010148.
10. Weiner DK and Herr K. Comprehensive interdisciplinary assessment and treatment planning: an integrative overview. In: Weiner DK, Herr K, Rudy TE, editors. Persistent pain in older adults: an interdisciplinary guide for treatment. New York, NY: Springer Publishing Company; 2002.
11. The Pain Toolkit. (2018). Retrieved from: https://www.paintoolkit.org/.

12. Baird E, Williams ACDC, Hearn L, et al. Interventions for treating persistent pain in survivors of torture. Cochrane Database of Systematic Reviews 2017; 8(CD012051).

13. Stewart C, Schofield P, Elliot AM, et al. What do we mean by "older adults' persistent pain self-management"? a concept analysis. *Pain Medicine 2014; 15:214-224.*

14. Castillo RC, Wegener ST, Heins SE, et al. Longitudinal relationships between anxiety, depression, and pain: Results from a two-year cohort study of lower extremity trauma patients. *Pain 2013;* 154:2860-2866.

15. Henne E, Morrissey S and Conlon E. An investigation into the relationship between persistent pain, psychological distress and emotional connectedness. *Psychology, Health & Medicine 2015*; 20(6): 710-719.

16. Meretoja TJ, Andersen KG, Bruce J, et al. Clinical Prediction model and tool for assessing risk of persistent pain after breast cancer surgery. *J Clin Oncol 2017;* 35(15):1660.

17. PubMed. (2018). "Pain." https://www.ncbi.nlm.nih.gov/mesh/68010146

18. Merriam-Webster. (2018). "Pain." Retrieved from: https://www.merriam-webster.com/dictionary/pain

19. McCaffery M. (1968). *Nursing practice theories related to cognition, bodily pain, and man-environment interactions*. Los Angeles: University of California at Los Angeles.

20. Bernhofer E. Ethics and Pain Management in Hospitalized Patients. *OJIN: The Online Journal of Issues in Nursing 2011*; 17(1).

21. International Association for the Study of Pain. (1986). Retrieved from: https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698#Pain

22. Moayedi M, Davis KD. Theories of pain: from specificity to gate control. J Neurophysiol 2013; 109: 5–12.

23. Merriam-Webster. (2018). "Persistent." Retrieved from: https://www.merriam webster.com/dictionary/persistent.

24. Merriam-Webster. (2018). “Chronic.” Retrieved from: https://www.merriam-webster.com/dictionary/chronic
25. PubMed. (2012). “Chronic pain.” Retrieved from: https://www.ncbi.nlm.nih.gov/mesh/?term=chronic+pain
26. World Health Organization (WHO). A guidelines on the pharmacological treatment of persisting pain in children with medical illnesses 2012; Persisting Pain in Children package.
27. Merriam-Webster. (2018). “Acute.” Retrieved from: https://www.merriam-webster.com/dictionary/acute
28. PubMed. (2012). “Acute pain.” Retrieved from: https://www.ncbi.nlm.nih.gov/mesh/68059787
29. PubMed. (2017). “Cancer pain.” Retrieved from: https://www.ncbi.nlm.nih.gov/mesh/?term=cancer+pain
30. Merriam-Webster. (2018). “Cancer.” Retrieved from: https://www.merriam-webster.com/dictionary/ cancer#medicalDictionary
31. Juhl AA, Karlsson P, Damsgaard TE. Fat grafting for alleviating persistent pain after breast cancer treatment: A randomized controlled trial. *JPRAS 2016;* 69:1192-1202.
32. Fain KM, Castillo-Salgado C, Dore DD, et al. Inappropriate fentanyl prescribing among nursing home residents in the United States. *JAMDA 2017;* 18:138-144.
33. Nunez-Cortes R, Cruz-Montecinos C., Vasquez-Rosel A, et al. Dry Needling Combined with Physical Therapy in Patients with Chronic Postsurgical Pain Following Total Knee Arthroplasty: A Case Study. *Journal of Orthopaedic & Sports Physical Therapy 2017; 47(3):209-216.*
34. Weiss R, Ling W, Potter JS, et al. A two-phase randomized controlled clinical trial of buprenorphine/naloxone treatment plus individual drug counseling for opioid analgesic dependence. *NIDA-CTN Protocol v3.4 2007.*
35. Magnusson N, Gunnarsson U, Nordin P, et al. Reoperation for persistent pain after groin hernia surgery: a population-based study. *Hernia 2015; 19:45-51.*

36. Mandell MS, Smith AR, Dew MA, et al. Early postoperative pain and its predictors in the adult to adult living donor liver transplantation cohort study. *Transplantation* 2016; 100(11): 2362-2371.
37. Tham TSW, Palermo TM, Wang J, et al. Persistent Pain in Adolescents Following Traumatic Brain Injury. *The Journal of Pain 2013*; 14(10):1242-1249.
38. Emilson C, Demmelmaier I, Bergman S, et al. A 10-year follow-up of tailored behavioural treatment and exercise-based physiotherapy for persistent musculoskeletal pain. *Clinical Rehabilitation 2017;* 31(2):186-196.
39. Higgins DM, Kerns RD, Brandt CA, et al. Persistent pain and comorbidity among operation enduring freedom/operation Iraqi freedom/operation new dawn veterans. *Pain Medicine 2014;* 15:782-790.
40. Hawker GA, Mian S, Kendzerserska T, et al. Measures of Adult Pain. *Arthritis Care & Research 2011*; 63 (S11): S240–S252.
41. Kim H, Kim J, Loggia ML, et al. Fibromyalgia is characterized by altered frontal and cerebellar structural covariance brain networks. *NeuroImage Clinical 2015;* 7:667-677.
42. Honerlaw KR, Rumble ME, Rose SL, et al. Biopsychosocial predictors of pain among women recovering from surgery for endometrial cancer. *Gynecologic Oncology 2016;* 140:301-306.
43. Burns E, Chipchase LS, Schabrun SM. Altered function of intracortical networks in chronic lateral epicondylagia. *European Journal of Pain 2016;* 20:1166-1175.
44. Makris UE, Abrams RC, Gurland B, et al. Management of persistent pain in the older patient a clinical review. *JAMA 2014;* 312(8):825-836.
45. Lucas S, Smith BM, Temkin N, et al. Comorbidity of headache and depression after mild traumatic brain injury. *Headache 2016;* 56: 323-330.
46. King PR, Beehler GP, Wade MJ. Self-reported pain and pain management strategies among veterans with traumatic brain injury: A pilot study. *Military Medicine 2015;* 180(8): 863.
47. Stewart C, Leveille SG, Shmerling RH, et al. Management of persistent pain in older adults: the MOBILIZE Boston Study. *J Am Geriatr Soc 2012*; 60(11): 2081–2086.

48. Pollard CA. Preliminary validity study of the pain disability index. *Perceptual and motor skills 1984*; 59: 974.
49. Soh ED & Portanova J. Chronic Noncancer Pain Management: Systemic Inequities in Access. *J Gerontological Nursing 2017;* 43(10):4-6.
50. Johannsen M, Christensen S, Zachariae R, et al. Socio-demographic, treatment-related, and health behavioral predictors of persistent pain 15 months and 7-9 years after surgery: a nationwide prospective study of women treated for primary breast cancer. *Breast Cancer Res Treat 2015;* 152:645-658.
51. Cleeland CS and Ryan KM. Pain assessment: Global use of the Brief Pain Inventory. *Ann Acad Med Singapore* 1994; 23: 129-138.
52. Tan G, Jensen MP, Thornby JI, et al. Validation of the brief pain inventory for chronic nonmalignant pain*. J Pain 2004*; 5:133–137.
53. Melzack R. The short-form McGill pain questionnaire. *Pain* 1987, 30, 191–197.
54. Pecina M, Azhar H, Love TM, et al. Personality trait predictors of placebo analgesia and neurobiological correlates. *Neuropsychopharmacology 2013;* 38:639-646.
55. Scott W, Milioto M, Trost Z, et al. The relationship between perceived injustice and the working alliance: a cross-sectional study of patients with persistent pain attending multidisciplinary rehabilitation. *Disability and Rehabilitation* 2016; 38:24, 2365-2373.
56. Green CR, Anderson KO, Baker TA, et al. The unequal burden of pain: Confronting racial and ethnic disparities in pain. *Pain Medicine 2003*; 4(3):277-294.
57. Edwards CL, Fillingim RB, Keefe F. Race, ethnicity and pain. *Pain 2001;* 94:133-137.
58. Pitkala KH, Strandberg TE, Tilvis RS. Management of nonmalignant pain in home-dwelling older people: a population-based survey. *J Am Geriatr Soc 2002*; 50:1861–1865.
59. Thielke S, Sale J, and Reid MC. Aging: Are these 4 pain myths complicating care? J Fam Pract. 2012; 61(11): 666–670.

60. Broyles JM, Tuffaha SH, Williams EH, et al. Pain after breast surgery: Etiology, diagnosis and definitive management. *Microsurgery 2016; 535-538.*
61. Campbell L, Kenardy J, Andersen T, et al. Trauma-focused cognitive behavior therapy and exercise for chronic whiplash: protocol of a randomized, controlled trial. *J Physiotherapy 2015;* 61:218.
62. Lefebvre-Kuntz D, Duale C, Albi-Feldzer A, et al. General anaesthetic agents do not influence persistent pain after breast cancer surgery. *Eur J Anaesthesiol 2015;* 32:697-704.
63. Gabay C. Interleukin-6 and chronic inflammation. *Arthritis Research & Therapy*. 2006;8(Suppl 2):S3. doi:10.1186/ar1917.
64. Munk, N., Kruger, T., & Zanjani, F. Massage therapy usage and reported health in older adults experiencing persistent pain. Journal of Alternative and Complementary Medicine, 17;7.
65. Cleeland, CS. Measurement of pain by subjective report. Chapman, CR.; Loeser, JD., editors. New York: Raven Press; 1989. p. 391-403.
66. Tan G, Jensen MP, Thornby JI, et al. Validation of the brief pain inventory for chronic nonmalignant pain. J Pain. 2004; 5:133–137.
67. Turk DC, Rudy TE, Salovey P. The McGill pain questionnaire reconsidered: confirming the factor structure and examining appropriate uses. Pain. 1985;21:385–397.
68. Veilleux S, Sicard D, Bohuon A. Traductionde mcgill pain questionnaire. In: Melzack R, editor. Lede´fideladouleur. PDW. 3rd edn. St-Hyacinthe (QC): Edisem; 1989. p. 290–296.
69. Schmelzer, A.C., Salt, E., Wiggins, A. et al. Role of stress and smoking as modifiable risk factors for nonpersistent and persistent back pain in women. Clin J Pain; 2016, 32(3):232-7.
70. Dhingra, L.K., Homel, P., Grossman, B. et al. Ecological momentary assessment of smoking behavior in persistent pain patients. Clin J Pain; 2014, 30(3): 205-13.
71. Wren, A.A., Wright, M.A., Carson, J.W. et al. Yoga for persistent pain: new findings and directions for an ancient practice. Pain, 2011; 152(3):477-480.

72. Hall, A.M, Maher, C.G., Lam, P. Tai chi exercise for treatment of pain and disability in people with persistent low back pain: a randomized controlled trial. Arthritis Care and Research, 2011; 63(11).
73. Gureje, O., Von Korff, M., Simon, G.E. Persistent pain and well-being: a world health organization study in primary care. JAMA, 1998; 280(2): 147-151.
74. Larson, M.J., Paasche-Orlow, M., Cheng, D.M. et al. Persistent pain is associated with substance use after detoxification: a prospective cohort analysis. Addiction 2007; 102(5).
75. VanDenKerhof, E.G., Macdonald, H. M. & Macfarlane, G.J. Diet, lifestyle and chronic widespread pain: Results from the 1958 British Birth Cohort Study. Pain Res Manag., 2011; 16(2): 87-92.

Tables

Table 1. Articles in Analysis

Reference	Pain Type	Definition
Romero A, Tora-Rocamora I, Bare,M, et al. (2016).	Persistent	“Pain in the breast area, axilla, shoulder or arm for more than 3 months after breast cancer surgery.”
Burns E, Chipchase LS, Schabrun SM. (2016).	Chronic (T) & Persistent	N/A
Wijayasinghe N, Andersen KG, Kehlet H. (2017).	Persistent (T)	N/A; “Mention pain after breast cancer surgery, locations, and multifactorial pathophysiology.”
Lefebvre-Kuntz D, Duale C, Albi-Feldzer A, et al. (2015).	Persistent (T)	“Self-reported pain around the surgical site. Two primary outcomes were considered separately: the risk of nPPSP defined by the presence of PPSP with at least 4 positive items from the DN4 either at the 3rd or 6th month after surgery.”
Castillo RC, Wegener ST, Heins SE, et al. (2013).	Persistent & Chronic (Phase)	“Pain beyond the period of healing after an injury or surgery.”
Honerlaw KR, Rumble ME, Rose SL, et al. (2016).	Persistent	“Persisting well beyond the end of treatment.”
Campbell L, Kenardy J, Andersen T, et al. (2015).	Persistent & Chronic (Used as phase)	“Persist past the acute to sub-acute stage and become chronic.”
Stewart C, Schofield P, Elliot AM, et al. (2014).	Persistent & Chronic (Used as same)	“Complex physical and psychological phenomenon lasting longer than 3 months.”
Juhl AA, Karlsson P, Damsgaard TE. (2016).	Persistent (T)	“Persistent pain after breast cancer treatment, defined by the International Associated for the Study of Pain as pain in the anterior thorax, axilla, and/or medial upper arm, persisting for >3 months after end of treatment.”
Fain KM, Castillo-Salgado C, Dore DD, et al. (2017).	Persistent	“Moderate to severe daily pain on consecutive MDS assessments at least 90 days apart.”
Kim H, Kim J, Loggia ML, et al. (2015).	Persistent, Chronic, Persistent Chronic	N/A
Johannsen M, Christensen S, Zachariae R, et al. (2015).	Persistent (T)	N/A

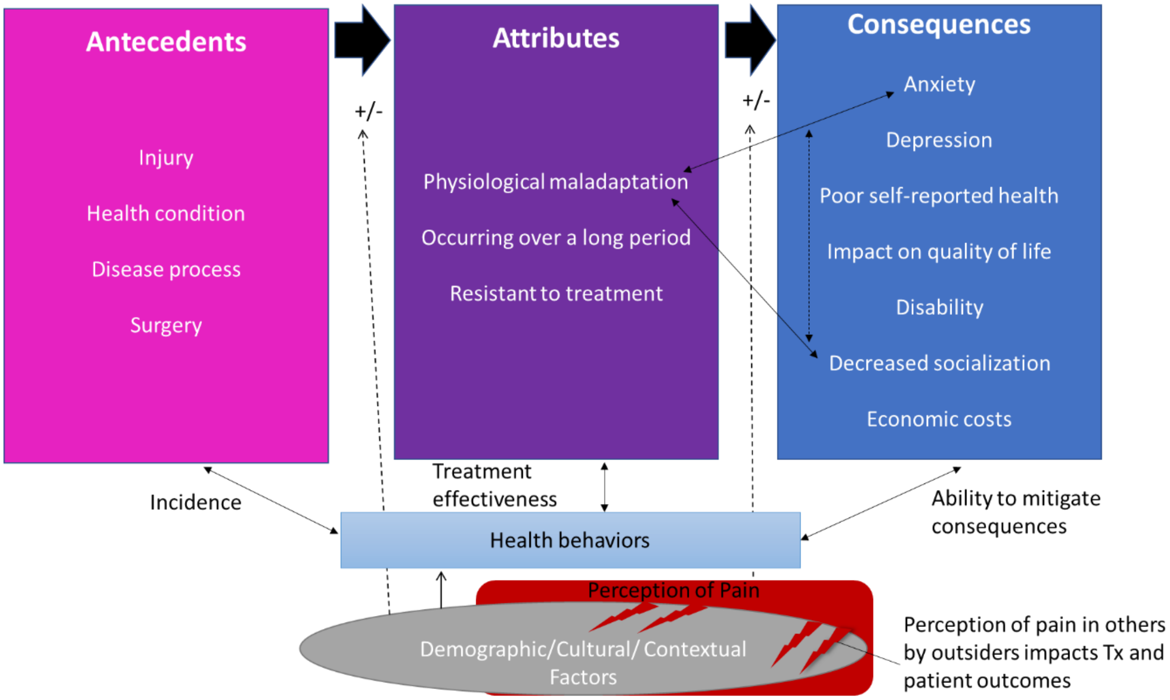
Stewart C, Leveille SG, Shmerling RH, et al. (2012).	Persistent(T)	"Measured it as pain lasting longer than just a couple of weeks."
Emilson C, Demmelmaier I, Bergman S, et al. (2017).	Sub-acute, recurrent, or persistent musculoskeletal pain	N/A
Galicia-Castillo, M. (2016).	Persistent (T)	"A multifaceted manifestation of an unpleasant sensation that continues for a prolonged time and may or may not be related to a distinct disease process." "Persistent pain" is preferred as it does not have the negative connotations of "chronic pain."
Broyles JM, Tuffaha SH, Williams EH, et al. (2016).	Persistent, Neuropathic	N/A
Henne E, Morrissey S and Conlon E. (2015).	Persistent (T), Chronic	"More than 6 months of continual pain."
van Helmond N, Steegers MA, Filippini-de Moor, GP, et al. (2016).	Persistent (T)	N/A
Makris UE, Abrams RC, Gurland B, et al. (2014).	Persistent (T) & Chronic	N/A
Scott W, Milioto M, Trost Z, et al. (2016).	Persistent (T) & Chronic	N/A
Baird E, Williams ACDC, Hearn L, et al. (2017).	Persistent & Chronic (Same)	"Pain that is present for more than 3 months, assuming the initial injury to have healed in that time."
Somers TJ, Abernethy AP, Edmond SN, et al. (2015).	Persistent Cancer Pain (T)	N/A
Pecina M, Azhar H, Love TM, et al. (2013).	Persistent	N/A
Mandell MS, Smith AR, Dew MA, et al. (2016).	Persistent & Chronic	"Occurring 12 months after surgery."
Meretoja TJ, Andersen KG, Bruce J, et al. (2017).	Persistent (T) & Chronic	"Moderate to severe intensity at 1 year postoperatively."
Nunez-Cortes R, Cruz-Montecinos C., Vasquez-Rosel A, et al. (2017).	Persistent & Chronic (T)	"Included those with "persistent pain" 3 months after total knee arthroplasty."
Magnusson N, Gunnarsson U, Nordin P, et al. (2015).	Persistent (T) & Chronic	"Pain persisting more than 3-6 months after surgery was considered to be chronic."
Tham TSW, Palermo TM, Wang J, et al. (2013).	Persistent (T) & Chronic	N/A

Higgins DM, Kerns RD, Brandt CA, et al. (2014).	Persistent (T) & Chronic	“Persistent pain group was defined by the presence of one or more of the following pain criteria each year during a period of 5 consecutive years of Veterans Health Affairs health services use: 1) an NRS pain intensity of greater than or equal to 4; 2) any ICD-9 pain diagnosis code; 3) one or more Pain Clinic visits; or 4) receipt of a prescription opioid medication”
Weiss R, Ling W, Potter JS, et al. (2007).	Persistent & Chronic	“Presence of "chronic pain" will be operationalized by a "yes" answer to the first question of the Brief Pain Inventory and a duration of pain of a least 3 months.”

Note. DN4 Douleur Neuropathique 4, MDS= Minimum Data Set, N/A= not applicable, PPSP= persistent postsurgical pain, nPPSP= neuropathic PPSP (T)=Term used in title, N/A=No definition was given.

Figures

Figure 1. Persistent Pain Model



Legend

Figure 1 is a model developed from the concept analysis of persistent pain.

- - - - - - -> +/-	This symbol indicates the increased or decreased likelihood of one progressing to the next step in the persistent pain model.
↔	This symbol indicates a bidirectional relationship between two variables.
⚡	This symbol indicates how the perception of pain by others impacts an individual's treatment and outcomes.
➡	This symbol illustrates one's progression from experiencing antecedents, to attributes, to consequences of persistent pain.
→	This symbol indicates a unidirectional relationship between two variables.

Chapter 3

Factors Associated with the Development of Persistent Pain after mTBI

Abstract

Background

Persistent pain after mild traumatic brain injury (mTBI) is widely experienced, yet little is known about who is at risk for experiencing persistent pain after their injury.

Purpose/Aims

The purpose of this study was to 1) determine if there are factors associated with later experiencing persistent pain after mTBI and 2) examine if there are symptom patterns associated with the experience of persistent pain.

Methods

Secondary analysis was conducted using de-identified data from an NIH-funded longitudinal study that included participants with mTBI. We examined baseline characteristics, symptoms, and injury related variables associated with the endorsement of persistent pain among those with mTBI (N= 183) from baseline to 6 months post-injury. In order to identify a persistent pain phenotype, exploratory factor analysis was used to determine which symptoms co-occur with persistent pain.

Results

Persistent pain was found in 78% of those with mTBI. There were no significant differences in baseline factors between those who experienced persistent pain and those who did not. However, those with lower overall health status at day 7 and at 1-month following injury had greater odds of developing persistent pain. Those with higher levels of general health status and physical function health status at day 7 and 1 month, and those with higher levels of health-related status at 1 month had significantly lesser odds of persistent pain at 6 months. Factor analysis revealed that persistent pain and co-occurring symptoms (anxiety, depression, dizziness, nausea and vomiting, sleep disturbance, poor memory, poor concentration, longer to think and light sensitivity) loaded on one factor, indicating that these symptoms are associated.

Discussion

Those at increased risk for persistent pain should be screened beginning early in the recovery trajectory to reduce their risk of developing persistent pain. Identification of a phenotype offers potential for recognition of symptoms that cluster with persistent pain, improving the ability to treat patients more holistically, and develop interventions to support recovery from injury.

Background

Pain after mild traumatic brain injury (mTBI) is common and problematic (Lavigne et al., 2015). Persistent pain is defined as “pain due to an injury, health condition, disease process, or surgery that lasts beyond the normal period of healing, continues for at least 3 months, is resistant to treatment, and is moderate or severe in intensity” (Portanova & Thompson, 2019 (abstract)). The prevalence of persistent pain according to this definition is not known, however long-term pain in those with mTBI is common, occurring in over 75% of patients (Nampiaparampil, 2008). Persistent pain perpetuates itself and other co-occurring symptoms in patients who are already vulnerable. Those with pain after mTBI often have co-occurring health conditions such as PTSD, which can cause higher pain intensity and make pain and symptom management more challenging (Stojanovic et al., 2016).

Following TBI, symptoms such as persistent pain have long-term consequences in terms of returning to pre-injury activities, job loss, and life satisfaction (Centers for Disease Control and Prevention [CDC], 2015). While persistent pain is associated with negative outcomes following TBI such as depression (Lucas et al., 2016), There are gaps in knowledge concerning who is at risk for developing persistent pain after mTBI and whether symptom clusters may be predictive for risk of persistent pain. The purpose of this study is to address these gaps.

Pain after mTBI

Those who experience a mTBI often have greater subsequent pain symptoms compared to those with more severe TBI, with one study showing higher prevalence of chronic pain (75.3% in mTBI vs. 32.1% in moderate to severe TBI) (Nampiaparampil, 2008). Patients who experience TBI and pain present a unique challenge for healthcare professionals to address due to the unpredictable nature of pain during recovery (Sherman, Goldberg, & Bell, 2006). Furthermore, there is a lack of knowledge about which patients are most at risk to develop it after mTBI. By identifying patient-specific characteristics or other co-morbid symptoms, i.e., a persistent pain phenotype, early interventions to prevent future persistent pain can be identified and introduced to those at risk for persistent pain after mTBI.

Risk factors for Persistent Pain after TBI

The pain experience following TBI differs vastly based on demographic features and comorbid conditions.

Demographic features. Age, sex and race/ethnicity may all play a role in the development or reporting of persistent pain. In one study, older participants experienced less headache than younger participants after mTBI (Lucas et al., 2016). Younger people had worse outcomes in Sawyer's 2015 study of those with headaches after mTBI. However, in Stratton's 2014 study, older age was related to reporting current experience of pain. With regards to sex differences, while men and women have similar levels of pain following TBI, pain intensity is more predictable in men than women (Mollayeva et al., 2017). Mollayeva and colleagues (2017) found that socio-demographic, injury-related, behavioral and clinical variables accounted for 14% more of the pain variance found among men compared to women. Racial differences are less studied in pain following mTBI. In one study, Black race was a predictor for greater odds of experiencing severe or very severe post-concussive symptoms at three months after mTBI compared to those who did not identify as Black (Schwab et al., 2017). In Jamora and colleagues' (2013) study, there were no between-group differences in ethnicity between the high pain and low pain groups. In the broader pain literature, ethnic differences in pain management have been found between those from White, Black, and Hispanic ethnic backgrounds (Green et al., 2003). Pain is undertreated in those from minority race/ethnic backgrounds compared to Whites (Green et al., 2003). Given the scant and varied findings in this area, the present study will examine the impact of patient's demographic on the odds of experiencing persistent pain after mTBI.

Co-morbid health conditions or symptoms. The pain experience is influenced not only by the initial mTBI, but also any coexisting health conditions. Having a diagnosis of both mTBI and PTSD is associated with experiencing higher levels of pain than having a diagnosis of mTBI alone (Stojanovic et al., 2016). Those who experience headache after mTBI are also at-risk for experiencing other conditions such as depression (Lucas et al., 2016). Lucas and colleagues (2016) suggest that those who present with headache after mTBI should also be evaluated for depression.

In one study about the outcomes of college students (N=1,075) who had sustained a mTBI, results indicated that there were possibly groups of symptoms related to multiple aspects of their well-being including physical health, cognitive ability, behavioral health and social interactions (Laforce & MacLeod, 2001). The most commonly cited changes were in the physical category which consisted of dizziness (83.9%), headache (78.7%), fatigue (52.5%) and blurred vision (51.5%) (Laforce & MacLeod, 2001). Some of the other physical changes that were also highly reported included light sensitivity (43.4%), noise sensitivity (40.4%), sleep disturbances (37.7%), nausea/vomiting (33.5%), and restlessness (29.7%) (Laforce & MacLeod, 2001). In the behavioral category, 20.9% reported mood changes and 12.8% reported personality changes (Laforce & MacLeod, 2001). In the cognitive realm, attention (16.3%) and memory (12.0%) changes were most commonly reported (Laforce & MacLeod, 2001). Participants cited changes in social areas, most commonly with extracurricular activities (12.0%) (Laforce & MacLeod, 2001). While Laforce and MacLeod (2001) uncovered possible symptom groups that were prevalent in college aged students with mTBI, their study had multiple limitations including the participants' self-report of events and symptoms that had occurred long before data was collected.

Persistent pain is prevalent and problematic after mTBI, but little is known about who will develop persistent pain. Without knowing who will develop persistent pain, there are few opportunities for early intervention to prevent future pain. Identifying a persistent pain phenotype based on patient characteristics or co-occurring symptoms could help providers target individuals early in their recovery trajectory for intervention to prevent or mitigate the development of persistent pain, as well as addressing the symptom experience and overall health status.

Purpose

The purpose of this study is to fill a gap in knowledge by first identifying risk factors for development of persistent pain following mTBI. The first aim is to examine baseline characteristics, symptoms, and injury related variables to determine whether these are associated with the endorsement of persistent pain from baseline to 6 months post injury. The second goal is to determine if there are symptom clusters in those who have persistent pain following TBI to identify a persistent pain phenotype. These factors provide evidence to determine if there are early indicators that persistent pain will develop, and a potential window for early screening and intervention.

Methods

Design

Secondary analysis was conducted using de-identified data from an NIH-funded longitudinal study, "Impact of Aging on the Immune Response to Traumatic Brain Injury (AIm: TBI)." The parent study used a prospective cohort design in adults following mTBI as well as non-injured controls. The parent study's aim was to learn more about the process of TBI recovery in older adults compared to younger adults and to examine the role of inflammation in recovery to six months post-injury. The parent study received full IRB approval with participants (or a proxy) providing consent to participate. The inclusion criteria for the parent study were having a clinical diagnosis of mild TBI within the past 24 hours, a Glasgow Coma Scale Score greater than 12 in the emergency department, ability to read and speak English and a documented home address and telephone number within western Washington State. The exclusion criteria were having other severe medical conditions, life expectancy less than 6 months or plans to leave the area within 6 months. The full inclusion and exclusion criteria can be found in Appendix A.

Participants. Inclusion criteria for present study: must be participants in the parent study with mTBI (no controls) who had available data on pain experience at day 7 or month 1 as well as at months 3 and 6 (N=183). Patients were only included if they had an abbreviated injury score (AIS) of 1-4 indicating severity of injury ranging from minor to severe and life threatening (Abbreviated Injury Scale [AIS], 2008). Those with no injury (score=0); critical injury with survival uncertain (5); maximum, fatal (6) or unknown (9) were excluded.

Procedures. De-identified demographic, injury and symptom data from baseline (<24 hours from time of injury) as well as 7 days, 1 month, 3 months and 6 months post-injury time points were provided from the parent study for analysis.

Measures

Demographics. Demographic variables included in the analysis included age, sex (male/female), race (White/non-White) and years of education.

Pre-Injury characteristics. Prior diagnoses of depression and multimorbidity were included to determine whether baseline diagnoses had an impact on experiencing persistent pain after injury. These data were measured by patient self-report at baseline. Patients identified as having depression (yes, no). Co-morbid health conditions were coded as present or absent based on whether any were checked off using the Elixhauser method at baseline (Elixhauser et al., 1998).

Injury variables. The severity of head injury was included as an indicator of the classification of the injury using both the abbreviated injury scale (AIS) for the head region (AIS, 2008) and CT scan results. In order to understand the relationship between mild or complex mild TBI and the development of persistent pain, data on CT scan results (positive or negative) were included as a predictive variable for those who had one performed. Complex mTBI is indicated by a positive head CT.

We recoded variables for injury type to examine mechanism of injury, and if that is associated with development of persistent pain. Specifically examined were the relationship of injury from motor vehicle crash (yes/no) and an injury from fall (yes/no) to the development of persistent pain.

Social support. Social support variables were taken from the Medical Outcomes Study (MOS) Social Support Survey at baseline (Sherbourne et al., 1993). Four dimensions of social support were chosen from the 19-item survey for inclusion. Each category scores range from no support to the highest level of support 1-5 (1= None of the time; 2= A little of the time; 3=some; 4=most; 5=All of the time): emotional/informational support, tangible support, affectionate support, and positive social interaction. An overall functional social support score was constructed (Sherbourne et al., 1993). The MOS Social Support Survey is reliable (alpha >0.91) and valid in adult patients with chronic health conditions (Sherbourne et al., 1993).

Persistent pain. Persistent pain was defined as being endorsed at day 7 or 1 month post-injury as well as at 3 months and 6 months after injury. The pain items examined included the headache question from the *Rivermead Post-Concussion Questionnaire* (RPQ) "Compared with before the accident, do you now suffer from headaches?" and the two Bodily Pain Scale items from the SF-36 acute recall "How much bodily pain have you had during the past 7 days?" and "During the past 7 days, how much did pain interfere with your normal work?" (Hawker et al, 2011).

The Rivermead Post Concussion Questionnaire (RPSQ) is used to assess 16 symptoms following TBI (King et al., 2991). Patients are asked to rate each symptom based on how they are feeling compared to how they were feeling before the accident (King et al., 1995). Items on this questionnaire are rated on a Likert scale from 0-4 with 0 representing "not experienced at all," 1 is "no more of a problem than prior to injury", 2 is "a mild problem," 3 is "a moderate problem," and 4 is "a severe problem (King et al., 1995)." In this study a 2 or higher was an indication of pain. The Rivermead is validated for use in TBI population with high reliability in head-injured patients (King et al., 1995) and validated for use in those with post-concussion symptoms (Ingebrigtsen, 1998)***.*** The Short From-36 (SF-36) has been used in previous studies involving patients with TBI (Michaels et al., 2000; Ouellet et al., 2009), and found to be both valid and reliable for use in individuals with mTBI (Findler et al., 2001).

Other symptoms. The presence of symptoms was measured using the SF-36, RPQ and Brief Symptom Inventory-18 (BSI-18).

Depression and anxiety. The BSI-18 was used to evaluate depression and anxiety as co-occurring symptoms by patient self-report. The BSI-18 has good internal consistency and is considered a reliable instrument for assessing psychological distress in the general population (Franke et al., 2017). Depression and anxiety was measured using the relevant subscales of the BSI-18. The BSI is both valid (Alpha= .84-.91) and reliable (Alpha=.61-.84) in the TBI population with higher reliability in the outpatient TBI population compared to the impatient TBI population (Meachen et al., 2008). The questions from the BSI-18 that were used to reflect depression (alpha=.87) are: 2) Feeling no interest in things; 5) Feeling lonely, 8) Feeling blue; 11) Feelings of worthlessness; 14) Feeling hopeless about the future; and 17) Thoughts of ending your life (Franke et al., 2017). For anxiety, the following questions from the BSI-18 were used (alpha=.84): 3) Nervousness or shakiness inside, 6) Feeling tense or keyed up; 9) Suddenly scared for no reason; 12) Spells of terror or panic; 15) Feeling so restless you couldn’t sit still; and 18) Feeling fearful (Franke et al., 2017).

Overall health status. In addition to the bodily pain scale, the SF-36 was used to evaluate vitality, physical functioning, general health perceptions, physical role functioning, emotional role functioning, social role functioning and mental health. The Short Form-36 is a valid and reliable measure of pain and other areas of overall health status in those who have mTBI (Findler et al., 2001).

TBI-related symptoms. The Rivermead was used to examine endorsement of symptoms besides pain (headache), including: dizziness, nausea and/or vomiting, noise sensitivity, sleep disturbance, fatigue, irritability, feeling depressed, feeling frustrated, forgetfulness, poor concentration, taking longer to think, blurred vision, light sensitivity, double vision and restlessness (Waljas et al., 2015; King et al., 1995). This questionnaire has 16 symptom items, including one on headaches (King et al., 1995). Patients are asked to rate each symptom based on how they are feeling compared to how they were feeling before the accident (King et al., 1995). Items on this questionnaire are rated on the Likert scale from 0-4 with 0 representing “not experienced at all,” 1 is “no more of a problem”, 2 is “a mild problem,” 3 is “a moderate problem,” and 4 is “a severe problem (King et al., 1995).” In those with head injury, Rivermead has construct validity and is reliable when the 16 questions are split into two groups (Eyres et al., 2005). One group includes three questions (headache, dizziness and nausea) and the other group consists of the remaining 13 questions (Eyres et al., 2005). The Rivermead is validated for use in TBI population with high reliability in head-injured patients (King et al., 1995) and validated for use in those with post-concussion symptoms (Ingebrigtsen, 1998).

Analyses

Descriptive statistics (means and standard deviations or counts and percent where appropriate) were used to characterize the prevalence of persistent pain as well as baseline characteristics (social support as well as prior diagnosis of depression or anxiety), symptoms, injury related variables and demographics. As appropriate, either Chi-squared or independent t-tests were used to evaluate differences in baseline characteristics, social support variables and overall health status variables between the groups with and without persistent pain following TBI. Logistic regression was used to determine the odds of developing persistent pain at 6 months. Predictor variables included baseline measures: demographics (age, sex, education, race/ethnicity), baseline characteristics (depression, multimorbidity, pain condition) injury related variables (mechanism of injury, severity of injury, CT scan results). There were not enough observations of various race/ethnic groups to include multiple race/ethnicity variables in the logistic regression of demographic factors; therefore, race/ethnicity was collapsed to a dichotomous variable for the analysis (white/non-white). Univariate logistic regression was completed, followed by multivariate modeling for those items significantly associated ($p<.05$) with persistent pain in univariate analyses.

Exploratory factor analysis was used to determine which co-morbid symptoms are associated with persistent pain in order to identify a persistent pain phenotype. Data elements included in the analysis are: persistent pain, anxiety, depression, as well as dizziness, nausea/vomiting, sleep disturbance, poor memory, poor concentration, longer to think and light sensitivity. The additional variables chosen for inclusion were based on qualitative interviews with persons experiencing pain following a mTBI (see Chapter 4 for further details). The exploratory approach to factor analysis is preferred in instances when the researcher wants to ensure that the results are controlled by the data. The Kaiser-Guttman rule was used to determine the number of factors (Kaiser, 1958; Kaiser, 1961) in conjunction with the Scree test (Cattell, 1966).

All data were analyzed using the STATA statistical program. An alpha of $p<.05$ was used to determine significance for all analyses and an alpha of $p<.10$ was considered trending toward significance.

Results

Sample Characteristics

A total of 183 persons with mTBI were included in the study. Demographic and baseline sample characteristics are described in Table 1. Of the participants included in the study, the mean age was 49.1 years (Range 21-92 SD: 18.3). The sample contained a higher percentage of men (62.8%) compared to women (37.2%). Most of the sample identified their race/ethnic background as white (82.5%; n=151). While those identifying as non-white (17.5%; n=32) included African American (10.9%; n=20), Asian (2.7%; n=5), Other (2.2%; n=4), and American Indian (1.6%; n=3). There were no significant differences in baseline characteristics between the persistent pain group and those who did not develop persistent pain.

Factors Associated with Persistent Pain

The majority (78.1%; n=143) of the sample experienced persistent pain after their injury while 21.9% (n=40) did not. Differences between persistent pain groups and overall scores on overall health status variables are outlined in Table 2. Neither overall social support nor subscale scores at baseline were significantly different between those who did/did not develop persistent pain. Having a fall as a mechanism of injury was significantly different between groups, with those with persistent pain more likely to experience a fall than those who did not experience persistent pain.

In regard to demographic characteristics, there was a trend (p<.099) toward those who identified as White race/ethnicity experiencing higher odds of persistent pain. On univariate logistic regressions examining baseline characteristics; injury characteristics; and symptoms, those with no health conditions at baseline trended toward lower odds of persistent pain than those with multimorbidity at baseline (OR: .537, p<.108, CI: .25-1.1). Other pain/chronic pain condition was omitted by STATA due to low sample size (n=7). Results are reported in Table 3.

The univariate logistic regression of overall health status variables was conducted examining day 7 and 1 month. At day 7, those with higher scores on the physical function, social function, vitality and general health subscales were significantly less likely to later experience persistent pain. At 1 month, those with higher scores on all subscales including mental health were significantly less likely to later experience persistent pain. Results can be found in Table 3.

After adjusting for age, sex, and education, the overall health status categories were loaded into the model for day 7and 1 month. In this multivariate model, higher general health at day seven was significantly associated with lower odds of experiencing persistent pain at 6 months post-injury (OR: .97 p<.016 CI: .95-.99). Higher physical function at one-month post-injury was associated with lower odds of experiencing persistent pain at 6 months (OR: .97 p<.039 CI:.95-.99). Results can be found in Table 4.

Symptoms Clustering with Persistent Pain

We conducted a factor analysis to determine what other symptoms accompany persistent pain. Factors included in the model were persistent pain, anxiety (BSI anxiety subscale from BSI-18), depression (BSI depression subscale from BSI-18), dizziness (RPQ), nausea and vomiting (RPQ), sleep disturbance (RPQ), poor memory (RPQ), poor concentration (RPQ), longer to think (RPQ) and light sensitivity (RPQ). Factor analysis was conducted on this group of variables at both 3 months and 6 months post-injury. Variables loaded onto primarily one factor at both 3 months (Factor 1 Eigenvalue: 5.02; Factor 2 Eigenvalue: .633) and 6 months (Factor 1 Eigenvalue: 5.30; Factor 2 Eigenvalue: .788).

Discussion

The purpose of this study was to explore the pain experience among those with mTBI and determine if there are factors associated with expericing persistent pain. Similar to other studies (Nampiaparampil, 2008; *Lavigne et al., 2015*), we found that persistent pain was prevalent among those with mTBI, occurring in 78% of our sample. Given that mTBI can be physically and mentally disruptive to individuals without other health conditions, we hypothesized that those with additional health concerns would fare worse in terms of experiencing persistent pain after their injury. Consistent with this hypothesis, those without any other morbidities at baseline were trending toward ($p<.105$) being less likely to experience persistent pain compared to those with other health conditions at baseline. The sample included few individuals with a history of chronic pain condition (n=7/183), so this relationship was unable to be examined. However, the development of persistent pain among this group was very high (n=7/7).

Since overall health status can be impacted by a traumatic injury, we found that some dimensions of health status were significantly associated with persistent pain outcomes. Those with higher general health at day 7 were significantly less likely to experience persistent pain after adjusting for age, sex, education, physical functioning, mental health, social functioning, and vitality variables. Having high general health at day 7 might suggest that one is recovering quickly from injury. It is possible that those who have report higher general health experience lower severity of pain or length of pain during their early recovery; we were unable to examine this as a potential explanation because the parent study did not collect data on pain severity. Additionally, higher general health at day 7 might enable the return to their normal activities, thereby mitigating symptoms.

When overall health status variables were examined at 1 month after injury, those with higher physical function had significantly lesser odds of experiencing persistent pain. Potential explanations are that those with high physical functioning at 1 month experienced lower pain severity (though we were not able to examine this) or that high physical functioning allowed for engagement in physical activity, which has been shown protective against pain (Tan et al., 2014). Tan's (2014) review suggests that post-mTBI symptoms including headache might be able to be treated by engaging in exercise, as this could target underlying mechanisms causing the symptoms by promoting cerebrovascular regulation. Some studies indicate that persistent back pain can be reduced by engaging in physical activities such as tai chi and yoga (Wren et al., 2011; Hall et al., 2011).

In our analysis, those with higher mental health did not have significantly lower odds of later experiencing persistent pain at day 7 but did have lower odds at 1 month post-injury. Although the reasons for this delayed association are not clear, it may be that the mutually exacerbating effects of poor mental health and pain may take time to manifest. Seal and colleagues (2017) found that those with TBI, PTSD and depression concurrently had the highest risk of experiencing chronic pain. In a sample of adults with mTBI, Jamora and colleagues (2013) found evidence to suggest that pain makes one's emotional challenges more difficult.

Taken together, these findings indicate that better health at baseline, 7 days after injury and 1 month after injury is associated with lesser odds of experiencing persistent pain at 6 months after mTBI. Results from this study support other studies that report associations between pain and other health outcomes throughout recovery from mTBI (Seal et al., 2017;

Jamora et al., 2013). Clinicians can screen for multimorbidities at baseline as well as general health, mental health and physical functioning during the early recovery phase to help determine if patients are at risk for later experiencing persistent pain. Seal and colleagues (2017) suggest that treating the mental health issues such as depression or PTSD in conjunction with pain might be most effective in improving mental health and pain outcomes in patients who have experienced TBI. Jamora and colleagues (2013) put forth the idea that treatment should consist of helping patients develop coping-strategies to deal with emotional difficulties related to the pain they experience after mTBI. When patients with mTBI access health services, a multidimensional approach to screening for persistent pain and treating persistent pain and associated difficulties should be utilized by clinicians.

We loaded common post-mTBI symptoms into a factor analysis including persistent pain, depression, anxiety, dizziness, nausea and vomiting, sleep disturbance, poor memory, poor concentration, longer to think and light sensitivity. These symptoms loaded onto just one factor which means that in this model they are highly associated with each other. Theadom and colleagues (2016) found that about half of patients with mTBI continued to experience at least four post-concussion symptoms at one year after their injury. At one year after injury, patients with mTBI (N=341) still reported a high prevalence of headache (36.1%), sleep disturbance (32.0%), fatigue (40.5%), irritability (32.3%), frustration (33.7%), forgetfulness (40.9%), poor concentration (34.0%), and taking longer to think (40.5%) (Theadom et al., 2016). Clinicians can use this information to screen those with mTBI not only for persistent pain but also for the other symptoms and develop treatment plans that are comprehensive and holistic. The link we found between persistent pain and these other symptoms is associative rather than causal. Treating one symptom at a time might not be effective but treating more than one symptom might benefit patients even if they are occurring at different times (Walsh & Rybicki, 2006). Further work needs to be done to determine which treatment options benefit patients who have persistent pain and these associated symptoms.

Limitations

We are unable to obtain the severity of the pain that the participants experienced due to using secondary data. We do not have data on pain treatment in participants. This study was limited to those who only speak English, so diversity in our sample was limited.

Conclusion

This study fills a gap in the literature on persistent pain after mTBI by identifying factors throughout early recovery that impact one’s odds of experiencing persistent pain after injury. Since persistent pain is prevalent among those with mTBI, clinicians should screen all patients for pain as well as other associated symptoms, e.g. the “persistent pain phenotype” throughout their recovery from mTBI. During recovery, poor general health status is a risk factor for development of persistent pain. Future research should focus on better understanding the relationships between pain and the other common post mTBI symptoms to elucidate the mechanisms underlying the development of the persistent pain phenotype. Future research is needed to determine treatments to best prevent persistent pain in those at greatest risk. Lastly, additional work is needed to identify tailored, effective, multimodal and holistic approaches to persons experiencing persistent pain and related symptoms in order to reduce symptom burden and improve overall health status in persons following mTBI.

References

Abbreviated Injury Scale (AIS). (2008). Association for the Advancement of Automotive Medicine.

Cattell, R.B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research, 1,* 245–276

Centers for Disease Control and Prevention. (2015). Report to congress on traumatic brain injury in the United States: Epidemiology and rehabilitation. National Center for Injury Prevention and Control; Division of Unintentional Injury Prevention. Atlanta, GA.

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment, 49*, 71–75.

Elixhauser, A., Steiner, C., Harris, D.R., Coffey, R.M. (1998). Comorbidity measures for use with administrative data. *Medical Care, 36*, 8–27.

Findler, M., Cantor, J., Haddad, L., Gordon, W., Ashman, T. (2001). The reliability and validity of the SF-36 health survey questionnaire for use with individuals with traumatic brain injury. *Brain Injury, 15*, 715–23.

Franke, G., Jaeger, S., Glaesmer, H., Barkmann, C., Petrowski, J. & Braehler, E. (2017). Psychometric analysis of the Brief Symptom Inventory 18 (BSI-18) in a representative German sample*. BioMed Central Medical Research Methodology, 17*(14), 1-7.

Hall, A.M, Maher, C.G., Lam, P. (2011). Tai chi exercise for treatment of pain and disability in people with persistent low back pain: A randomized controlled trial. *Arthritis Care & Research, 63*(11), 1576-83.

Hawker, G.A., Mian, S., Kendzerserska, T., & French, M. (2011). Measures of adult pain. *Arthritis Care & Research, 63*(S11), S240–S252.

Ingebrigtsen, T., Waterloo, K., Marup-Jensen, S., Attner, E., Romner, B. (1998) Quantification of post-concussion symptoms 3 months after minor head injury in 100 consecutive patients. *Journal of Neurology, 245*, 609–612.

International Association for the Study of Pain (IASP). (2018). Real women, real pain. Retrieved from https://www.iasp-pain.org/GlobalYear/PaininWomen.

Jamora, C.W., Schroeder, S.C. & Ruff, R.M. (2013) Pain and mild traumatic brain injury: The implications of pain severity on emotional and cognitive functioning, *Brain Injury*, *27*(10), 1134-1140.

Kaiser, H.F. (1958) The varimax criterion for analytic rotation in factor analysis. *Psychometrika, 23*,176–200.

Kaiser, H.F. (1961) A note on Guttman's lower bound for the number of common factors. *British Journal of Statistical Psychology, 14*(1),1.

King, N.S., et al. (1995). The Rivermead Post-concussion Symptoms Questionnaire: A measure of symptoms commonly experienced after head injury and its reliability. *Journal of Neurology, 242,* 587-592.

Lavigne, G., Khoury, S., Chauny, J., Desautels, A. (2015). Pain and sleep in post-concussion/mild traumatic brain injury. *Pain*, *156*(4), S75-S85.

Lucas, S., Smith, B.M., Temkin, N., et al. (2016). Comorbidity of headache and depression after mild traumatic brain injury. *Headache, 56*, 323-330.

Meachen, S. Hanks, R.A, Millis, S.R, & Rapport, L.J. (2008). The reliability and validity of the brief symptom inventory-18 in persons with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 89,* 958-965.

Mollayeva, T., Shapiro, C.M., Mollayeva., et al. (2015). Modeling community integration in workers with delayed recovery from mild traumatic brain injury. *BioMed Central Neurology*, *15,*194.

Nampiaparampil, D. E. (2008). Prevalence of chronic pain after traumatic brain injury: A systematic review. *Journal of the American Medical Association, 300*(6), 711–719.

Ouellet, M.C., Sirois, M.J., Lavoie, A. (2009). Perceived mental health and needs for mental health services following trauma with and without injury. *Journal of Rehabilitation Medicine, 41*,179–186.

Portanova, J. & Thompson, H. (2019). Persistent Pain: A Concept Analysis. Presented at Western Institute of Nursing Conference, San Diego, CA.

Sawyer, K., Bell, K.R., Ehde, D.M., et al. (2015). Longitudinal study of headache trajectories in the year after mild traumatic brain injury: relation to posttraumatic stress disorder symptoms. *Archives of Physical Medicine and Rehabilitation, 96*, 2000-2006.

Schwab, K., Terrio, H.P., Brenner, L.A., et al. (2017). Epidemiology and prognosis of mild traumatic brain injury in returning soldiers. *Neurobiology BB*, 88,1571-1579.

Seal, K.H., Bertenthal, D., Barnes, D.E., et al. Association of traumatic brain injury with chronic pain in Iraq and Afghanistan veterans: Effect of comorbid mental health conditions. *Archives of Physical Medicine and Rehabilitation, 98*(8),1636-1645.

Sherbourne, Cathy D. and Anita Stewart. (1993). The MOS Social Support Survey. Santa Monica, CA: RAND Corporation. Retrieved from https://www.rand.org/pubs/reprints/RP218.html.

Sherman KB, Goldberg M, Bell KR. (2006). TBI and pain. *Physical Medicine & Rehabilitation Clinics of NorthAmerica*,*17*(2), 473-490.

Stojanovic, M.P., Fonda, J., Brawn Fortier, C., et al. (2016). Influence of mild traumatic brain injury and posttraumatic stress disorder on pain intensity levels in OEF/OIF/OND veterans. *Pain Medicine, 17,* 2017-2025.

Tan, C.O., Meehan, W.P., Iverson, G.L, & Taylor, J.A. (2014). Cerebrovascular regulation, exercise, and mild traumatic brain injury. *Neurology, 83*(18): 1665-1672.

Theadom, A., Parag, V., Dowell, T. et al. (2016) Persistent problems 1 year after mild traumatic brain injury: A longitudinal population study in New Zealand. *British Journal of General Practice*, *66*(642): e16-e23.

Waljas, M., Iverson, G.L, Lange, R.T., et al. (2015). A prospective biopsychosocial study of the persistent post-concussion symptoms following mild traumatic brain injury. *Journal of Neurotrauma, 32*, 534-547.

Walsh, D. & Rybicki, L. (2006). Symptom clustering in advanced cancer. *Supportive Care in Cancer, 14*(8), 831-836.

Wren, A.A., Wright, M.A., Carson, J.W. et al. (2011). Yoga for persistent pain: New findings and directions for an ancient practice. *Pain, 152*(3), 477-480.

Tables

Table 1.

Demographic and Baseline Characteristics.

	Overall (N=183)	No Persistent Pain (n=40)	Persistent Pain (n=143)	P-Value*
Baseline Demographics				
Age (years)	49.2 (18.3)	51.2 (16.6)	48.6 (18.8)	0.441
Male N(%)	109 (62.3%)	24 (63.2%)	85 (62.0%)	0.015
White N(%)	144 (82.3%)	29 (76.3%)	115 (83.9%)	1.186
Education (years)	15.1 (2.8)	15.1 (3.6)	15.1 (2.6)	0.982
Injury Characteristics				
Injury Severity (AIS Head)	1.6 (1.1)	1.6 (.96)	1.7 (1.2)	0.687
Mechanism: Fall N(%)	52 (29.7%)	11 (29.0%)	41 (29.9%)	0.013
Mechanism: Motor Vehicle Crash N(%)	67 (38.3%)	13 (34.2%)	54 (39.4%)	0.341
CT Scan Positive N(%)	62 (35.4%)	15 (39.5%)	47 (34.3%)	0.347
Baseline Health Conditions				
Depression N(%)	25 (14.3%)	3 (7.9%)	22 (16.1%)	1.619
Pain Condition/ Chronic Pain N(%)	7 (4%)	0 (0%)	7 (5.1%)	2.022
No Multimorbidities N(%)	52 (29.7%)	15 (39.5%)	37 (27.0%)	2.213
Social Support at Baseline				
Emotional/Informational	4.1 (.83)	4.1 (.93)	4.2 (.81)	0.8
Tangible	4.1 (1.0)	4.1 (1.1)	4.0 (1.0)	0.617
Affectionate	4.4 (1.1)	4.2 (1.2)	4.4 (1.0)	0.39
Positive Social Interaction	4.2 (.86)	4.3 (.79)	4.2 (.91)	0.572
Overall MOS Score	4.2 (.79)	4.2 (.89)	4.2 (.77)	0.97

Note. P-values are for Chi-squared tests of categorical variables and independent t-tests of continuous variables

All means and standard deviations except as noted.

MOS= Medical Outcomes Survey

AIS= Abbreviated Injury Score

Table 2.

Characteristics of Overall Health Status after Injury in those with and without Persistent Pain

	Overall	No Persistent Pain	Persistent Pain	P-Value
Overall Health Status (day 7)				
Physical Functioning	57.1 (31.2)	65.7 (28.2)	54.4 (31.7)	0.054
Mental Health	59.5 (16.7)	62.4 (17.1)	58.6 (16.5)	0.224
Social Functioning	48.6 (30.8)	59.5 (29.1)	45.3 (30.7)	0.014
Vitality	41.4 (17.8)	47.6 (18.0)	39.5 (17.4)	0.015
General Health	66.3 (21.7)	75.2 (17.1)	63.6 (22.3)	0.004
Overall Health Status (1 month)				
Physical Functioning	69.2 (28.6)	84.6 (19.1)	64.6 (29.5)	<.001
Mental Health	63.1 (16.4)	68.8 (13.8)	61.4 (16.8)	0.018
Social Functioning	68.1 (28.7)	81.9 (23.6)	63.9 (28.9)	<.001
Vitality	49.9 (17.5)	58.6 (13.3)	47.3 (17.8)	<.001
General Health	66.7 (20.4)	75.9 (16.0)	64.0 (20.8)	<.001

Note. P-values are for Chi-squared tests of categorical variables and independent t-tests of continuous variables

Table 3.

Univariate Logistic Regression Analysis of Predictors for Persistent Pain from Baseline to 1 Month After Injury

Characteristic	Odds Ratio (95% CI)	P-Value
Age	.992 (.972-1.01)	0.438
Male	1.00 (.476-2.12)	0.986
Education	.998 (.878-1.13)	0.182
White	2.06 (.871-4.88)	0.099

Motor Vehicle Accident	1.18 (.556-2.52)	0.657
Fall	.999 (.451-2.20)	0.998
CT Scan Positive	.876 (.413-1.85)	0.73
Depression	2.14 (.606-7.61)	0.236
No Multimorbidity	.537 (.252-1.14)	0.108
Other Pain/ Chronic Pain Condition	omitted	omitted
Injury Severity (AIS Head)	1.06 (.774-1.47)	0.685
Overall Health Status (Day 7)		
Physical Functioning	.987 (.975-1.00)	0.057
Mental Health	.985 (.962-1.00)	0.224
Social Functioning	.984 (.972-.997)	0.016
Vitality	.974 (.953-.995)	0.017
General Health	.971 (.951-.991)	0.006
Overall Health Status (1 Month)		
Physical Functioning	.964 (.945-.985)	0.001
Mental Health	.968 (.943-.995)	0.021
Social Functioning	.973 (.957-.989)	0.001
Vitality	.958 (.934-.983)	0.001
General Health	.967 (.945-.988)	0.003
Social Support (Baseline)		
Emotional/Informational	1.06 (.672-1.67)	0.799
Tangible	.906 (.617-1.33)	0.615
Affectionate	1.15 (.827-1.62)	0.389
Positive Social Interaction	.877 (.558-1.37)	0.57
Overall MOS Score	1.00 (.621-1.63)	0.969

Note. MOS= Medical Outcomes Survey, AIS= Abbreviated Injury Score, P-values are for Chi-squared tests of categorical variables and independent t-tests of continuous variables

Table 4.

Multivariate Logistic Regression Analysis of Predictors for Persistent Pain

	Odds Ratio (95% CI)	P-Value
Model 1. Age, Sex, Education, White		
Age	0.990 (.970-1.01)	0.373
Male	1 (.470-2.14)	0.99
Education	0.982 (.861-1.11)	0.788
White	2.21 (.906-5.39)	0.081
Model 2. Age, Sex, Education, Overall Health Status Day 7		
Age	.996 (.973-1.02)	0.703
Male	.686 (.267-1.76)	0.433
Education	1.15 (.980-1.35)	0.087
Physical Functioning	.995 (.980-1.01)	0.476
Mental Health	1.01 (.980-1.04)	0.453
Social Functioning	.991 (.975-1.01)	0.293
Vitality	.992 (.962-1.02)	0.61
General Health	.973 (.951-.995)	0.016
Model 3. Age, Sex, Education, Overall Health Status 1 Month		
Age	.984 (.960-1.01)	0.224
Male	.735 (.276-1.95)	0.537
Education	1.14 (.967-1.43)	0.121
Physical Functioning	.975 (.952-.999)	0.039
Mental Health	1.02 (.975-1.07)	0.975
Social Functioning	.991 (.967-1.02)	0.458
Vitality	.982 (.941-1.03)	0.419
General Health	.978 (.951-1.01)	0.111

Note. P-values are for Chi-squared tests of categorical variables and independent t-tests of continuous variables

Appendix

Appendix A.

Parent Study Inclusion Criteria

- Have a clinical diagnosis of mild TBI within the past 24 hours;
- Glasgow Coma Scale score > 12 in ED;
- Speak and read English; and
- Have a documented home address and telephone number within western Washington State.

Parent Study Exclusion Criteria

- Be planning to leave the area within 6 months;
- Have a known life expectancy < 6 months;
- Have a cervical spine trauma at time of injury;
- Have a previous head injury or stroke in the past year;
- Have a history of dementia;
- Have a penetrating head injury;
- Have injuries to other body regions (non-head) that are classified as greater than a moderate injury;
- Be using Cox-2 Inhibitors or NSAIDS more than 3 days/week, or oral or injectable steroids in the last month that would alter cytokine levels; or
- Be unable to provide a 12 mL blood sample within 24 hours of injury.

Parent Study Recruitment Strategy

Women and men aged 21 and above with a diagnosis of TBI at Harborview Medical Center were recruited for the study. Waivers of HIPAA authorization for screening were obtained, but all subjects or legally authorized representative (LAR) provided and consent at time of study enrollment. Subjects were screened for meeting inclusion/exclusion criteria in the emergency department. Once potential subjects were identified, the ED nurse asked subject/LAR if they were interested in participating. If yes, the study protocol was reviewed, and written informed consent obtained. If the LAR provided initial consent, the subject was approached at day 3 and given the option to:

1) continue participation;
2) end participation and have Day 0 sample retained; or
3) end participation and have all data destroyed.

Chapter 4

Pain and Symptoms following mTBI: Should Technology Play a Role in Self-Management?

Abstract

Introduction/Background

Those with mild traumatic brain injury (mTBI) often experience pain and symptoms long after their initial injury. A gap in current knowledge is how persons would prefer to monitor and manage these symptoms following mTBI. The purpose of this study was to explore self-management strategies in order to inform design of an informatics tool to support self-management of pain and symptoms following mTBI.

Methods

A qualitative descriptive approach using semi-structured phone interviews of participants with recent mTBI was used to meet study aims. A descriptive approach was utilized to determine what the tool should address, and which features should be included in a future tool.
Themes were identified using a Qualitative Description analysis approach, which is based in naturalistic inquiry.

Results

Seven female participants completed interviews. Participants described difficulty coping with symptoms, limited access to or knowledge of treatments and trial and error with compensatory strategies. These challenges often led to difficulty keeping up with work, school and other commitments. All participants indicated that they were interested in a tool that addresses pain, memory and concentration. The main features that participants wanted were pain and symptom tracking as well as suggestions based on tracking information. Sharing their recovery with others, including customizing what was to be shared, was wanted as a feature in a future tool.
An app on the phone was the most popular platform, but voice recognition was also recommended to reduce screen time.

Discussion

Participants reported a significant pain and symptom burden during their recovery from mTBI often with multiple symptoms lasting weeks to months after injury. Lack of knowledge around managing pain and symptoms as well as competing demands with work, school and other responsibilities hindered their recovery. Participants thought that a technology tool would help them with self-management of pain and other symptoms following mTBI.

Conclusions or Implications for Practice

Patients are interested in using technology to help with self-management of their pain and symptoms following mTBI. Enhanced communication with providers and ability to gain enough rest earlier in their recovery may provide better pain and symptom outcomes for patients. In the future, tools that help patients with self-management should integrate into health systems and provide ways to effectively interact with providers during the most vulnerable phases of recovery. End-user testing of a future technology tool for self-management would be important in this population due to the multiple challenges they face in their recovery from injury.

Background

Pain management after mild Traumatic Brain Injury (mTBI) is a challenge for patients, who often have co-occurring symptoms and diagnoses. Self-management strategies have been successful in promoting recovery and symptom management in those with mTBI (King et al., 2015), which suggests that a future informatics tool that utilizes self-management strategies might be successful in this population. While there are informatics tools with many different designs, features, and targeted populations in the literature, few informatics interventions currently exist for patients with mTBI who are at risk for persistent pain. This study aims to understand the experience of pain and symptom management in patients during their recovery from mTBI and understand what gaps there are in self-management after injury. This study also aims to elicit feedback from participants about thoughts regarding if a technology tool could aid them with self-management of their pain and symptoms during recovery from mTBI.

Self-management.

Self-management strategies have been successfully implemented for pain after mTBI (King et al., 2015). These strategies, including exercise and antidepressant use, significantly reduced pain among those with mTBI (King et al., 2015). Mindfulness meditation is an effective self-management tool to reduce pain severity and improve quality of life among those with chronic pain (Khusid & Vythilingham, 2016). Other self-management strategies for pain such as complementary and alternative medicine may improve outcomes, but this has not been studied (King et al., 2015). King and colleagues (2015) suggest that self-management for pain after mTBI might benefit from concurrent mental health interventions. Self-management of pain among those experiencing chronic pain has been effective in reducing pain and improving mental health (Mann et al., 2013). Some formats for delivery of self-management interventions for pain include group and individual sessions, telephone calls and/or study toolkits, online websites and delivering an intervention using more than one method (Mann et al., 2013). Some facilitators to self-management for pain include flexible self-management strategies and scheduling as well as having treated the patient's mental health concerns (Mann et al., 2013).

The current self-management strategies for mTBI are important to learn from and to integrate into future interventions. A study of a self-management program for symptoms following TBI had promising results and demonstrated improvement in daily functioning (Kendrick et al., 2012). The program approach was based in the community for a limited duration consisting of 8 sessions with an occupational therapist and psychologist (Kendrick et al., 2012). Multidisciplinary coaching to compensate for challenges has been favored over traditional rehabilitation in this population (Kendrick et al., 2012) and would be important to include in any self-management program. A possible explanation for difficulty with standard rehabilitation is because the nature of mTBI injury can vary widely between those with the same diagnosis (Barman et al, 2016).

Various injury-related and personal factors should be considered in the planning of self-management approaches, and research is needed to guide such work. Demographic and cultural factors are imperative to consider when designing an intervention for those vulnerable to pain after mTBI and are understudied. The design of an interventions needs to consider how demographic and cultural characteristics influence one's preferences, language, and daily activities in order to improve the chances of the patient's success with self-management. Including aspects of education for the patient or family/caregiver could be a key element to making a self-management intervention successful in populations at an increased risk for poor pain management. Given the likely need for a tailored approach to pain management in this diverse population, an informatics tool may be highly beneficial. This is reinforced by Sawyer and colleagues' (2015) recommendation to target interventions in order to improve early detection and secondary prevention of headaches in those with mTBI.

Current Informatics Tools to Support Pain Self-Management

Consideration of current informatics tools may help identify facilitators and barriers to use of self-management support tools for pain and symptoms by persons with mTBI. Several informatics tools for pain tracking are currently available as mobile phone applications and computerized questionnaires. Some of the current tools used to record, track, manage, and report pain are PainCompanion, CatchMyPain, PainScale and PainTracker. Knowledge about the pain experiences of those with mTBI can be used to create more relevant and effective tools targeted at this population.

Some features that have been used in other pain applications might be successful with an informatics tool for those who have TBI. For example, ranking items of importance, as seen in the PainTracker computerized questionnaire, might be beneficial for those with TBI who have multiple issues to address when they meet with their healthcare providers. Suggestions from Valenti's (2016) study about increasing font size and working around scrolling capacity might make the application more usable for those with sensory issues as well as those who are older adults. The 2-way messaging capabilities explored by Jamison and colleagues (2017) might be able to increase use of the application in some participants. Mindfulness meditation could be integrated into an informatics tool to support patients who would benefit from this self-management method as a way to self-manage their pain.

Adapting Informatics Tools for TBI Population

Little is known about how to adapt informatics tools to populations suffering from TBI. Some of the challenges that are commonly experienced by those with TBI include co-occurring symptoms and diagnoses such as depression, memory and sensory deficiencies as well as PTSD (Irvine & Clark, 2017). Attention to these challenges is important to consider when designing an intervention for this population. Pairing what we know from the evidence about pain in those with TBI with what we ask users to input on mobile apps should increase the usefulness of self-management tools and reduce the burden on the user (Reynoldson et al., 2014).

Many common co-existing symptoms and diagnoses should be considered in the process of understanding pain and its management in the TBI population. While a future application design should consider the additional challenges that those with TBI may be facing, creating a one-size fits all application might prove challenging. An alternative approach could be to develop a prototype with additional options added on as Griffith (2017) did for females with her Interstitial Cystitis/Painful Bladder Syndrome informatics tool design. Once a basic tool design proves feasible for tracking and managing persistent pain in those with TBI, expanding the features and adaptations to accommodate those with more severe co-existing health challenges would be a worthwhile next step. By keeping the end-user in mind, linking evidence-based content to user requirements, and evaluating the usability throughout the design, development and implementation of the application, a tool can be created to reduce or eliminate persistent pain in individuals with TBI.

Purpose

The purpose of this study is to learn more about the pain and symptom experience, find out how patient’s view their own self-management during recovery and to explore what a future tool could do to improve patient self-management of pain and symptoms. Currently informatics interventions to address pain following traumatic brain injury are not widely used. This project challenges current clinical practice paradigms by introducing early intervention for those at risk of persistent pain and tailoring it to specific patient needs. This research aims to inform a future prototype of a pain management tool using a design approach guided by qualitative interviews with participants who have recently experienced pain after a mTBI.

Methods

Design

A qualitative approach was employed, using semi-structured interviews to obtain feedback on the experience of pain and symptoms after mTBI, self-management during recovery and feedback about a future technology tool to assist with self-management after mTBI.

Participants

Participants were recruited from a wide range of community organizations and universities nationwide by convenience sampling. Paper recruitment flyers were posted throughout the University of Washington (UW) campus and an e-mailed flyer was sent to physicians, sports centers, and universities. Interested individuals contacted the principal investigator via phone or email to indicate interest in participating and to be screened for eligibility. To participate in this study, participants had to self-report having a clinician diagnosed mTBI or concussion within the past 6 months and having experienced pain following their injury. Inclusion criteria were: aged 18 or older, able to provide consent, and access to the internet or willingness to meet in person at the University of Washington campus. Those who were recruited were evaluated for their overall ability to participate in this study and excluded if they were unable to provide informed consent or if their participation would be harmful to their health. The UW Institutional Review Board approved all study procedures.

Procedures

Participants were interviewed individually and asked a series of questions. Participants were first asked to describe their injury, symptoms, and current self-management approaches. The participants were then prompted by the researcher to provide feedback about what type of informatics tool would be beneficial to them. Participants were shown a list of potential tool features, based on findings from quantitative results; participants provided feedback on whether these features would be helpful and facilitate their use of this type of tool. Participants were asked to respond with yes, no or unsure to questions about what should be addressed in a future tool and which features should be included in a future tool. Questions about facilitators and barriers as well as features and motivations to use the tool were included. The interview guide can be found in Appendix A. Written or verbal informed consent for participation was obtained from all participants. Participants were compensated for their time via a $25 gift card provided to the participant after the interview concluded. Data were recorded during the interview sessions and transcribed in Microsoft Word by the researcher and then the transcript was verified.

Analysis

Qualitative Description, based on naturalistic inquiry, was used to analyze the data (Sandelowski, 2000). The qualitative descriptive approach was chosen because it is appropriate when collecting data in order to, "discover the who, what, and where of events or experiences," (Sandelowski, 2000, p.338). In this study, we sought to understand the experiences of those who have pain after mTBI in order to try to create an informatics tool that alleviates pain and symptoms.

ATLAS.ti 8 (ATLAS.ti, Berlin) was used to manage data during analysis. There was an independent second coder and codes were reconciled after all interviews had been coded between the two coders by discussing discrepancies until 100% coder agreement was reached. The steps of the descriptive qualitative research analysis as outlined by Elliot and Timulak (2005) were followed:

1. Data preparation
2. Delineating and processing meaning units
3. Finding an overall organizing structure for the data
4. Generation of categories
5. Abstracting the main findings
6. Validity of analysis.

Trustworthiness of the data was addressed by auditing throughout the analysis using a "constructively skeptical process," (Elliot & Timulak, 2005). Resonation with the reader, by providing several examples that they can form their own judgments about, was used as a form of validation (Elliot & Timulak, 2005).

Results

Nine persons contacted us between October and December 2018 with interest in the study. Seven (all female, aged 18-23) agreed to be screened for eligibility, were qualified, and enrolled in the study. Interviews lasted between 20 and 40 minutes in length. Three overarching themes pertaining to symptom self-management emerged from the qualitative descriptive analysis: 1) Difficulty coping with pain and post-mTBI symptoms; 2) Lack of knowledge and access to treatment strategies; 3) Trial and error with compensatory strategies and 4) Recommendations for technology to support recovery. Sub-codes in each of these three areas were constructed based on the interviews. An additional theme, recommendations for technology to support recovery, was identified *a priori*, given that this topic was addressed explicitly in the interviews; subthemes were coded using content analysis in the same manner as was done for the other themes. Exemplary quotes can be found in Table 1.

Theme 1: Difficulty Coping with Pain and Post-TBI Symptoms

Participants reported multiple types of symptoms including headaches, trouble concentrating, irritability, neck pain, forgetfulness, confusion, tiredness/sleepiness, nausea, dizziness and light sensitivity. Headaches were the most commonly reported type of pain and often intermittently impacted participants for weeks to months after injury. Neck pain resulted in severe pain for one participant. Trouble concentrating and forgetfulness were widely reported among participants and had a negative impact on activities such as school.

Areas of challenges. Areas of challenges included continuing work and school activities including studying/homework and taking time to reintegrate into exercise and sports activities.

Theme 2: Lack of Knowledge and Access to Treatment Strategies

Participants widely reported that they did not know what they should do to help with their recovery. Interaction with providers primarily happened immediately following injury, but additional resources throughout their recovery were not often reported.

Treatments. Participants tried different approaches to cope with or mitigate their pain and symptoms. Treatments that were reported as alleviating pain and symptoms were mindfulness meditation, resting, napping, and Tylenol.

Needs related to self-management. Needs related to self-management included access to the correct medication, knowledge about the benefits of resting and limiting triggering activities and a checklist of things to do after injury.

Theme 3: Trial and Error with Compensatory Strategies

Participants found that some of the treatments they tried were ineffective, including ibuprofen and exercise/movement. Some participants reported that they sought information about treatment on the internet.

Facilitators. Facilitators to self-management included adapting to forgetfulness by employing new techniques such as list-making.

Barriers. Barriers to self-management included trying to figure out the correct treatment for pain and symptoms through trial and error.

Theme 4: Recommendations for Technology to Support Recovery

Give a little lead-in here. E.g., remind the reader that respondents were presented a list to prompt discussion.

Features. Features of a technology tool that would focus on pain, memory and concentration were listed as desired features by all participants and were the features most frequently cited by participants as helpful. Further, when asked what would be most helpful, participants most frequently cited pain, memory and concentration. The least popular area of focus for a technology tool was quality of life. The most commonly endorsed features of a technology tool were pain and symptom tracking, including occurrence, triggers, treatments and response to treatments as well as suggestions based on symptom tracking information and ability to share with others were agreed upon by all participants. The least popular features were video educational content about symptoms and virtual brain injury support groups.

Sharing. Participants unanimously agreed that they would like to share their health information with others through the tool. An important feature to participants was selection of who may access to their information and what aspects of this information they share. One participant suggested that the best way to design a tool would be to create boxes next to each item that the participant could check off if they wanted to share.

Platform. Each participant was asked what platform they would like to use for a future tool and phone access through an app was the most widely preferred platform. Some participants wanted a smart phone app that they could access by computer as well as on their phone. When asked about their current app use, participants did not report using apps to help them with pain and symptom management after mTBI but did report using health apps including fitness apps, a meditation app, and a menstrual cycle tracker app. A summary of participant feedback on technology features can be found in Table 2.

Prototype Design

The prototype design of a technology tool to help those who have experience a concussion has features that integrate our findings. Descriptive survey questions were used to determine which areas needed to be addressed with a future tool and what features the tool should include. The tool was designed based on the preferences conveyed during the interviews by the majority of our participants. The prototype design can be found in Appendix A of Chapter 5 and is described in Chapter 5.

Discussion

This study sought to explore the pain and symptom experience for those with mTBI, self-management of pain and symptoms during recovery, and the potential role of technology pain and symptom management after mTBI. Our participants reported a diverse set of symptoms and pain that varied over weeks to months. While most participants reported an attempt to self-manage their pain and symptoms, lack of knowledge about how to do so was a major barrier. Similar to other populations (Valenti et al., 2016), we found that patients with mTBI did want to use an app to help them with managing their pain and symptoms. Among our participants, returning to school after injury and completing homework assignments was a major challenge. This study confirmed the importance Rose and colleagues' (2015) recommendations about ways that clinicians could support students with mTBI with accommodations regarding return to school. We found that participants reported that they over-exerted themselves following injury and that better communication between them, their providers and their school or workplaces might expedite their recovery process. This study is the first to find that patients with mTBI are willing to electronically share information about their pain and symptoms throughout their recovery process with their physicians and in some cases with their coaches, teachers, and families. Patient autonomy in choice of what information to share and who to share it with is needed in a future tool.

Clinical Implications

This study suggests that patients would benefit from using technology to help with their needs related to self-management of their pain and symptoms following mTBI. Patients expressed a need for more information to help them with their self-management of pain and symptoms after recovery. Most interaction with providers took place during the acute phase of injury and perhaps educational information related to self-management after recovery should be easily available at multiple points during the recovery process as patients gain better self-management abilities.

A future tool should be able to effectively integrate into health systems and have user-friendly ways to interact with providers. Patients in this population cited needing to have a provider note to excuse absence from work and school responsibilities. Having easier ways to facilitate this communication by using the app would be beneficial. Many patients described "pushing" themselves to perform at school and work despite their injuries and recognized that this may have hindered their ability to recover successfully. With better communication with providers and ability to gain sufficient rest earlier in their recovery, patients may have better pain and symptom outcomes earlier in their recovery trajectory. The tool should ask questions that are clinically useful for the provider to be able to diagnose and treat the patient. Securely messaging this information to providers through the tool could be a useful first step before integrating the app into electronic medical records.

Limitations

The sample for the qualitative analysis was small and relatively homogenous with all the participants being young adult women, most of whom were college athletes. The results of this study might not be generalizable to other populations.

Research Implications

Future research in this population is needed to test future protypes of pain and symptom management apps that assist patients with recovery. This population expressed a need to reduce their screen time, so the idea of using voice recognition might be a successful feature in this population. This feature needs to be tested in the mTBI population to ensure that it can meet their needs. We also noted that some participants thought pen and paper would be a preferred way to manage their pain and symptoms. An option to write down their pain and symptoms either on their own blank paper or on a paper template and take a picture of it to upload to their pain and symptom app might be a possibility in the future.

In this study, we found that the participants in the acute period after mTBI (less than 1 month) and farther in the recovery trajectory (around 6 months) were less helpful in gathering information about pain and symptoms. Those who were interviewed early in their recovery trajectory were unable to remember some of the questions and were experiencing symptoms such as irritability during the interview. Those 3 months after injury were recovered enough to reflect on their past recovery trajectory and still experienced symptoms that could benefit from assistance. The design implications are presented in chapter 5.

Tables

Table 1.

Exemplary Quotes by Theme

Theme	Quote
Theme 1: Difficulty coping with pain and post-mTBI symptoms	
Type of symptom:	
Headache	"...anything that required concentration definitely hurt my head, like made my headaches worse." (P6)
Nausea	"...so the nausea stayed for a little bit. And then the nausea went away. " (P2)
Trouble concentrating	"I did have more difficulty concentrating…" (P1)
Irritability	"Two of the symptoms are overly emotional and overly irritable…" (p5)
Neck pain	"My neck pain was extremely bad like for a week after the injury... it was like excruciating... but the headaches like stayed a lot longer than my neck pain." (P6)
Forgetfulness	"Umm mainly just like forgetfulness. Like I literally have to write down everything still." (P7)
Confusion	"I like had memory gaps, pretty bad, and just like overall confusion." (P7)
Tired/sleepy	"Umm I've been super tired, sleepy and I have trouble concentrating like doing homework." (P3)
Light sensitivity and dizziness	"Umm one of the bothersome symptoms uh was dizziness. And, dizziness and light sensitivity." (P5)
Pain characteristics:	
Dullness	"It was also my jaw too it was like a dull pain." (P4)
Severity	"Umm probably a seven… Yeah, so pretty high up there." (P2) "Umm today yes, it's a little bit like a four…three." (P3) "At worst probably like a 4-5." (P1)
Impact on activities:	
School	"Yeah like usually I can study for like 2 hours straight...I was just jumping subject to subject and my mind was kind of frazzled." (P4)
Work	"I was working 12 hours a week and I quit my job mostly just because I felt terrible at my work and I couldn't do my job just physically and mentally." (P2)
Recovery trajectory:	
Duration	"I would always have at least a low level headache for like a month probably at least...Yeah I actually woke up with a splitting headache today. I have no idea where it came from (at 6 months)." (P7)
Factors impacting recovery time	"I had a concussed checked on the field right after I got hit and the sports medicine people at the university told me to come back and check in on Monday." (P5) "Umm I was also a medic and we have this

	problem of downplaying our injuries and I did so I didn't get treated right away." (P7)
Delay in recovery	"I know now, like if I had rested earlier, I wouldn't be in this position." (P2)
Areas of challenges:	"Going straight back into the schoolwork is what I needed to do but probably not the best thing I could have done for my symptoms." (P1)
Theme 2: Lack of knowledge and access to treatment strategies	
General	"There wasn't really like a connection between oh yeah don't study, don't go to class and all this...I think more reasons why would have helped me..." (P2)
Treatments:	
Medication	"...there's something in Tylenol, and I don't know what it is, but Tylenol helps specifically." (P2)
Rest and Meditation	"Umm but what has helped is just oh resting and then I did a bit of meditation." (P4)
Cannabis	"I did smoke marijuana…It did help, yeah." (P4)
Needs related to self-management	"My needs related are the education to know how to do it." (P5) "I think probably the difficulty concentrating on schoolwork was just frustrating and like I said, I had to kind of take a step back and be like you know it's okay that I'm not feeling 100% right now." (P1)
Theme 3: Trial and error with compensatory strategies	
Facilitators	"...I'm not really getting necessarily better at it, I'm just getting better at like managing it in the sense that like I keep a running grocery list on my phone for when I go and get groceries." (P7) "Uh probably try to talk like if you're in school try to communicate what's going on with you with your professors. So they can know what's going on and kind of comply a little bit with like, maybe extend the deadlines and things like that." (P3) "Well I would always repeat to myself what I needed to do, I don't know if that helps, but umm, and then also like setting reminders on my phone and things like that and umm for the concentration I would do the…I would do the Pomodoro technique of studying." (P4)
Barriers:	
Time	"Yeah cause I just when I was working I just didn't have the time throughout the day…(to take Tylenol)" (P2)
Memory	"...And I'd just forget and then I'd get my headaches and realize, oh I didn't take my Tylenol. " (P2)
Theme 4: Recommendations for Technology to Support Recovery	
Features	"What I had to do is write it on post it notes, like today I feel less dizzy, more dizzy and if I could track that on some type of phone or app, that would be great." (P5)
Sharing	"...as for what I would want to share, umm I guess if my symptoms had changed, or had gotten worse that's what I would want to share." (P2) "Umm I'd feel comfortable sharing with my coach and my doctor…" (P4)
Platform	"Umm definitely phone or computer nowadays because I feel like people are always on it nowadays that it would really help." (P6)

Table 2. Tools Results		**Participant Agreed**						
Interested in a tool that addresses:		**1**	**2**	**3**	**4**	**5**	**6**	**7**
	Memory	●	●	●	●	●	●	●
	Concentration	●	●	●	●	●	●	●
	Pain	●	●	●	●	●	●	●
	Physical Functioning	●	n	●	●	●	●	●
	Anxiety	●	●	●	●	u	●	n
	Depression	●	●	●	●	u	●	n
	Overall Mood	●	u	●	●	●	●	n
	Quality of Life	●	u	n	u	●	●	●
Interested in a technology that features:								
	Pain and Symptom Tracking	●	●	●	●	●	●	●
	Occurrence	●	●	●	●	●	●	●
	Triggers	●	●	●	●	●	●	●
	Treatments	●	●	●	●	●	●	●
	Response to Treatments	●	●	●	●	●	●	●
	Suggestions Based on Symptom Tracking Information	●	●	●	●	●	●	●
	Ability To Share Symptom Mgmt. Info. with Others	●	●	●	●	●	●	●
	Written Educational Content About Symptoms	●	●	●	●	●	●	n
	Tools for Relaxation	●	●	●	●	●	●	n

	Medication Management	**●**	**●**	**●**	**●**	**n**	**●**	**●**
	Fitness Tracking	**u**	**u**	**●**	**●**	**●**	**●**	**●**
	Tools for Distraction	**●**	**u**	**●**	**●**	**n**	**●**	**●**
	Virtual Brain Injury Support Groups	**●**	**n**	**●**	**●**	**n**	**●**	**n**
	Video Educational Content About Symptoms	**u**	**n**	**●**	**n**	**n**	**●**	**n**
Note. ●= yes u=unsure n=no								

Appendices

Appendix A.

Semi-Structured Interview Guide:

Welcome

Thank you for making time to attend our interview today.

- We are going to discuss needs of those who have experienced mild TBI.
- You can help by sharing your thoughts and ideas.
- Your unique perspective and opinion will help us better understand how to design a tool to help this population.

Explain the means to record the session.

Explain that the participants have the right to withdraw from the session at any time.

Introduce and ask the participant to sign the consent form

- Make sure participant has access and understands the consent form (e.g. should we have participant with impaired vision, you must read out the consent form)
- Ask the participant to sign and return the consent form or give verbal consent.

Introduce yourself.

Rules

We would like this to be a non-judgmental, relaxed environment for you to feel safe to discuss your thoughts about how you have managed your post-injury pain as well as your preferences for technology use. Please don't hesitate to ask questions or if you need any clarification please do. There is no right or wrong answer, but just different experiences and opinions. Your thoughts and opinions will also be important to help guide further study work in the development of technology tools for those who have pain following a brain injury.

Open-ended Questions:

Tell me a little about your injury, and what your recovery has been like.

Can you please tell me a little about your pain post-injury. (when, severity, has it changed over time, challenges/problems)?

What has helped with your pain? Not helped? Do you have any specific things or lessons learned that you'd recommend to others experiencing pain post-injury to help them manage it?

What other symptoms have you experienced that have been bothersome? Why?

What has helped with this symptom? Not helped? Any "lessons learned" you'd wished you'd known before or would recommend to others?

What problems or challenges have you experienced related to managing symptoms following your injury? What has been the most bothersome/problematic?

Prompt: Self-management is the active participation by a patient in their own health care decisions and interventions for optimal health or recovery.

What are your needs related to self-management of your pain?

What do you want/need to help with your needs?

Do you think that technology could play a role to help with you managing your pain? Why or why not?

Describe what the ideal pain management tool would do for you.

Use prompts as needed:

What preferences would they have in terms of delivery? (use on paper/pencil, computer, phone, tablet)

What tasks or goals should a symptom management tool help you accomplish?

What would you want a tool to do (show data? Graph/track? Help identify triggers?)

Who would you want to share your information with if anyone? What controls would you want in place for your information?

What features do you not need/want? Which features might be the most/least helpful? (feature list made from findings of aims 1 and 2.) Ask to rank 1-3 for most important.

Are you interested in a technology tool that addresses: (yes/no/unsure)

- pain
- anxiety
- depression
- overall mood
- memory
- concentration
- quality of life
- physical functioning
- Other: write in.

Are you interested in a technology that features: (yes/no/unsure)

- pain and symptom tracking
    - occurrence
    - triggers
    - treatments
    - response to treatment
- suggestions based on symptom tracking information
- written educational content about symptoms
- video educational content about symptoms
- tools for distraction
- tools for relaxation
- ability to share symptom management information with others
- virtual brain injury support groups
- medication management
- fitness tracking
- Other (write in)

What do you use apps for now?

How do you envision using the pain app?

Please tell me about why you chose what you did.

Ask for any additional feedback.

Thank participant and give gift card.

References

Barman, A., Chatterjee, A., & Bhide, R. (2016). Cognitive impairment and rehabilitation strategies after traumatic brain injury. *Indian Journal of Psychological Medicine*, *38*(3),172-181.

CatchMyPain. (2018). Retrieved from: https://www.catchmypain.com/.

Elliot, R., & Timulak, L. (2005). Descriptive and interpretive approaches to qualitative research. In J. Miles & P. Gilbert (Eds.), A handbook of research methods for clinical and health psychology (pp. 147-159). New York, NY, US: Oxford University Press.

Griffith, J. (2017). Designing a mobile health application prototype for the management of interstitial cystitis/painful bladder syndrome. *Medinfo 2017: Precision Healthcare through Informatics, 245*, 94-97.

Irvine, K.A. & Clark, J.D. (2017). Chronic pain after traumatic brain injury: pathophysiology and pain mechanisms. *Pain Medicine, 0*,1-19.

Jamison, R. N., Jurcik, D.C., Edwards, R.R., Huang, C.C. & Roos, E.L. (2017). A pilot comparison of a smartphone app with or without 2-way messaging among chronic pain patients: who benefits from a pain app? *Clinical Journal of Pain*, *33*(8), 676-687.

Kendrick, D., Silverberg, N.D., Barlow, S., Miller, W.C., Moffat, J. (2012). Acquired brain injury self-management programme: a pilot study. *Brain Injury*, *26*(10), 1243-1249.

Khusid, M.A. & Vythilingham, M. (2016). The emerging role of mindfulness meditation as effective self-management strategy, part 2: clinical implications for chronic pain, substance misuse and insomnia. *Military Medicine*, *181*(9), 959-975.

King, P.R., Beehler, G.P., Wade, M.J. (2015). Self-reported pain and pain management strategies among veterans with traumatic brain injury: a pilot study. *Military Medicine*, *180*(8), 863-868.

Mann, T., De Ridder, D., Fujita, K. Self-regulation of health behavior: social psychological approaches to goal setting and goal striving. *Health Psychology*, *32*(5), 487-498.

PainCompanion. (2018). Retrieved from: https://itunes.apple.com/us/app/pain-companion/id985521736?mt=8.

PainTracker. (2017). Retrieved from: https://paintracker.cirg.washington.edu/demo/users/index.

PainScale. (2018). Retrieved from: https://itunes.apple.com/us/app/painscale-pain-diary-and-coach/id1240897273?mt=8.

Reynoldson, C., Stones, C., Allsop, M., Gardner, P., Bennett, M.I, Closs, S.J., Jones, R., & Knapp, P. (2014). Assessing the quality and usability of smartphone apps for pain self-management. *Pain Medicine*, *15*, 989-909.

Rose, S.C., McNally, K.A., & Heyer, G.L. (2015). Returning the student to school after concussion: what do clinicians need to know? *Concussion*, *1*(1), CNC4.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, *23*, 334-340.

Sawyer, K., Bell, K.R., Ehde, D.M., Temkin, N., Dikmen, S., Williams, R.M…& Hoffman, J.M. (2015). Longitudinal study of headache trajectories in the year after mild traumatic brain injury: relation to posttraumatic stress disorder symptoms. *Archives of Physical Medicine and Rehabilitation*, *96*, 2000-2006.

Valenti, K.G., Portanova, J., Laguna, J., Wu, S., Ell, K., Stone, S., Enguidanos, S. (2016). Feasibility of smartphone use in monitoring pain and symptoms among patients with serious illness. *Clinical Nursing Studies*, *4*(3), 18-24.

Chapter 5

Prototype and Conclusion

Abstract

This chapter is a summarization of the background described in chapter 1 and the results of aims 1-3 found in chapters 3 and 4. Results from chapters 3 and 4 were used to develop a prototype for a self-management mHealth tool which will be presented in this chapter. The Persistent Pain Model described in chapter 2 will then be revisited to discuss how results from the aims of this dissertation contribute to a better understanding of the concept and the needs of those with persistent pain following a mild traumatic brain injury (mTBI). Findings from the dissertation are placed into context with the current literature on persistent pain. Lastly, future directions for research in this area are suggested.

Overview

Aim 1

The goal of the first study aim, presented in chapter 3, was to examine baseline characteristics, symptoms, injury related variables and demographic factors associated with the endorsement of persistent pain among those with mTBI from baseline to 6 months post injury. Aim 1 found that persistent pain was prevalent among our participants with mTBI with 78% experiencing persistent pain. Results indicate a need to focus more on pain detection and pain management for those who had lower levels of general health status and physical function-related health status who had a trend toward increased odds of experiencing persistent pain. Clinicians can screen general health-related health status and physical function-related health status during the early recovery phase to help determine if patients are at risk for later experiencing persistent pain.

Aim 2

The goal of the second study aim was to determine if there are symptom clusters in those who have persistent pain following TBI, a persistent pain phenotype. Findings from factor analysis identified that persistent pain at 6 months post-injury loaded on the same factor as other symptoms: anxiety, depression, dizziness, nausea and vomiting, sleep disturbance, poor memory, poor concentration, requiring longer to think and light sensitivity. These results indicate that in this model the symptoms and persistent pain are highly associated with each other. The results from this aim have expanded the knowledge about the patient experience of having both pain and symptoms after mTBI. Clinicians can use this information to screen those with mTBI for persistent pain as well as the associated symptoms in order to develop more comprehensive treatment plans.

Aim 3

The goal of the third study aim was to design a prototype of a mHealth intervention for self-management of pain after TBI using data obtained from Aims 1 and 2 as well as participant feedback. Findings from this aim filled a gap in knowledge about how persons monitor and manage pain and symptoms following mTBI. Participants reported various types of pain including headaches and neck pain as well as other symptoms such as trouble concentrating, irritability, forgetfulness, confusion, tired/sleepy, nausea, dizziness and light sensitivity. Headaches were the most commonly reported type of pain and often intermittently impacted participants for weeks to months after injury. A barrier to self-managing their pain and symptoms was not knowing what to do and having to employ a trial and error approach. An area of challenge for participants was keeping up with their work, school, and other commitments without exacerbating their pain and symptoms. All participants indicated that they were interested in a tool that addresses pain, memory and concentration. The main features that participants wanted were pain and symptom tracking as well as suggestions for management based on tracking information. Sharing their recovery with others including coaches, healthcare providers and family members and selecting what was to be shared were wanted as a features in a future tool. A phone-based app was the desired platform for the majority of participants. Having the option of voice recognition feature was also recommended to reduce screen time. Information gleaned from this aim has expanded the knowledge about the self-management needs of those recovery from mTBI and potential role of technology in meeting them after mTBI.

Taken together, the three aims from this study informed the development of a paper prototype for an informatics tool to support self-management of pain and symptoms after mTBI (See Features). The recommendations for this tool and rationale are discussed below.

Prototype Recommendations

1.0 Platform

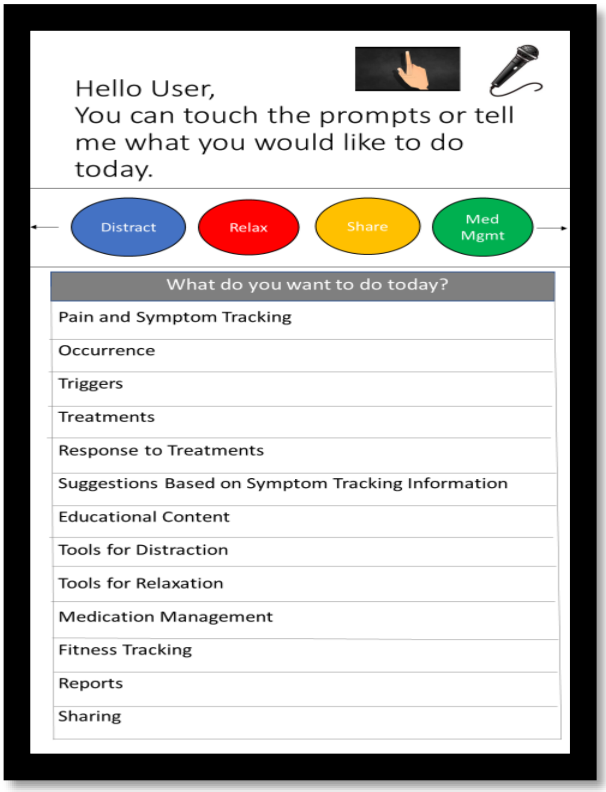
A phone-based app was chosen as the primary platform for a future pain and symptom technology tool for those with mTBI. An app that can be accessed on the computer would reach those who prefer computer as well. As the use of cell phones increases among those aged 50 and older (Barrett, 2011), these technologies might be able to expand the benefit to the older adult population as well which are a growing population of those experiencing TBI.

2.0 Features

Features were chosen based on feedback gained from qualitative interviews of participants recovering from mTBI in Chapter 4. Participants responded to survey questions with whether they wanted each feature (yes, no or uncertain). If the majority of participants wanted the feature, we included it in our prototype. Qualitative feedback from the interviews was used to design the tool and learn how it would be ideally used by the end-user. In our prototype, all features (Table 1) are listed on the home screen in a click-based dropdown menu and a colored scroll menu. A prompt at the top of the screen greets the user and tells them to either touch the feature that they want or tell the program what they want to do. Each screen after the home screen (Figure 1) will contain a home icon on the top right corner of the screen which will navigate them back to the home screen. Alternatively, the scroll option between features will be on each screen so users can directly navigate between features.

Table 1. Features of the mTBI Pain App Prototype

1	Pain and Symptom Tracking
2	Occurrence
3	Triggers
4	Treatments
5	Response to Treatments
6	Suggestions Based on Symptom Tracking Information
7	Educational Content
8	Tools for Distraction
9	Tools for Relaxation
10	Medication Management
11	Fitness Tracking
12	Reports
13	Sharing



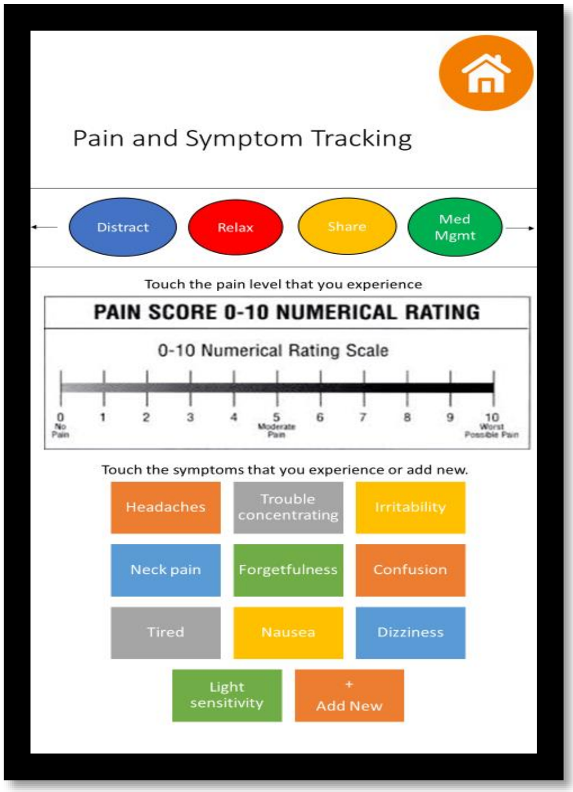
Hello User,
You can touch the prompts or tell me what you would like to do today.

Figure 1. This figure shows the home screen of a TBI pain self-management app prototype.

This page is the overall menu of features.

2.1 Pain and Symptom Tracking

The pain and symptom tracking feature (Figure 2) includes pain scores on a 0-10 numeric rating scale. The user can touch the number that they are feeling with word-based guides on the scale so that a score of 0 indicates “no pain,” a 5 indicates “moderate pain” and 10 means it is the “worst pain possible.” This 0-10 rating system was chosen based on its familiarity among the participants we interviewed. Below the pain numeric rating, we ask the user to touch the symptoms that they are currently experiencing or to add a new symptom. The symptoms are listed in colored boxes and are the most common symptoms our participants with mTBI reported during qualitative interviews.



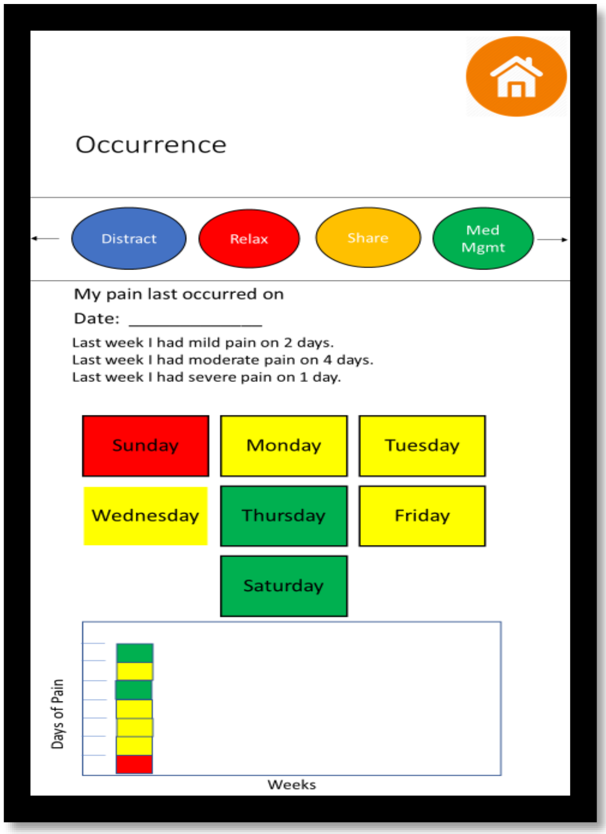
Touch the pain level that you experience

Touch the symptoms that you experience or add new.

Figure 2. This figure shows the prototype Pain and Symptom Tracking screen, including a rating scale and symptom check-off.

2.2 Occurrence

The occurrence feature (Figure 3) shows the user when their last date of pain was recorded. It also shows users how many days they had mild, moderate, and severe pain in the previous week. Days of the week are colored in red for severe, yellow for moderate and green for mild pain. This design was chosen so that patients could better visualize how they are doing with their pain. Participants in the qualitative interviews requested ways to visualize how they are doing over time. At the bottom of the occurrence feature a figure will populate based on previous patient pain and symptom entries. This will allow patients to see what symptoms precede or accompany their pain. This figure shows days of pain with the pain level color for each day and stacks the days so that if you look across weeks, a picture of the patient's pain during their recovery trajectory that might last weeks to months can be better understood.



My pain last occurred on

Date: ____________

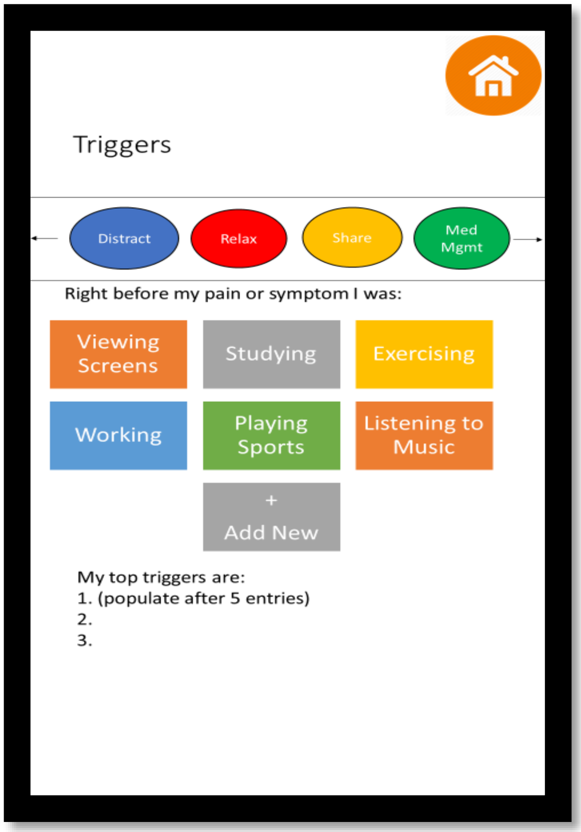
Last week I had mild pain on 2 days.
Last week I had moderate pain on 4 days.
Last week I had severe pain on 1 day.

Figure 3. This figure shows the occurrence of symptoms including when it last occurred, which days of the week it occurred and the severity over time.

2.3 Triggers

The triggers feature (Figure 4) will include a prompt "right before my pain or symptom I was…" so the patient can tap the colored square of what their triggers were or add new triggers.

The patient will be able to choose whether the trigger(s) were before pain or symptoms (specified). The triggers in the colored squares are based on participant feedback about their most common triggers. At the bottom of the screen we have a top trigger ranking where after 5 entries the top trigger will populate in this area. The top triggers section should help patients identify their top triggers so that they can avoid or limit their exposure to them during recovery.



Right before my pain or symptom I was:

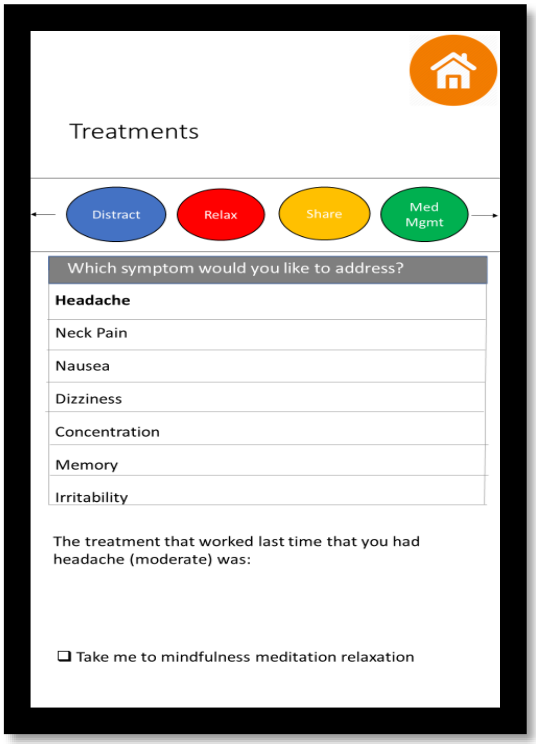
My top triggers are:
1. (populate after 5 entries)
2.
3.

Figure 4. This figure shows the triggers that precede pain and lists the top triggers for pain.

2.4 Treatments

The treatment feature (Figure 5) is designed to help the patient select which symptom they would like to address and recommend a specific treatment. The most com mon symptoms are listed in a drop-down menu and the recommendation will populate based on past treatments. A patient might also check off the box to take them directly to mindfulness meditation if that is the treatment that they desire. In the “Suggestions Based on Symptom

Tracking Information” feature, patients will be able to use this information to inform their self-management choices.



Which symptom would you like to address?

Headache
Neck Pain
Nausea
Dizziness
Concentration
Memory
Irritability

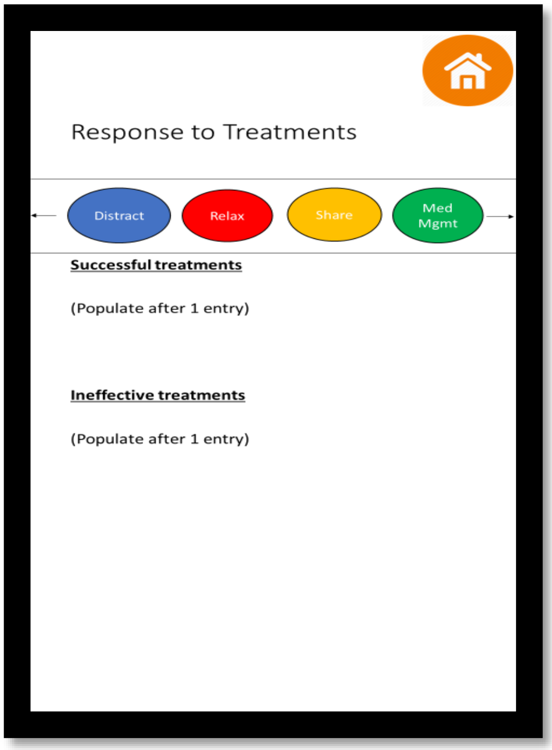
The treatment that worked last time that you had headache (moderate) was:

☐ Take me to mindfulness meditation relaxation

Figure 5. This figure shows treatment options and lists which symptoms the user would like to address.

2.5 Response to Treatments

The response to treatments feature (Figure 6) will populate with successful treatments and ineffective treatments in order to help the patient keep track of what works and what does not work for them.



Response to Treatments

Successful treatments

(Populate after 1 entry)

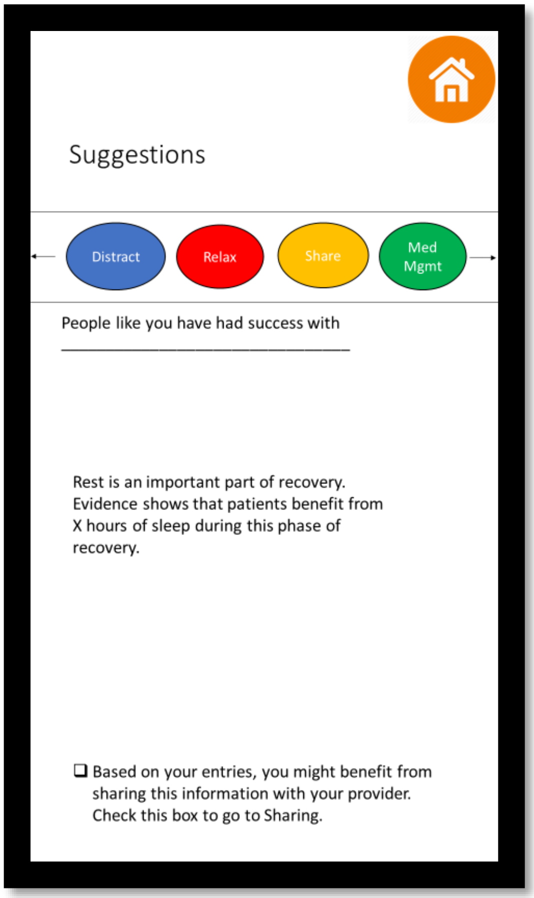
Ineffective treatments

(Populate after 1 entry)

Figure 6. This figure shows response to treatment with lists of successful treatments and ineffective treatments for the individual.

2.6 Suggestions Based on Symptom Tracking Information

The suggestions feature (Figure 7) will populate with suggestions based on evidence in the literature about recovery from mTBI. The suggestions will be tailored to the patient based on best evidence. There will also be broad suggestions about common issues such as getting enough rest throughout recovery. The suggestion might include a prompt that they should share new information with their provider based on their recent reports. We include a feature where they can click a box and go directly to sharing if their reports indicate they might benefit from sharing with a provider. This interoperability with patient health records systems in electronic medical records would require further development to meet privacy laws and make sure it is HIPAA compliant. We hope this will increase patient-provider communication in cases where patients could benefit from increased medical services.



People like you have had success with ______________________________

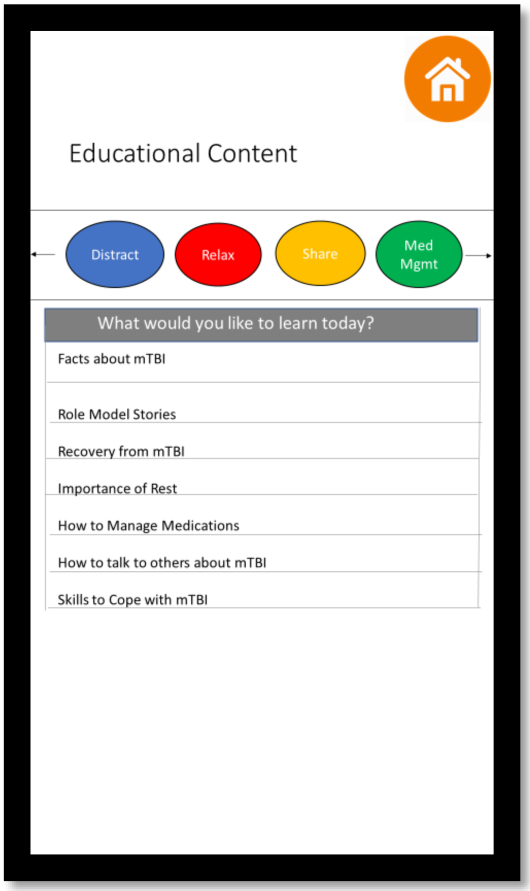
Rest is an important part of recovery. Evidence shows that patients benefit from X hours of sleep during this phase of recovery.

☐ Based on your entries, you might benefit from sharing this information with your provider. Check this box to go to Sharing.

Figure 7. This figure shows suggestions for users based on the information they have submitted to the app.

2.7 Educational Content

The educational content (Figure 8) will be presented as selections from a dropdown menu where users are asked what they would like to learn today. The options will include written content about: facts about mTBI, role model stories, recovery from mTBI, importance of rest, how to manage medications, how to talk to others about mTBI, and skills to cope with mTBI. The educational content will not be delivered with video clips because the qualitative findings in Chapter 4 indicated that videos were not wanted. Participant reasons for not wanting videos included “waste of time,” and “reading would be sufficient.” The educational content topic areas were chosen based on feedback from qualitative interviews. When participants were asked about what they wish they knew, these topic areas were reported the most often.



Educational Content

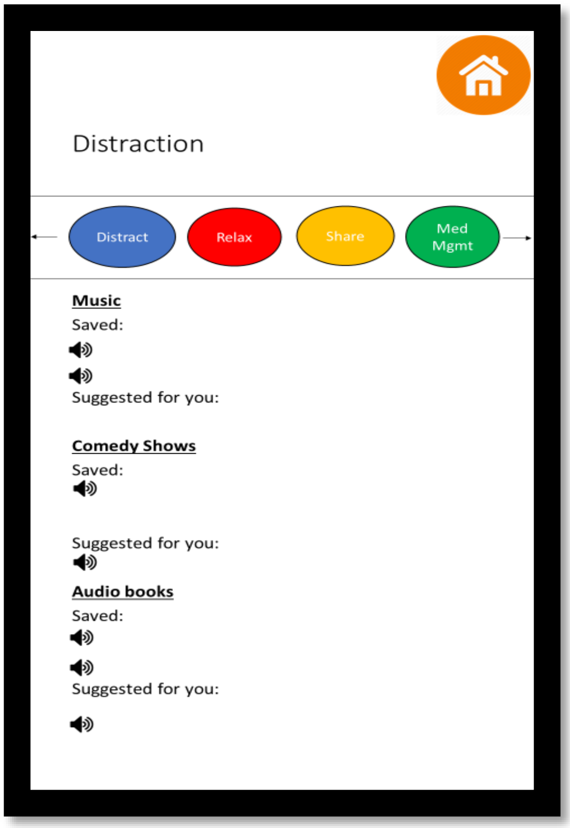
What would you like to learn today?

- Facts about mTBI
- Role Model Stories
- Recovery from mTBI
- Importance of Rest
- How to Manage Medications
- How to talk to others about mTBI
- Skills to Cope with mTBI

Figure 8. This figure shows educational content based on what the user wants to learn.

2.8 Tools for Distraction

The tools for distraction section (Figure 9) includes audio media such as music, comedy, and audio books. We aim to provide entertainment that can distract users from their pain and symptoms. This section includes their saved selections as well as suggestions of media content they might like under each category.



Distraction

Music
Saved:
🔊
🔊
Suggested for you:

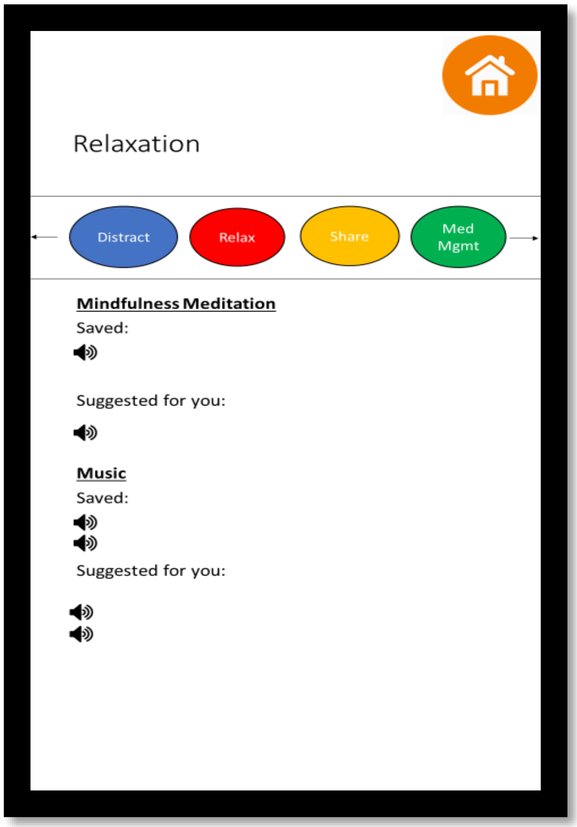
Comedy Shows
Saved:
🔊

Suggested for you:
🔊
Audio books
Saved:
🔊
🔊
Suggested for you:
🔊

Figure 9. This figure shows distraction options including music, comedy shows, and audio books.

2.9 Tools for Relaxation

The tools for relaxation feature (Figure 10) includes audio media, including mindfulness, meditation and music. Like the distraction feature, the relaxation feature would include ability to save favorite selections as well as suggestions of media content they might like under each category.



Relaxation

Mindfulness Meditation
Saved:
🔊

Suggested for you:
🔊

Music
Saved:
🔊
🔊
Suggested for you:
🔊
🔊

Figure 10. This figure shows relaxation including mindfulness meditation and music.

2.10 Medication Management

The medication management feature (Figure 11) will help users take their pain and other medications (e.g. antiemetics) safely. In this section we aim to help people choose their medication, take the correct dose, know when they can take another dose and be aware of maximum daily dose. This feature will allow users to know what time they last logged in a medication and what dose they took. There is also a box to check if they would like to explore medication management from a previous day.

Medication Management

When I have Moderate Pain I take _______________.
My dose for Moderate Pain is _________mg.
I can take another dose in _____ hours.
The maximum amount I can take in 24 hours is ______.

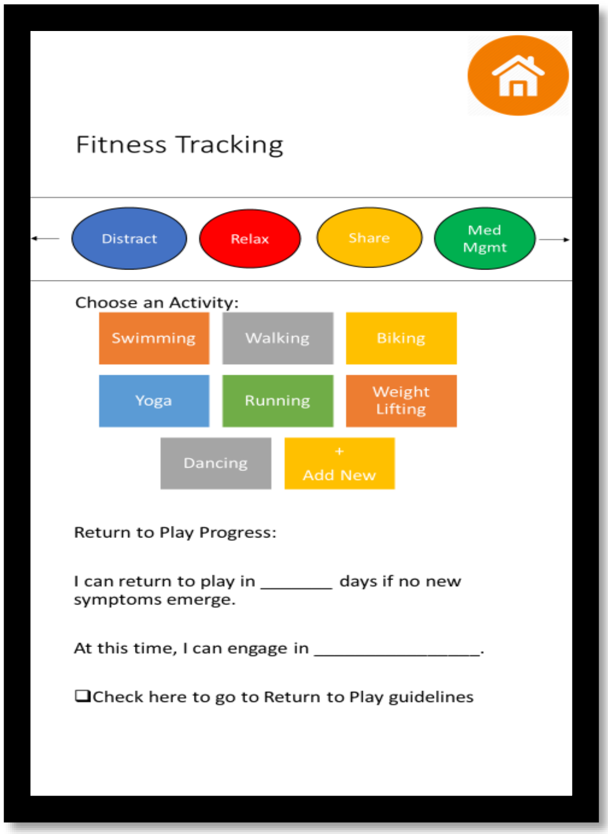
So far today, I have logged _____mgs of _________ and my last dose was _______ hours ago.

☐ View medication management from a previous day.

Figure 11. This figure shows medication management including type of medication, timing of medication and dosage of medication.

2.11 Fitness Tracking

The fitness tracking feature (Figure 12) can be used by athletes or non-athletes. In the fitness tracking feature, we allow users to log in their activities by tapping a colored box with the activity name or adding a new activity. We also include information for athletes about return to play progress. The number of days before they can return to play and the activities that they can engage in will populate throughout their recovery based on the information they input to the app based on provider instructions. There is also a box that can be checked if they want to navigate to return to play guidelines which apply to adults of all ages and can be modified to accommodate the recommendation of a two-week minimum rest period in children and adolescents (World Rugby, 2019).



Choose an Activity:

Return to Play Progress:

I can return to play in ________ days if no new symptoms emerge.

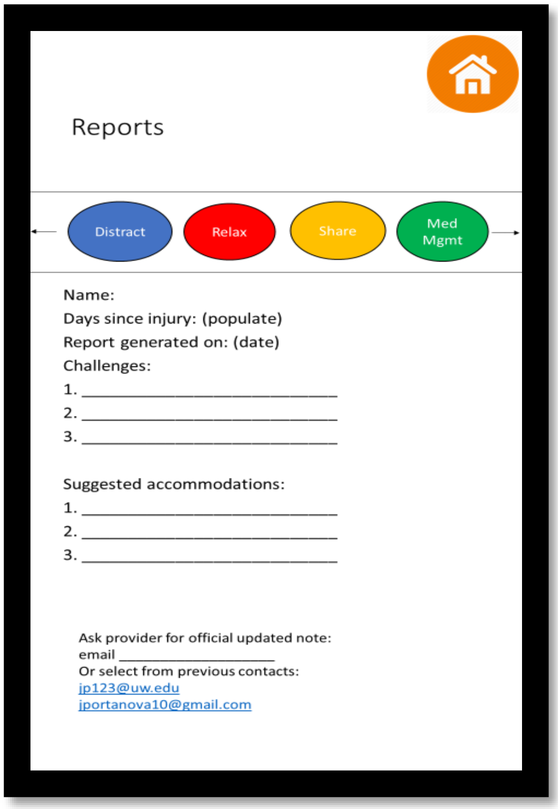
At this time, I can engage in __________________.

☐Check here to go to Return to Play guidelines

Figure 12. This figure shows fitness tracking including activities and returning to play guidelines.

2.12 Reports

The reports feature (Figure 13) will generate an informal report with the patient's name, days since injury, date of report, challenges and suggestion accommodations. At the bottom of the screen the user will be able to ask their provider for an official note that might excuse them from work, sports, or school by linking it to their patient health record. The app will save frequently used contact phone numbers for ease of use.



Reports

Name:
Days since injury: (populate)
Report generated on: (date)
Challenges:
1. ____________________________
2. ____________________________
3. ____________________________

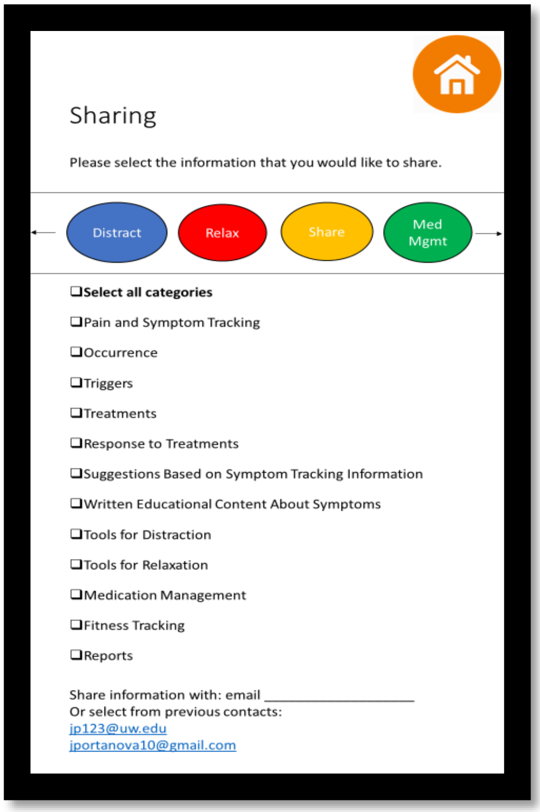
Suggested accommodations:
1. ____________________________
2. ____________________________
3. ____________________________

Ask provider for official updated note:
email _________________
Or select from previous contacts:
jp123@uw.edu
jportanova10@gmail.com

Figure 13. This figure shows reports with a user's injury information as well as challenges and suggested accommodations.

2.13 Sharing

The sharing feature (Figure 14) allows users to choose who they share their information with from the app and what information is shared. Each feature from the app will be a distinct category. The user can either select all categories or select fewer categories and e-mail the person who they wish to share it with. The app will save frequently used contact phone numbers and/or e-mail addresses for ease of sharing information via SMS or attachment.



Sharing

Please select the information that you would like to share.

☐**Select all categories**
☐Pain and Symptom Tracking
☐Occurrence
☐Triggers
☐Treatments
☐Response to Treatments
☐Suggestions Based on Symptom Tracking Information
☐Written Educational Content About Symptoms
☐Tools for Distraction
☐Tools for Relaxation
☐Medication Management
☐Fitness Tracking
☐Reports

Share information with: email ___________________
Or select from previous contacts:
jp123@uw.edu
jportanova10@gmail.com

Figure 14. This figure shows sharing including the categories to share and the contact to share it with.

Next Steps for Prototype Development

The next steps for protype development include gathering feedback about the proposed features and paper prototype design. Informatics experts need to be consulted to ensure that high-quality design and informatics principles are being incorporated into the prototype. Once the prototype is approved by end-users from the mTBI population of various ages as well as healthcare providers and informatics experts have been consulted, the prototype can be developed. Special attention needs to be paid to end-user feedback on looking at the screen after their injury because headaches after staring at screens for too long was reported by some participants. Patients in this population would likely benefit from the inclusion of the ability to use voice recognition instead of looking at the screen. Using voice recognition in this population needs to be tested prior to disseminating this tool. Some users reported wanting to use pen and paper to manage their pain and symptoms. Future research might explore how to include a feature where a patient can upload a picture of their pen and paper information into the app. Clinician feedback about the usability and validity of this app will be needed before integrating it into electronic medical records.

Limitations

The prototype was informed by a relatively homogenous sample and might not be generalizable to other populations. The participants were all young women, and most were college athletes who played rugby. While we did learn about what young female rugby players want after experiencing a mTBI, this sample was not representative of the mTBI population. It would be important in the design phase to incorporate other individuals with mTBI representing the broader population as the app would be targeted to people with mTBI of all ages and sexes. We need to ensure that patients are not at risk for overstimulation from features chosen to meet the patient's needs for distraction or relaxation.

Conclusion

Contribution to Literature

This study adds new knowledge to the literature about the experience of persistent pain after mTBI. In our sample, 78% of those with mTBI experienced persistent pain. This is similar to Nampiaparampil's (2008) finding that 75.3% of those with mTBI report pain following injury. We found that there were differences in those who had persistent pain in general health-related health status and physical function-related health status compared to those who did not experience persistent pain. We learned that those with better general health-related health status and physical function-related health status at 7 days as well as at 1 month had lesser odds of experiencing persistent pain at 6 months post-injury. This means that there are opportunities to identify patients who are at-risk for persistent pain early in their recovery trajectory. Early identification of at-risk individuals can provide opportunities for early intervention to prevent persistent pain or to reduce its severity or duration, with the goal of improving quality of life. We identified that multiple co-occurring symptoms with persistent pain including: anxiety, depression, dizziness, nausea and vomiting, sleep disturbance, poor memory, poor concentration, longer to think and light sensitivity. It is therefore important to assess the patient for other symptoms that may be contributing to overall symptom experience and burden and to develop a holistic treatment plan that addresses these other symptoms. Further work is needed to better understand the relationships between pain and the other common post-mTBI symptoms to elucidate the mechanisms underlying the development of the persistent pain phenotype. Future studies need to determine how to best treat those at risk for experiencing persistent pain after mTBI in order to reduce its' occurrence. Additional work is needed to identify tailored, effective multimodal and holistic approaches to persistent pain and related symptoms in order to reduce symptom burden and improve quality of life in persons following mTBI.

Our findings indicate that an informatics tool to help patients self-manage their pain after mTBI could support patient self-management. We learned that patients need help with addressing pain, anxiety, depression, overall mood, memory, concentration and physical functioning. We learned that patients in our sample were interested in a tool that features: pain and symptom tracking; occurrence; triggers; treatments; response to treatments; suggestions based on symptom tracking information; written educational content about symptoms; tools for distraction; tools for relaxation; ability to share symptom management information with others; medication management and fitness tracking. Our proposed protype described above visually displays how we envision incorporating these needs in a future informatics tool.

Persistent Pain Model

The study reinforced many of the ideas presented in the Persistent Pain Model. In the model, health behaviors influence the individual's ability to mitigate the consequences of persistent pain. In this study, those who reported the health behavior of effectively self-managing pain and symptoms were less likely to report severe consequences from pain after mTBI than those who reported that they were not self-managing or were not self-managing well. We found that there were contextual factors that influenced one's ability to self-manage their pain and symptoms. For example, one participant cited having experienced several prior concussions. She reported that she knew what to expect and had activated her resources. Another person cited that her academic field of study, biology, was a benefit to her in understanding why she could not perform the activities she wanted to until she recovered. A barrier to self-management of pain was not having enough time. One participant cited not having time to take her pain medication while she was at work. The context of her work environment made her less able to mitigate the consequences of her pain. This same participant described having to quit her job due to her pain and symptoms after mTBI, which demonstrates economic costs, one of the consequences included in the Persistent Pain Model.

The consequences in the Persistent Pain Model were reaffirmed by both the qualitative and quantitative findings. We found that anxiety, depression, decreased socialization and impact on quality of life were experienced by those with persistent pain after mTBI. Participants in the qualitative portion of this study reported that anxiety and depression were symptoms that they needed help with self-managing. We learned that participation in social activities such as school, work and sports was decreased throughout recovery. Our quantitative findings indicate that quality of life is poorer in those with persistent pain compared to those without persistent pain.

Implications for Practice

Clinicians can use findings from this study to inform their practice when treating patients who have experienced mTBI. This study reaffirms our knowledge that persistent pain is a common experience among those with mTBI. Clinicians can use these findings to look out for other symptoms associated with the experience of persistent pain after mTBI and use this to address their patients' broader pain and symptom concerns. Our findings indicate that patients would benefit from using technology to help with their needs related to self-management of pain and symptoms after mTBI. If a tool like the prototype is developed in the future, clinicians will be able to interact with the most vulnerable patients more often during their recovery. Further, a tool might be able to reinforce information clinicians provide at the first post-injury visit throughout their recovery. A tool that reinforces fundamental recovery guidelines from clinicians, might reduce the poor pain and symptom outcomes that occur due to lack of knowledge. Patients usually visit their clinician during the most acute stage of their injury when they might not be able to memorize and understand the information they receive. Overall healthcare utilization could decrease in the average patient if patients are given the tools to refer to recovery guidelines throughout their recovery. If the informatics tool is developed, clinician feedback will be needed to determine what information should be transmitted to them from the app in order to provide better treatment to patients.

Future Research

This study provides new knowledge about pain after mTBI, but there are still questions that remain. The participants in our qualitative interviews cited a need for an informatics tool to help with self-management of pain and symptoms. We need more information to determine if the tool would be useful in the general population. Men and middle-aged to older adults should be targeted for feedback on a future tool. Further research is needed in testing the prototype, developing the self-management informatics tool and incorporating it into the healthcare system. Cooperation between researchers and clinicians is needed in order to ensure that any tool that is developed would be clinically relevant and compatible with clinical practice.

An information gap remains around how the consequences of persistent pain interact with each other and how consequences of persistent pain can perpetuate pain. Future model testing of the Persistent Pain Model could help answer some questions about how these factors interact with each other. This study focused on the experience of persistent pain after mTBI. Future work should examine persistent pain that results from other proposed antecedents (injury, health condition, disease process, surgery) of persistent pain. A wider understanding of how to identify and treat patients at-risk for or already experiencing persistent pain will improve patient outcomes and reduce healthcare utilization.

References

Barrett LL. (2011). Health and caregiving among the 50+: Ownership, use, and interest in mobile technology. Retrieved from: http://assets.aarp.org/rgcenter/general/health-caregiving-mobile-technology.pdf

Nampiaparampil, D. E. (2008). Prevalence of chronic pain after traumatic brain injury: A systematic review. *Journal of the American Medical Association*, 300 (6), 711–719.

World Rugby. (2019). Returning to play after concussion or suspected concussion. Retrieved from: https://assets.usarugby.org/docs/membership/medical/World_Rugby_GRTP.pdf?v=1549243252842