Title
Functional Recovery in Adults with Brain Injury

Author
Nelson, Michele Diaz

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Functional Recovery in Adults with Brain Injury

by

Michele Diaz

DISSERTATION

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Approved:

DocuSigned by:

Laura Wagner ______________________________ Laura Wagner

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Chair

DocuSigned by:

Heather Leutwyler ______________________________ Heather Leutwyler

DocuSigned by: ...37...

Raquel Gardner ______________________________ Raquel Gardner

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Committee Members

Functional Recovery in Adults with Brain Injury

Abstract

Michele Diaz Nelson

Background. Older adults (age 65+) with traumatic brain injury (TBI) are often underrepresented in TBI research. Additionally, Health-related quality of life (HRQoL) after TBI in older adults is minimally explored. Among all adults with brain injury, there are limited illness-specific wellness programs and psychoeducation resources available post-incident. Existing literature demonstrates that participant wellness programs like yoga and meditation can improve quality of life after brain injury.

Methods. This dissertation study includes: 1) a systematic review of the literature evaluating the state of the evidence that measures functional status and HRQoL among older adults who experience a TBI; 2) a data-based paper which investigates the value of co-enrollment with a study partner for improving follow-up completion and evaluates level of agreement between participant and study partner report of functional recovery; 3) a data-based paper on the evaluation of a virtual, 6-week, yoga and meditation Quality Improvement program for adults with TBI, stroke, and their caregivers at a level-1 trauma center.

Results. The variability in HRQoL follow-up time points and methodologies among HRQoL measures across the six studies included in the systematic review made it challenging to synthesize HRQoL findings. Chapter 3 demonstrates that research is feasible among medically complex older adults, and the inclusion of a study partner improves longitudinal follow up and functional recovery agreement among all domains was high: 78%-100%. Chapter 4 Quality Improvement program evaluation demonstrates feasibility and acceptability of a virtual yoga and meditation program.

Conclusions/Implications. More studies are needed to understand functional status and HRQoL outcomes and their impact on the lives of older adults with a TBI-related disability during the rehabilitation and post-rehabilitation phases. Future research is needed to evaluate efficacy of wellness programs to improve health-related quality of life after brain injuries.

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Chapter 1: Introduction

Traumatic brain injury in older adults

Traumatic brain injuries (TBI) are a complex phenomenon that can affect anyone at any age and are currently disproportionately affecting the aging population (CDC, 2018). Older adults (aged 65 and older) experience the highest and fasting-rising number of TBI-related incidences (e.g., emergency visits, hospitalizations, and deaths) compared to any other age group (Faul, Xu, Wald, Coronado, & Dellinger, 2010; Gardner, Dams-O'Connor, Morrissey, & Manley, 2017; Taylor, Bell, Breiding, & Xu, 2017). Additionally, older adults will represent nearly 20% of the total U.S. population in 2030, more than doubling the number of older adults in 2000 (Ortman, Velkoff, & Hogan, 2014). This demographic is expanding, which suggests that the incidence of older adults sustaining a new TBI or experiencing re-injury of a previous TBI will likely increase as well (Gardner et al., 2017; Sendroy-Terrill, Whiteneck, & Brooks, 2010).

Over 3 million older adults are treated in emergency departments for fall-related injuries annually (Centers for Disease Control and Prevention [CDC], 2016). In 2014, the rate of TBI-related emergency department (ED) visits was highest among older adults aged 75 years or older. The rate of TBI-related deaths was also highest in that age bracket, followed by adults aged 65–74 years old (Taylor et al., 2017). The leading cause of TBI in older adult populations are unintentional, ground-level or low-level falls (Taylor et al., 2017). One out of five falls among older adults may result in a traumatic brain injury (TBI) (Alexander, Rivara, & Wolf, 1992; Sterling, O'Connor, & Bonadies, 2001). According to the CDC, four out of five (81%) TBI-related ED visits among adults aged 65 years and older are due to a fall-related injury. Additionally, TBI-related hospitalizations among adults aged 55 years and older were primarily

caused by falls (Taylor et al., 2017). After an older adult sustains one fall, their likelihood of falling again is doubled (O'Loughlin, Robitaille, Boivin, & Suissa, 1993).

A TBI is defined as a change in normal brain function or brain pathology caused by an external force (Manley & Maas, 2013). A TBI can range in severity and can be classified as mild, moderate, or severe. Classification is based on clinical presentation and evaluation of a patient's consciousness, structural imaging, post-traumatic amnesia, and Glasgow Coma Scale (GCS) scores (Peters & Gardner, 2018; Thompson, McCormick, & Kagan, 2006). Fall-related TBIs among older adults commonly result in mass lesions or subdural hemorrhage, and changes that typically occur with aging (e.g., brain atrophy, white matter changes, cerebrovascular atherosclerosis, etc.) may increase risk of intracranial bleeding, even among TBIs of less severity (Peters & Gardner, 2018; Thompson et al., 2006). Preexisting comorbidities and increasing prevalence of anticoagulant medication usage in this population may also increase risk of intracranial bleeding. It is estimated that approximately 11-21% of older adults who present to the ED with mild TBI (GCS 13-15) exhibit intracranial trauma on head CT (Altman et al., 2015; Haydel et al., 2000; Stiell et al., 2001; Styrke, Stalnacke, Sojka, & Bjornstig, 2007). Additionally, even older adults who present with a normal GCS score (GCS 15) have higher rates of intracranial trauma (Gardner et al., 2017; Haydel et al., 2000).

Financial impact is also significant. The average annual treatment cost per older adult treated for a TBI is approximately $73,000 - $78,000 per year (Gardner et al., 2017; Thompson, Weir, et al., 2012). In 2015, medical costs among older adults with fatal and nonfatal falls was estimated to be approximately 50 billion dollars (Florence et al., 2018; Thompson, Weir, et al., 2012).

Although advances in neuroscience have allowed us to better understand TBI pathology on a molecular level, TBI research and disease management among older adults lags in comparison to development regarding other prevalent diseases (Manley & Maas, 2013). Additionally, minimal TBI guidelines exist to inform acute or long-term management, resulting in few diagnostic and prognostic tools or treatments, lack of structured follow up care, and varying levels of post-injury rehabilitation for geriatric populations (Gardner et al., 2017; McIntyre, Mehta, Janzen, Aubut, & Teasell, 2013).

Research specific to older adults' experiences following a TBI is necessary to improve functional and psychosocial outcomes and management of post-injury care among older adults, primarily with respect to recovery trajectories, and to explore factors that potentially influence post-TBI well-being and independence. While assessments exist that are designed to quantify functional outcomes after TBI, fewer studies assess and evaluate function and health-related quality of life (HRQoL) among the geriatric TBI populations (K. Brown, Cameron, Keay, Coxon, & Ivers, 2017a; Eum et al., 2017; A. C. Mosenthal et al., 2004). Measurements that assess HRQoL offer a way to evaluate facets of health status in relation to subjective patient well-being. Further understanding of overall HRQoL and functional status is imperative among older adults as they may have multidimensional needs throughout recovery from TBI.

Conceptual Model: Health-Related Quality of Life

HRQoL reflects an individual's perception of their illness and their overall satisfaction of physical, mental, and social aspects of life (Scholten et al., 2015; Siponkoski, Wilson, von Steinbuchel, Sarajuuri, & Koskinen, 2013). Health Related Quality of Life (HRQoL) is an important outcome measure after a TBI and provides important predictors of disability (Neugebauer, Bouillon, Bullinger, & Wood-Dauphinée, 2002b; Scholten et al., 2015).

The HRQoL conceptual model proposed by Wilson and Cleary unites the clinical and the psychosocial methodologies within healthcare (Wilson & Cleary, 1995). The model links biological and physiological factors, both objective and subjective, to measure HRQoL (Ojelabi, Graham, Haighton, & Ling, 2017). Wilson and Cleary's conceptual model is comprised of five health concepts which are presented in a linear sequence: biological and physiological variables, symptom status, functional status, general health perceptions, and overall quality of health. These domains are influenced by the characteristics of the individual and the characteristics of the environment which are impacted by sub categories (symptom amplification, personality motivation, value preferences, psychological supports, social and economic support) (Wilson & Cleary, 1995). Overall quality of life assesses the subjective well-being with generic measures of how satisfied they are with their life as a whole (Ojelabi et al., 2017; Wilson & Cleary, 1995)

As TBI patients continue to survive and live with TBI related disabilities, it is important to understand the overall affects one may experience as they recover. Utilizing and testing the HRQoL as a conceptual model to assess the various domains of recovery may be an initial approach in tackling the overwhelming nature of managing care for patients post TBI.
The HRQoL may provide a useful framework to better understand patient's self-report of functioning abilities, and recovery patterns which include mental, cognitive, and emotional outcome domains. Given our limited ability to understand TBI related disability and patient outcomes over the TBI recovery trajectory among older adults, there is an important need to close existing knowledge gaps around understanding the effects of a TBI (all classifications) and its impact on one's overall health and impact on quality of life.

Health-Related Quality of Life and Recovery Trajectories in Older Adults with TBI

Many etiologies and risk factors that contribute to fall-related TBI in older adults, concomitantly, serve as contributing factors for repeat falls and reinjury after TBI (Boye et al., 2014; Milos et al., 2014; Rubenstein, 2006; Teo et al., 2018; Tinetti, Speechley, & Ginter, 1988). The effects following a TBI, paired with the normal aging process, may ultimately impact the older adult's health-related quality of life and prevention and management of symptoms.

The presence of TBI related effects can impact important aspects of health and illness which can disrupt physical, mental, and social functioning (Humphreys et al., 2014; Sendroy-Terrill et al., 2010). In addition to the factors that contribute to increased incidence of TBI and rates of reinjury among older adults, commonly reported physical post-TBI symptoms such as balance and coordination issues, fatigue, and dizziness may also impair physical function after TBI (Haller et al., 2017; Anne C. Mosenthal et al., 2004; Thompson, Rivara, & Wang, 2020a) and survivors may have increased functional dependence post-injury. Psychiatric disturbances such as depression (37%) and anxiety (17%) are common after TBI among older adults, which are also associated with poorer recovery outcomes related to physical function and cognition (Albrecht, Kiptanui, et al., 2015; Albrecht, Peters, Smith, & Rao, 2017; Rapoport, Kiss, & Feinstein, 2006; Rapoport, McCullagh, Streiner, & Feinstein, 2003).

Given older adults living with TBI typically have worse or prolonged recovery trajectories, it is important to understand the impact of a TBI on an older adult's function and health-related quality of life (HRQoL) post-injury. The ongoing burden of TBI-related symptoms and comorbid symptoms, functional impairment which may affect levels of independence, and mood disorders after TBI in older adults are important indicators which may affect HRQoL over time (Albrecht et al., 2017; Cheng, Chi, Williams, & Thompson, 2018; Menzel, 2008). In order

to understand objective and subjective disability outcomes related to function and HRQoL, it is imperative to measure pre-injury and post-injury outcomes during the rehabilitative and post rehabilitative phases of recovery. Such assessments may help clinicians and multidisciplinary teams to provide specialized management and treatment for TBI symptoms with goals to improve functional status and HRQoL outcomes.

Purpose and specific aims

The overall purpose of this dissertation study is to analyze and synthesize existing literature that measures functional status and HRQoL among older adults with TBI, to understand longitudinal follow-up and the reliability of proxy informants in a cohort of older adults with pre-existing medical conditions after TBI and evaluate a virtual Yoga and Meditation Quality Improvement project at a level-1 trauma center for adults with TBI, stroke, and their caregivers. This study has three specific aims:

AIM 1: To evaluate and describe the state of the evidence that measures functional status and HRQoL among older adults who experience a TBI, assess the association between functional status and HRQoL using validated outcomes measures, and identify knowledge gaps regarding functional status and HRQoL outcomes in older adults after TBI.

AIM 2: To investigate the value of co-enrollment with a study partner for improving time-point follow-up completion and evaluate level of agreement between participant and study partner report of functional recovery, stratified by pre-injury cognitive status.

AIM 3: To evaluate the feasibility, acceptability, and safety of delivering a virtual 6-week, Yoga and Meditation program for adult TBI, and stroke survivors, and their caregivers.

Presentation of the dissertation

This dissertation is divided into five chapters. Chapter 1 is an introduction describing the significance of traumatic brain injuries among older adults and implications on recovery. Chapter 2 is a systematic review of the literature evaluating the state of the evidence that measures functional status and HRQoL among older adults who experience a TBI. Chapter 3 is a data-based paper on the analysis of a pilot study which investigates the value of co-enrollment with a study partner for improving follow-up completion and evaluate level of agreement between participant and study partner report. Chapter 4 is a data-based paper on an evaluation of a Quality Improvement program for adults with TBI, stroke, and their caregivers at a level-1 trauma center. Chapter 5 summarizes each of the findings, discusses the strengths, limitations, and implications for future research and nursing considerations.

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Chapter 2: Functional Status Outcomes and Health-Related Quality of Life among Older Adults after Traumatic Brain Injury: A Systematic Review

Abstract

Background. The purpose of the systematic review is to describe the evidence for functional status outcomes and health-related quality of life (HRQoL) among adults aged 65 years and older who experience a traumatic brain injury (TBI).

Methods. A systematic review of the literature was conducted using PRISMA guidelines. Databases searched included PubMed and EMBASE. Articles included were published in the last 20 years, in English, included adults aged 65 years and older, assessed the perspective of the TBI survivor and/or proxy, and assessed functional status and HRQoL as outcome measures using validated quantitative instruments. Data items analyzed included study goals, inclusion/exclusion criteria of study, functional status and HRQoL outcomes, TBI severity, and data collection methods.

Results. A total of six studies were included in this review. The study characteristics and methodologies varied. Five studies compared functional and HRQoL outcomes among younger and older adults with TBI. Five studies identified some improvement of HRQoL and functional outcomes among study participants over a 12-month follow-up period, but older adults had experienced less improvement compared to younger adults. One study assessed the relationship between HRQoL outcomes and functional outcomes, and another determined association between baseline symptom scores and disability in older adults.

Conclusions/Implications. Older adults continue to be underrepresented in TBI research. More studies are needed to understand functional status and HRQoL outcomes and their impact on the lives of older adults with a TBI-related disability during the rehabilitation and post-rehabilitation

phases. Future research can aid in understanding the heterogeneous nature of global outcomes for this population and inform evidence-based management of post-injury care with the goal of improving function and HRQoL.

Keywords: traumatic brain injury, aged, geriatric, functional status, health-related quality of life, quality of life, functional outcomes.

Introduction

Overview and Significance

Older adults who survive a TBI may experience physical, cognitive, emotional, and behavioral effects after injury (CDC, 2019). Regardless of TBI severity, older adults may experience short- and long-term effects resulting in death or disability (Dams-O'Connor et al., 2013; Gardner et al., 2017; McIntyre et al., 2013; A. C. Mosenthal et al., 2004; Peters & Gardner, 2018; Ramanathan, McWilliams, Schatz, & Hillary, 2012). Comorbidities, physical frailty, and functional status are well-established as predictors of poor outcomes among geriatric trauma patients (Boye et al., 2014; Milos et al., 2014; Rubenstein, 2006; Teo et al., 2018; Tinetti et al., 1988). Older adults who are hospitalized after TBI have an increased likelihood to require longer hospitalizations and rehabilitation and may be more disabled and functionally dependent after discharge (Gardner et al., 2017; Peters & Gardner, 2018; Thompson et al., 2006; Thompson, Rivara, Becker, Maier, & Temkin, 2019; Thompson, Rivara, & Wang, 2020b; Thompson, Rue, & Rivara, 2012). Increased medical complications during acute care have been associated with worse Activities of Daily Living (ADL) outcomes up to 12 months after injury (Lecours, Sirois, Ouellet, Boivin, & Simard, 2012). Existing studies regarding disability after TBI found that older adults have increased functional dependence after injury (Lecours et al., 2012; A. C. Mosenthal et al., 2004; Thompson et al., 2020b). Additionally, older adults who sustain a TBI have increased rates of long-term disability with more impairments in the cognitive and behavior domains (Lecours et al., 2012; A. C. Mosenthal et al., 2004; Thompson et al., 2020b).

In some cases, an older adult may have improved recovery outcomes similar to younger patients regardless of TBI severity, which suggests that chronological age and TBI severity alone

are not reliable predictors of outcome (Gardner et al., 2017; Hawley, Sakr, Scapinello, Salvo, & Wrenn, 2017; McIntyre et al., 2013; A. C. Mosenthal et al., 2004). In these cases, the older adult may experience optimal recovery trajectories, indicating that a likely return to baseline function, cognitive status, and/or emotional well-being is feasible; however, ongoing follow-up is warranted to determine if improvement continues over time or post-TBI disability develops. Post-injury clinical outcomes are influenced by various factors including injury mechanisms, pre-injury functional status, preexisting conditions, TBI severity, individual patient characteristics, social-environmental factors, and access to post-injury care (Frieden, Houry, & Baldwin, 2015; Gardner et al., 2017).

Health-Related Quality of Life and Function after TBI in Older Adults

Decreases in TBI-related mortality rates among younger adults have contributed to an increased focus on the survivors and their long-term outcomes, functional abilities, disabilities, and quality of life. In the last decade, research has focused on the impact of functional disabilities and Health-Related Quality of Life (HRQoL) outcomes among working-age adults. Particular attention has been paid to lifestyle-related outcomes relevant to this population and their effect on quality of life (e.g., returning to work, loss of income, unemployment, etc.) (K. Brown, Cameron, Keay, Coxon, & Ivers, 2017b; Gabbe et al., 2016). HRQoL measures an individual's perception of their illness and their overall satisfaction and well-being, including physical, mental, and social aspects of life (Scholten et al., 2015; Siponkoski et al., 2013; I. B. Wilson & P. D. Cleary, 1995).

To date, little is known about the long-term influence of post-TBI disability on functional status and HRQoL among older adult populations. Many facets of life may be impacted, such as social and leisure activities, volunteering, Activities of Daily Living (ADL)/Instrumental

Activities of Daily Living (IADL), engaging with family and friends, and overall recovery trajectories (K. Brown et al., 2017b). Understanding subjective experiences related to HRQoL is key to recovery (Nichol et al., 2010), and assessing HRQoL has been recently acknowledged as an important measure of outcome following TBI (Harfmann, deRoon-Cassini, McCrea, Nader, & Nelson, 2020; Hunt et al., 2019; Polinder, Haagsma, van Klaveren, Steyerberg, & van Beeck, 2015). Measuring HRQoL among older adults provides data regarding the effect of TBI related injuries on mental and physical health perceptions, which can provide insight into associations between HRQoL and post-injury functional disabilities. Understanding how functional disability impacts HRQoL is imperative for providing effective rehabilitation and clinical management over the recovery trajectory among geriatric populations with TBI (Neugebauer, Bouillon, Bullinger, & Wood-Dauphinée, 2002a; Scholten et al., 2015).

As the U.S. population continues to grow and age, the number of older adults who experience a TBI will continue to increase, resulting in the need for greater knowledge related to factors that influence functional, psychosocial outcomes, and HRQoL outcomes throughout recovery. In previous literature, functional status outcomes and disability are well measured, but the psychosocial and subjective factors associated with HRQoL are less explored (McIntyre et al., 2013). The impact of a TBI on an older adult's HRQoL was researched in the context of symptom reduction in acute and rehabilitative care and based on familial and clinician HRQoL perspective and/or ratings (Hunt et al., 2019).

The purpose of this systematic review is to evaluate and describe the state of the evidence that measures functional status and HRQoL among older adults who experience a TBI, assess the association between functional status and HRQoL using validated outcomes measures, and identify knowledge gaps regarding functional status and HRQoL outcomes in older adults after

TBI. Although there are studies measuring functional status and HRQoL outcomes for older adults after TBI, there has not been a literature review of these studies to synthesize findings. This knowledge is necessary to better understand recovery patterns among all older adult populations, especially the differences between individuals who recover well and those who experience worse functional and HRQoL outcomes over the rehabilitation and post-rehabilitation phases.

Methods

Protocol and Registration

This systematic review was conducted utilizing the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Liberati et al., 2009). This review was not registered in any electronic database or PROSPERO.

Eligibility Criteria

Types of studies included were quantitative study designs, including randomized control trails, cohort studies, case control studies, or clinical trials that measured functional status and/or disability and HRQoL among older adults who experienced a TBI of any severity in adulthood (Table 2.1). For the purposes of this review, an "older adult" is defined as those aged 65 years and older, using the Medicare eligibility cut-off age for reference. Studies that included younger adult populations (<65 years old) in addition to older adults were included as long as they reported outcomes stratified by ages differentiating outcomes between the age groups (as opposed to reporting results by age as a continuous variable).

Studies were included in this review if they assessed "function," or "functional status/disability" and HRQoL after TBI among older adult samples using validated methods to measure both function and HRQoL. Studies that examined primary or secondary outcome measures related to functional status, functional disability, functional impairment, and quality of

life or HRQoL after TBI were included. Some HRQoL tools measure physical function and others do not, so this review included studies that measured function and HRQoL using validated tools. Participant-reported and/or caregiver/family proxy-reported outcome measures of the patient's post-TBI functional status and HRQoL were also included.

This review was limited to studies published in English between January 1, 2000 and May 16th, 2020. Articles were excluded if they were narrative reviews or editorials, case reports, or published protocols, or if they solely evaluated the psychometric properties of HRQoL outcome measurements.

Information Sources and Search Strategy

With the assistance of a UCSF librarian, a systematic literature review was performed between April 1, 2020 and May 16th, 2020 following the PRISMA guidelines (Liberati et al., 2009). A Cochrane library search was initially conducted to identify any existing relevant systematic reviews or meta-analyses. Individual search strategies were developed for searching the PubMed and EMBASE databases (Appendix 2.1). Medical Subject Heading (MeSH) and keyword searches were used to extrapolate relevant articles based on inclusion criteria. Keyword searches and MeSH terms in PubMed included: "Brain Injuries, Traumatic"[Mesh], "Brain Concussion"[Mesh], OR "Post-Concussion Syndrome"[Mesh] OR "concussion" OR "head injuries" OR "closed head injuries" AND ("aged" [MeSH] OR aged OR elder* OR old-age OR geriatric*) OR "Social security" OR retired OR Nonagenarians OR Nonagenarian OR Octogenarians OR Octogenarian OR Centenarians OR Centenarian) AND ("Quality of life" [MeSH] OR " life quality" OR "Health-related Quality of Life" OR HRQOL) AND ("glasgow outcome scale"[MeSH] OR "recovery of function"[MeSH] OR "functional outcome" OR "functional outcomes" OR "Functional Independence Measure"). The most commonly used

scales, assessments, and validated measurement tools used to measure function and/or functional status and HRQoL were also included as PubMed search terms: Patient Health Questionnaire-9, Brief Symptom Inventory-18, SF-12, SF-36, Glasgow Outcome Scale Extended, Satisfaction with Life Scale, QOLIBRI, Katz index, Barthel index, Functional Independence Measure, and Lawton index (Nichol et al., 2010). In Embase, a search was conducted using the following terms: “traumatic brain injury”, “brain injury”, “concussion”, “closed head injury”, “aged', “very elderly”, “senescence”, “geriatrics”, “quality of life questionnaire”, “quality of life index”, “quality of life”, “health related quality of life”, “health related quality of life questionnaire”, “Glasgow outcome scale”, “functional assessment”, “functional assessment”, “functional independence measure”. Dates were restricted in PubMed and EMBASE to 1/1/2000-5/16/2020. In PubMed and EMBASE, the following age filters were utilized: “aged 65+”, “aged”, and “very elderly.” A grey literature search was conducted using reference lists and bibliographies from identified studies of interest.

Study Selection and Data Management Process

Selected studies were imported into Endnote software (Clarivate Analytics, Endnote X8.1). One reviewer (M.D.) followed a three-step screening process:

1. Duplicates were identified via Endnote X8.1 software and removed.
2. Title and abstracts were screened.
3. The remaining articles were screened.

The single reviewer (M.D.) examined the remaining articles and applied the previously described inclusion and exclusion criteria.

Data Extraction

The single researcher (M.D,) created a data collection table of data points extracted from those studies and included in the final analysis. Data were extracted, organized, and then analyzed, including (a) study attributes (author, publication year, country, study design, study goal, enrollment criteria, setting, and theoretical framework); (b) sample characteristics (sample size, mean age, and injury severity); (c) measurement characteristics (functional status and HRQoL measurement tools used, data collection time points, follow-up assessment, and outcome); (d) summary of study findings (reported associations between HRQoL and function, additional associated factors of HRQoL and function, and relevant study conclusions). Table 2.2 presents a summary of study attributes and sample characteristics. Table 2.3 summarizes the measurement characteristics and relevant findings from each study. Table 2.4 describes the instruments used to measure functional status and HRQoL, as well as the domains each tool measures.

Results

Study Selection

The search of the Cochrane, PubMed and EMBASE databases provided a total of 236 citations. Forty-two were removed as duplicates. Of the 194 remaining articles, 172 articles were excluded after a review of titles and abstracts indicated the population of interest was not included (n = 65), functional status and quality of life outcomes were not measured (n = 90) or disqualifying study design (n = 17). Twenty-two studies were retained for full text review. Of these, 15 were excluded because functional status and HRQoL outcomes were not measured (n = 3), the study results were not stratified by age (n = 9), the study population was not specific to older adults with TBI (n = 2), or the topic study was redundant with studies covered by articles

already included in the review (n = 2). A total of six studies met inclusion criteria and are discussed in this systematic review (Figure 2.2 See PRISMA flow diagram (Liberati et al., 2009).

Study and Sample Characteristics

All six of the articles included were prospective cohort studies. Studies were published in English between 2017 and 2020, and data were collected between 2007 and 2016. The six studies were conducted in various countries, including one in Canada (Asselstine, Kristman, Armstrong, & Dewan, 2020), two in Switzerland (Gross & Amsler, 2018; Haller et al., 2017), one in France (Bouzat et al., 2019), and two in the United States (Cheng et al., 2018; Thompson et al., 2020b). None of the included studies discussed a theoretical framework or conceptual framework. Four studies enrolled participants from the Emergency Department (ED) at a level-one trauma center (Cheng et al., 2018; Gross & Amsler, 2018; Haller et al., 2017; Thompson et al., 2020b), one study enrolled participants from the ED at an acute care hospital (Asselstine et al., 2020), and one study enrolled particpants from the Intensive Care Unit (ICU) at a level-one trauma center (Bouzat et al., 2019). Four studies were conducted at a single center (Asselstine et al., 2020; Cheng et al., 2018; Gross & Amsler, 2018; Thompson et al., 2020b).

Study Participants

The studies included in this review involved a total of 1232 participants. The sample sizes of the six studies ranged from 33–427 participants (See Table 2). Five of the six studies compared outcomes between non-geriatric and geriatric adults (Bouzat et al., 2019; Cheng et al., 2018; Gross & Amsler, 2018; Haller et al., 2017; Thompson et al., 2020b). Among the total participants (n = 1232), approximately 283 were adults aged 65 years and older. For five studies, approximately 23% of study samples consisted of older adults (aged 65 years and older). One study (n = 46) exclusively examined older adults aged 65 years (Asselstine et al., 2020). Among

the four studies that reported mean age, the range was 73–77 years old among the older adult participants. The one study that only included adults aged 65 years and older did not report a mean age but did report that the majority of the participants' ages ranged from 65–85 years old (Asselstine et al., 2020). Another study did not report mean age among the older adult study participants but did report 60 participants were aged 70 years and older (Bouzat et al., 2019).

Of the six studies that reported demographics, the participants were predominately male in four studies and predominately female in two of the studies (Asselstine et al., 2020; Cheng et al., 2018). Race and ethnicity were only reported in three studies, which were conducted in the United States and Canada, and the older adults were racially diverse (25.5% white) (Asselstine et al., 2020; Cheng et al., 2018).

TBI Severity and Timing of Recruitment

The inclusion criteria regarding level of TBI severity varied among all six studies. Two studies included participants with mild or moderate TBI severity (Cheng et al., 2018; Thompson et al., 2020b), one study included severe TBI participants only (Haller et al., 2017), and one study only included mild TBI patients (Asselstine et al., 2020). One study determined eligibility using the New Injury Severity Scores (NISS ≥ 8) (Gross & Amsler, 2018), and one study included participants who had a TBI associated with a type-3 Abbreviated Injury Scale (AIS) score (Bouzat et al., 2019). Participants were enrolled either within 24 hours of injury (Cheng et al., 2018; Gross & Amsler, 2018; Thompson et al., 2020b), within 72 hours of injury (Asselstine et al., 2020), or while admitted into the ICU (Bouzat et al., 2019). Haller et al. (2017) did not specify criteria for timing of injury with respect to recruitment but reported that eligibility required agreement to participate in all three follow-up periods (3, 6, and 12-months post-injury). Two studies did not explicitly report exclusion criteria (Bouzat et al., 2019; Haller et al., 2017)

and four studies had varying exclusion criteria, which included various acute and chronic conditions (Asselstine et al., 2020; Cheng et al., 2018; Gross & Amsler, 2018; Thompson et al., 2020b).

Measuring Functional Status and HRQoL

Follow-up Procedures and Admininstration

The follow-up assessment time points and administration methods varied among all six studies (See Table 2.3). One study extracted demographic and specific TBI-related data via medical record extraction and HRQoL outcome measures were obtained through participant interviews, although the nature of the interview (e.g., in-person, phone, etc.) was not given (Cheng et al., 2018). Thompson et al. (2020) conducted all follow-up interviews face-to-face with the participant, and Gross et al. (2018) mailed all questionnaires to the participant for them to complete and mail back to study team. One study conducted follow-ups via Computer-Assisted Telephone Interview (CATI) (Asselstine et al., 2020), and Bouzat et al. (2019a) conducted structured telephone interviews with the study participant or their general practitioner if the patient was unavailable. Haller et al. (2017) conducted assessments via telephone or by mail.

One study included participants with a family member and conducted follow-up assessment with the participant and/or family member as necessary (Haller et al., 2017), and the other five studies conducted assessments with study participants only (i.e., did not include study proxy, study partner, etc.). Five studies followed participants for a 12-month period after injury. Two studies obtained follow-up measures only at 12 months after injury (Bouzat et al., 2019; Gross & Amsler, 2018); one study conducted follow-up at 3, 6, and 12 months after injury (Haller et al., 2017); one study conducted a baseline assessment and followed up with

participants at, 3, 6, and 12 months after injury (Cheng et al., 2018); and one study obtained follow-up at 1 week and 1, 3, 6, and 12 months after injury (Thompson et al., 2020b). Asselstine et al. (2020) followed participants for a total of six months and conducted a baseline assessment (within 10 days of ED visit), followed by one additional assessment 6 months after injury.

Functional Status and/or Disability

Overall, there was congruency among measures used to assess post-injury functional status. To measure functional status, one study used the Glasgow Outcome Scale (GOS) (Gross & Amsler, 2018), four studies used the Glasgow Outcome Scale-Extended (GOSE) (Asselstine et al., 2020; Bouzat et al., 2019; Haller et al., 2017), one study used the Functional Status Examination (FSE) (Cheng et al., 2018), and one study used both the FSE and GOSE (Thompson et al., 2020b). Five studies measured both functional status and HRQoL outcome at each of the study time points. One study measured only pre-injury HRQoL based on the week prior to injury and measured functional status at 3, 6, and 12 months after injury (Cheng et al., 2018).

Health-Related Quality of Life and/or Quality of Life

Health-related quality of life (HRQoL) assessments were measured using validated general and disease-specific tools. Five studies measured HRQoL using the 12-item Short Form Health Survey (SF-12), (Asselstine et al., 2020; Bouzat et al., 2019; Cheng et al., 2018; Haller et al., 2017; Thompson et al., 2020b). Gross et al. (2018) assessed HRQoL using three quality of life outcome measures, both general and disease-specific: SF-36, Euro Quality of Life Group Health-Related Quality of Life on Five Dimensions (EQ-5D), and Quality of Life after Brain Injury (QOLIBRI) (see Table 2.4).

Functional and HRQoL Outcomes

Study Goals. Four of the six studies evaluated age-related differences in recovery trajectories using HRQoL and functional status as primary and/or secondary outcome measures and comparing results between younger and older adult populations (Bouzat et al., 2019; Cheng et al., 2018; Haller et al., 2017; Thompson et al., 2020b). One study described long-term outcomes among younger and older major TBI trauma patients and investigated the reliability of using a TBI-specific HRQoL measure (QOLIBRI) among the geriatric patients with TBI (Gross & Amsler, 2018). Asselstine et al. (2020) explored the association between the Rivermead Post-Concussive Symptom Questionnaire (RPQ) score and future disability in older adults using the GOSE measurement tool to assess function.

Functional Status. One study found that GOSE scores significantly improved for all age groups 3–12 months after injury. Improvement of GOSE score was dependent on age and TBI severity (Haller et al., 2017). The GOSE score significantly improved among the non-geriatric participants, albeit less so among those with a more severe injury (Haller et al., 2017). Gross et al. (2018) did not find differences in functional status between younger versus older adults when measured by the GOSE at 12 months after injury. Thompson et al. (2020) found that functional health status was significantly worse among older adults compared to younger adults at all four time points, according to the GOSE and the FSE scores (Thompson et al., 2020b). Bouzat et al. (2019) found that 44% of study participants had favorable GOSE outcomes one year after injury (GOS-E score of 7 and 8). Predictors of death and poor outcomes (GOSE 1-4) were age, pupillary abnormalities, GCS score at time of injury, and CT findings. Study findings from Cheng et al. (2018) found that functional mobility was positively associated with the ability to travel, home maintenance, and social integration as measured by the FSE. One study additionally

measured post-concussive symptoms using the Rivermead Post-concussive Questionnaire (RPQ) after injury and found there were no associations between baseline RPQ and SF-12 PCS; however, an association was identified between baseline RPQ and 6-month GOSE scores. Those with more RPQ symptoms at baseline had poorer outcomes with respect to overall disability (measured by GOSE) than adults who had fewer RPQ symptoms, suggesting that overall disability and mental health outcomes six months after injury are associated with more RPQ symptoms at baseline (Asselstine et al., 2020).

HRQoL. Haller et al. (2017) found the SF-12 mental component score was similar across all time points for all participants regardless of age. The SF-12 physical component showed improvement among all age groups, although a smaller likelihood for improvement in geriatric patients was identified as statistically significant (Haller et al., 2017). Older adults reported poorer overall physical HRQoL (PCS). There were no differences in mental HRQoL (MCS) scores among age groups from one week to six months after injury, but at one year, older adults reported significantly higher average mental HRQoL compared to the younger group (Thompson et al., 2020b).

Cheng et al. (2018) explored the relationship between functional recovery trajectories and QoL among older and younger adults, as well as age-related differences. For both groups, pre-injury physical health was highly correlated with ability to travel and social integration at 12 months after injury. Among older adults with higher pre-injury MCS, there was a negative correlation with their functional status. Additionally, older adults consistently had worse functional performance in mobility, ability to travel, home maintenance, and overall functional status compared to younger adults. At one year after injury, Bouzat et al. (2019) found no age-related differences in HRQoL outcomes, and among older adult survivors, impairment of

HRQoL was not different from that of younger adults. Among those aged 70 years and older, an increased risk for mortality and poor neurological outcome was observed (Bouzat et al., 2019). Findings by Gross et al. (2018) showed no age-related differences in HRQoL (measured by the QOLIBRI at 12 months after injury). For the cognitive domain of the QOLIBRI and the SF-36, two physical subscores trended towards a lower outcome and were low in older adults, respectively. Additionally, adults aged 80 years or older had significantly reduced outcome as measured by the QOLIBRI in all domains except "social relationship" and "self" (Gross & Amsler, 2018).

Summary of Study Findings. Goals and outcomes related to HRQoL and functional status varied among the studies included. Five studies demonstrated variability in HRQoL outcomes and function among older and younger adults. There was variability in inclusion/exclusion criteria, study administration processes, follow-up time periods, and assessment of HRQoL and functional status. All but one study followed TBI participants over a 12-month period, and one study measured HRQoL at baseline only (Cheng et al., 2018). Asselstine et al. (2020) measured HRQoL and function up to six months after injury. Although five studies compared functional status and HRQoL outcomes of older adults versus younger adults and/or studied relationships between age and outcome, older adult representation in study samples ranged from 34–44% (Bouzat et al., 2019; Cheng et al., 2018; Haller et al., 2017; Thompson et al., 2020b). One study found there was significant improvement in HRQoL and functional status 3–12 months after injury (Haller et al., 2017). The five studies that evaluated age-related differences in outcome yielded differing results and conclusions. Two studies reported there were no age-related differences (Gross & Amsler, 2018; Haller et al., 2017), and three studies found older adults had worse functional and HRQoL outcomes compared to

younger adults (Bouzat et al., 2019; Cheng et al., 2018). Improvement in HRQoL and functional outcomes over time was also variable depending on the follow-up time points.

Discussion

To the single reviewer's (M.D.) knowledge, this systematic review of the literature is the first to evaluate and describe research that measured functional status and HRQoL among older adults after TBI. From research conducted over the last two decades, six studies were identified that specifically examined functional status and HRQoL outcomes following TBI for older adult populations using validated quantitative measures. Among these six studies, when age-related differences were found, older adults experienced less improvement during the recovery from TBI. Findings were similar to previous literature suggesting that older adults generally have worse functional, cognitive, and psychosocial outcomes, slower rates of recovery, and less improvement in function and HRQoL compared to younger patients 6–12 months following TBI (Cuthbert et al., 2015; McIntyre et al., 2013; A. C. Mosenthal et al., 2004; Rapoport & Feinstein, 2001; Stocchetti, Paterno, Citerio, Beretta, & Colombo, 2012; Thompson, Dikmen, & Temkin, 2012; Thompson et al., 2006). The variability in HRQoL follow-up time points and methodologies among HRQoL measures across the studies made it challenging to synthesize HRQoL findings. Additionally, none of the studies in this review used a conceptual model that measured HRQoL as a major domain or construct.

Older Adult Study Participants

Although TBI incidence has steadily increased among older adults, this population continues to be significantly underrepresented in TBI research. Five studies in this review included adults of all ages (15 years and older), resulting in the majority of the study participants being younger adults (aged 64 years old and younger) (Bouzat et al., 2019; Cheng et al., 2018;

Gross & Amsler, 2018; Haller et al., 2017; Thompson et al., 2020b). Approximately 23% of the total combined participants in those five studies were aged 65 years and older. Underrepresentation of older adults in TBI research is common, which limits generalizability to this population. Previous studies have identified the need to increase representation of older adults with a TBI in order to better understand global outcomes (Gardner et al., 2017; McIntyre et al., 2013; Peters & Gardner, 2018).

Exclusion Criteria and Preexisting Conditions

Two studies included in this review did not report exclusion criteria (Bouzat et al., 2019; Haller et al., 2017). The other four studies excluded older adults who were hospitalized during the prior six months or had history of a previous TBI, stroke, dementia, psychiatric disorder, lower extremity fracture, or cervical spine trauma (Cheng et al., 2018; Thompson et al., 2020b). Adults who lacked comprehension at any follow-up time point, experienced reinjury during the study, had a positive CT scan, or sustained a TBI due to alcohol, drugs, and/or medications were also excluded (Asselstine et al., 2020). Preexisting conditions (including neurological) commonly contribute to ongoing exclusion of this population in TBI research despite the fact that 99% of older adults presenting with a TBI have a preexisting condition, most commonly Alzheimer's disease and related dementias, depression, diabetes, cardiovascular disease, and/or pulmonary disease (Albrecht, Kiptanui, et al., 2015; Albrecht, Liu, et al., 2015; Hawley et al., 2017; Kumar et al., 2017). Preexisting conditions are highly prevalent among older adults with TBI, and older adults may exhibit polytrauma at the onset of a TBI and/or have disabilities related to comorbidities, so older adult TBI study samples that use these factors as exclusion criteria will fail to accurately reflect the general older adult TBI population and therefore limit generalizability.

When measuring functional status and HRQoL outcomes within this population, it can be challenging to capture true post-injury effects of TBI among those with preexisting disabling conditions and/or neurological impairments. Haller et al. (2017) collected outcome data from a report by a proxy if the participant was unable to complete assessment at any of the follow-up time points. The inclusion of older adults in longitudinal TBI research with proxy-reports could be a potential solution for collecting data on specific determinants among older adults with preexisting conditions that typically exclude these populations from eligibility, especially among those with preexisting cognitive impairment. Conducting studies of post-TBI function and HRQoL with broader inclusion criteria that would not disqualify older adults with cognitive impairment and would contribute to better understanding how older adults with various preexisting conditions recover functionally from TBI and how HRQoL may be affected, an area of interest that was not addressed in any of the included studies (Asselstine et al., 2020; K. Brown et al., 2017b; Cheng et al., 2018; Gross & Amsler, 2018; Thompson et al., 2020b).

Measurement of Fuctional Status and HRQoL

All six studies assessed functional status and HRQoL outcomes using validated measurement tools for adults with TBI (Nichol et al., 2010). Previous reviews and meta-analyses measuring outcomes among older adults assessed global and functional outcomes using the Glasgow Outcome Scale-Extended (GOSE) (McIntyre et al., 2013), which is considered the gold standard index. The GOSE measures functional outcomes across seven domains, including consciousness, independence at home, independence outside the home, work, social and leisure activities, family and friendship, and return to normal life (Thompson, Weir, et al., 2012). Although the GOSE has several strengths, the instrument is limited in its ability to identify disability and capture all physical, cognitive, and psychosocial problems that a patient may

experience after a TBI (Nelson et al., 2017). Additionally, the GOSE has not been validated in older adults and may be unreliable in patients with preexisting conditions as it may not accurately capture TBI-specific effects on functional status, especially in cases of mild TBI (Nichol et al., 2011; Wilson, Pettigrew, & Teasdale, 1998).

Disease-specific HRQoL measures have only recently been developed and continue to be refined. Instruments have been introduced like the Quality of Life After Brain Injury (QOLIBRI) assessment, a TBI-specific HRQoL measurement tool validated in TBI research, which captures cognition and self-domains of health, daily life, autonomy, social relationships, emotions, and physical problems (Gross & Amsler, 2018; Nichol et al., 2010). Previous studies have acknowledged that domains related to seizures, legal issues, driving abilities, community reintegration, environment, stigma, and sleep problems are lacking. Additionally, HRQoL is not being consistently measured in TBI research in older adults and different scales include different domains. Environment is a relevant domain that can influence subjective health outcomes, age-related changes, chronic disease, and disabilities, yet functional status and TBI-specific HRQoL measures consistently fail to take environmental factors into account (Hunt et al., 2019; Nichol et al., 2010). All of these limitations negatively impact the usefulness of TBI-specific HRQoL measures for TBI patients, especially with respect to older adults.

Generic HRQoL measures also have limitations. These tools typically evaluate only physical, social, and emotional/mental health, and they may not identify changes in HRQoL in a TBI population. Specifically, generic measures do include domains like cognition and environment, which are relevant to HRQoL among older adults with TBI due to age-related brain changes and impact of environment on overall heath (Nichol et al., 2010). The SF-12 questionnaire covers domains relevant to physical and mental health but does not provide

information about each of the eight domains included in the original SF-36 scales (see Table 5 for domains in HRQoL measurement tools). The SF-12 continues to be the most commonly used tool with the TBI population; however, it has only been validated in younger TBI populations and psychometric properties have not been assessed with respect to older adults (Nichol et al., 2010).

Gross et al. (2018) was the only included study that measured HRQoL using both a generic and disease-specific measurement tool. All other study authors used only generic measurement tools to assess HRQoL (Asselstine et al., 2020; Bouzat et al., 2019; Haller et al., 2017; Thompson et al., 2020b). The study by Gross et al. (2018) found that the cognitive domain of the QOLIBRI and the two physical subscores of the SF-36 trended towards a lower outcome only among older adults. Older adults aged over 80 years old demonstrated significant reduction in outcomes as measured by the QOLIBRI in all domains except "social relationship" and "self" (Gross & Amsler, 2018). All other studies had varied findings regarding HRQoL, which suggests that the generic HRQoL tools used may not capture the domains affected by TBI in older adults (Bouzat et al., 2019; Cheng et al., 2018; Haller et al., 2017). Haller et al. (2017) found similar scores across all time points regardless of age, and only the physical components of the SF-12 showed improvements among all age groups. Thompson et al. (2020) found that older adults reported poorer overall physical HRQoL (PCS) via SF-12. There were no age-related differences in mental HRQoL (MCS) scores among age groups from one week to six months after injury, but at one year, older adults reported significantly higher average mental HRQoL compared to the younger group (Thompson et al., 2020b). The findings from this review are similar to existing TBI studies which measure HRQoL using generic vs. disease-specific instruments (Lin et al., 2010; Von Steinbuechel et al., 2012).

Follow-up Time Points

The role of pre-injury health and functional status is important in predicting outcomes for this population. In 2013, the American College of Surgeons (ACS) Trauma Quality Improvement Program published Geriatric Trauma Management Guidelines, which highlight the importance of measuring preexisting comorbidities, functional status, and physical frailty in all geriatric trauma patients in order to guide prognostication. Asselstine et al. (2020) is the only study that measured both baseline and post-injury functional status and HRQoL. One study measured pre-injury HRQoL via SF-12 but did not measure HRQoL at any time point after injury (Cheng et al., 2018). Thompson et al. (2020) measured function and HRQoL at one week after injury but did not capture pre-injury functional status or HRQoL. The variability in study methods and data collection, as well as the lack of pre-injury function assessment or HRQoL assessment at various time points during the rehabilitative and post-rehabilitative phases, make it difficult to understand functional and HRQoL recovery trajectories over time for this population. A pilot cohort study that investigated prognostic markers of poor recovery among older adults with mild TBI (mTBI) concluded that recovery may be more specifically associated with psychosocial factors than biomedical or injury-related factors (Kristman, Brison, Bedard, Reguly, & Chisholm, 2016). Results from that study suggest older adults who report worse health one year prior to injury, as well as those who have poor expectations for recovery, depression, and/or fatigue immediately after injury, reported worse outcomes six months after injury.

In order to understand TBI-related injuries and recovery trajectories for older adults, it is necessary to follow this population over longer periods of time (rehabilitative and post-rehabilitative) and assess the effects of their TBI on overall health, HRQoL, functional status, and potential disability. To accurately measure older adults' pre- and post-injury HRQoL and

function over time, it is vital to capture self-report HRQoL outcomes, in addition to proxy-report, in all cases regardless of cognitive status. Collecting both the participant and the proxy report can be useful in this population in case post-injury changes over time cause self-reports to become unreliable or unattainable at various timepoints depending on preexisting conditions and overall health status after TBI.

Limitations

This systematic review has several limitations. Publication bias may have occurred given that only studies in English published during the last 20 years were reviewed. Additionally, only two electronic data bases were searched. The review may be limited by the nature of the search strategies, such as the key words selected to search the databases. Although every attempt was made to employ rigorous selection criteria that would ensure methodological quality and constancy, articles regarding the constructs of functional status and HRQoL were identified using outcome measures as search terms, which may have resulted in search-bias. The review was only conducted by one reviewer (M.D.) increasing potential for selection bias. This review used the cut-off age of 65 years old rather than a more inclusive definition of "older adults" (e.g., aged 55 years and older), limiting the life span range evaluated for functional status and HRQoL outcomes.

Nursing Implications for Practice and Research

Measuring HRQoL alongside objective measurements of independence, performance, and function throughout the entire recovery trajectory may be the best approach to ensuring optimal patient outcomes. By more closely examining the intersection between functional recovery and HRQoL following injury for all TBI severities over time, research in this field can help inform a more holistic approach to managing older adults' care after TBI. Understanding

the subjective HRQoL and functional status over the recovery trajectory can help to evolve and improve outpatient follow-up care after TBI, particularly with respect to rehabilitation needs. Additionally, prevention measures to improve function and HRQoL among older adults before and after TBI are necessary as older adults continue to age and live longer lives despite TBI-related disability and comorbidities. Given the lack of existing geriatric TBI management guidelines, significant opportunities exist to improve the care received by older adults, increase understanding of their unique needs across the life course, and develop interventions to improve post-injury function and HRQoL. Conceptual frameworks like the Health-Related Quality of Life Model, by Wilson & Cleary, can help conceptualize management of important post-injury outcomes (Ojelabi et al., 2017; I. B. Wilson & P. D. Cleary, 1995).

Conclusion

Previously published TBI literature report that older adults with TBI have poorer physical, cognitive, and psychosocial outcomes compared to younger adults, and the six studies included in this systematic review support the conclusion that this trend applies to the subset of older adults with TBI in the included studies. Overall, HRQoL and functional status outcomes after TBI have been minimally explored in the context of understanding the association between functional outcomes and HRQoL. The variation in inclusion/exclusion criteria and study methodologies (e.g., data collection) make it difficult to effectively synthesize the findings explored in this review, which precludes identification of definitive guidance to inform recovery trajectories and clinical practice for older adults after injury. More longitudinal observational studies with older adult representation are needed to understand multivariate relationships between functional status and HRQoL in older adults after TBI. Additionally, representation of

older adults with preexisting chronic conditions, including neurological disease, is necessary in TBI research to improve generalizability to this population.

Important gaps in the literature exist primarily with respect to measuring pre- and post-injury function and HRQoL for older adults with TBI. An older adult's subjective HRQoL can be a central outcome and should be measured systematically and repeatedly over a prolonged period. Given that some older adults recover well, a better understanding of recovery trajectories will help in predicting long-term outcomes and will aid nurses and clinicians who seek to diminish the problem of TBI-related disability in older adult populations. More research needs to be done to understand the effects of a TBI on well-being and which HRQoL domains are appropriate to focus on and measure in older adults throughout the life span. The search conducted for this review did not yield any existing qualitative studies, which would theoretically provide important descriptions regarding the lived experience and long-term impact of injury on older adults. More specifically, understanding how TBI impacts functioning and HRQoL in older adults is important to inform acute care, rehabilitation, and community health needs.

Appendix 2.1: Search Strategies

PubMed

Searches	Results
(TBI [tiab] OR "traumatic brain injury"[tiab] OR "traumatic brain injuries"[tiab] OR "brain injury"[tiab] OR "Brain Injuries, Traumatic"[Mesh] OR "Brain Concussion"[Mesh] OR "Post-Concussion Syndrome"[Mesh] OR concussion OR postconcussion OR post-concussion OR "closed head injury" OR "closed head injuries" OR ((nonpenetrating OR non-penetrating) AND ("head injury" OR "head injuries")))) AND ((aged [MeSH Terms] OR aged OR elder* OR old-age] OR geriatric* OR "Social security" OR retired OR Nonagenarians OR Nonagenarian OR Octogenarians OR Octogenarian OR Centenarians OR Centenarian))) AND ("Quality of life" [MeSH] OR " life quality" OR "Health-related Quality of Life" OR HRQOL) AND ("Patient Health Questionnaire 9" OR "Brief Symptom Inventory 18" OR "Satisfaction with Life Scale" OR QOLIBRI OR PROMIS "PI" OR PROMIS OR "katz index" OR "barthel index" OR "lawton index" OR "Expanded Disability Status Scale" OR "glasgow outcome scale"[MeSH] OR "recovery of function"[MeSH] OR "recovery of function" OR "functional outcome" OR "Functional Independence Measure")	100

Embase

Searches	Results
(('traumatic brain injury'/exp OR 'traumatic brain injury' OR 'brain injury'/exp OR 'brain injury' OR 'concussion'/exp OR concussion OR 'head'/exp OR head) AND ('injury'/exp OR injury) OR 'closed head injury'/exp OR 'closed head injury') AND ('aged'/exp OR aged OR 'very elderly'/exp OR 'very elderly' OR 'senescence'/exp OR senescence OR 'geriatrics'/exp OR geriatrics) AND ('quality of life questionnaire'/exp OR 'quality of life questionnaire' OR 'quality of life index'/exp OR 'quality of life index' OR 'quality of life'/exp OR 'quality of life' OR 'health related quality of life questionnaire'/exp OR 'health related quality of life questionnaire') AND ('glasgow outcome scale'/exp OR 'glasgow outcome scale' OR 'functional assessment'/exp OR 'functional assessment' OR 'functional independence measure'/exp OR 'functional independence measure')	136

Systematic Review of Functional Status and Health-Related Quality of Life Post Traumatic Brain Injury Among Older Adults

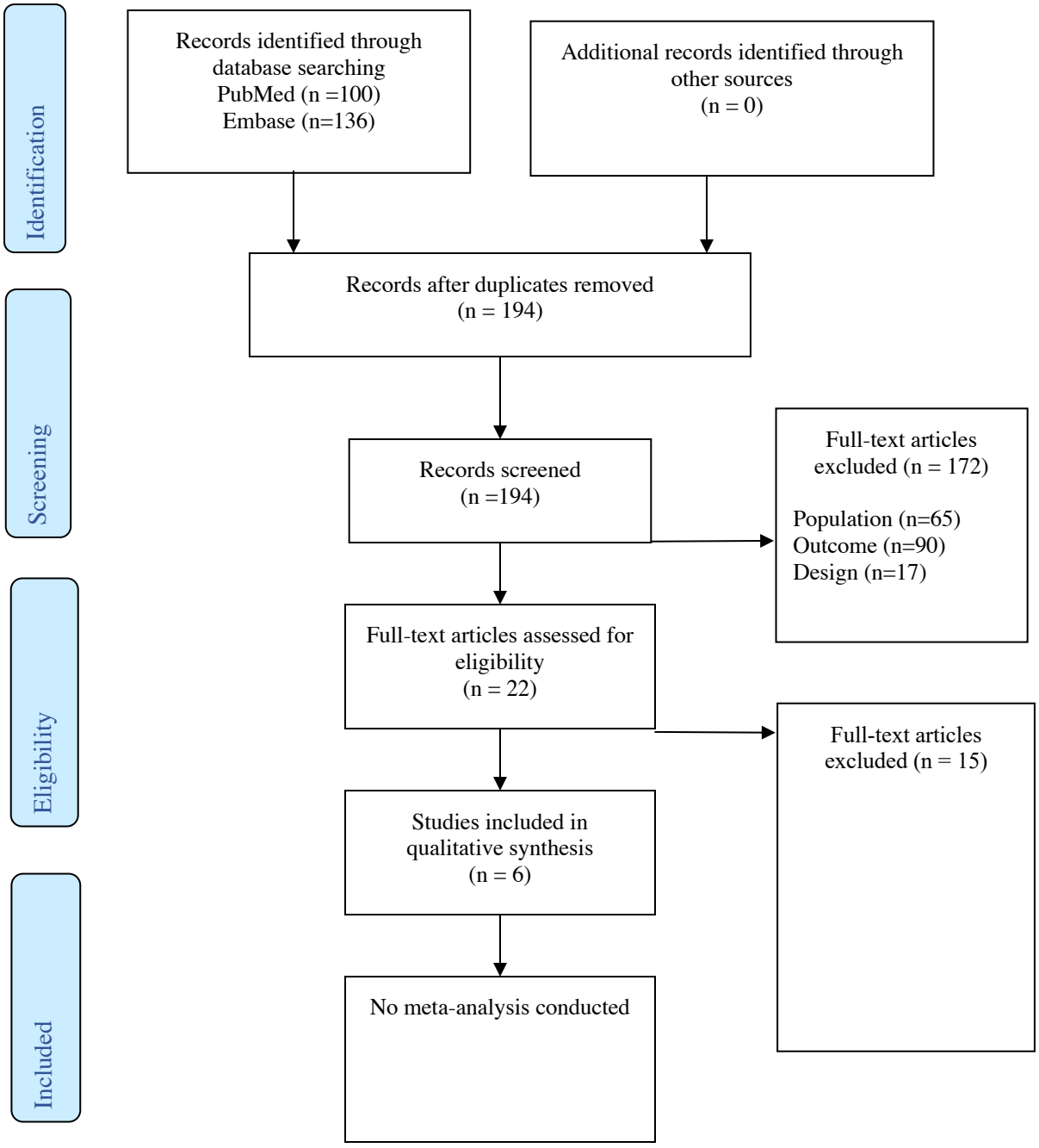

Figure 2.2. Identification of studies in systematic review between functional status and quality of life among older adults with a traumatic brain injury.

Table 2.1 Inclusion and Exclusion Criteria		
	Included	**Excluded**
Population	Studies that included adults >65 years old, experienced a Traumatic Brain Injury of any severity (mild, moderate, severe), TBI endured in adulthood	Adults <64 years old, studies that included adults ages> 65 and did not stratify results by age (i.e. adults >65), no TBI history, remote and/or TBI endured in youth.
Intervention		
Control		
Setting	Post-injury follow-up	
Design	Randomized controlled trials, cohort study, case control study, clinical trial	Qualitative, commentary, reviews, protocols, editorials, psychometric analyses
Outcome Measure	Generic or disease-specific HRQOL as outcome measure (health-related quality of life, quality of life) Functional status, disability, impairment as outcome measure post-injury	Studies that did not measure functional status or impairment and QoL or HRQoL Psychometric validation of HRQOL measurement tools
Dates	January 1, 2000 and May 16, 2020	Prior to January 1, 2000, After May 16, 2020
Language	Published in English	Not published in English

Table 2.2. Study characteristics; Functional status outcomes and health-related quality of life among older adults after traumatic brain injury (N=6)

	Author, Publication year, Country	Research question/Aim(s)	Study Design	Sample Characteristics				Data Collection method	Theoretical Framework
				Sample Size	Mean Age (SD)/ Age Range	Older Adults >65 (n, %)	Inclusion and Setting (Exclusion Criteria)		
1	Haller et al., 2017 Switzerland	Investigate disability and HRQoL at 3, 6- and 12-months post TBI in non-geriatric and geriatric patients (at time of injury)	Prospective cohort study	3 months: N=351 non-geriatric (Age ≤ 65) (n=254) geriatric (Age > 65) (n=97) 6 months: N=340 non-geriatric (n=252) geriatric (n=88) 12 months: N=305 non-geriatric (n=222) geriatric (n=83)	3 months: non-geriatric 38 (23-53) geriatric 74 (70-80) 6 months: non-geriatric 37 (23-53) geriatric 73 (69-80) 12 months: non-geriatric 49 (23-53) geriatric 74 (70-80)	3 months: (97, 38%) 6 months: (88, 35%) 12 months: (83, 37%)	≥16 y/o Severe TBI (HAIS >3) with study relative and agree to participate in all 3 study follow up periods Treated at any of 11 trauma centers from January 2007 to April 2011 (NR)	Telephone and/or by mail with study relative present	NR
2	Cheng et al., 2018 United States	Determine differences in functional recovery trajectories and quality of life between younger and older adults with mild-moderate TBI during first-year post-injury	Observational cohort	n=34 Younger adults ≤ 65 (n=19) Older adults > 65 (n=15)	Younger adults: 38.74 (12.0)/23-63 Older adults: 77.5 (9.1)/65-91	(15, 44%)	Younger and older adults within 24 hours post-injury Mild-moderate TBI (GCS 9-15) treated at level one trauma center from 2009-2010 (Lower extremity fracture or cervical spine trauma at time of injury, previous head injury in last 30 days, previous hospitalization for psychiatric disorder, diagnosis of dementia, regular steroid or non-steroidal anti-inflammatory use, prisoner status)	Interview with participant	NR

HRQoL Health Related Quality of Life **GCS** Glasgow Coma Score **NR** Not Reported **ASI** Abbreviated Injury Scale **HAIS** Abbreviated Head Scale of the head region **ISS** Injury Severity Scale **GOS** Glasgow Outcome Scale

Table 2.2. (continued) Study characteristics; Functional status outcomes and health-related quality of life among older adults after traumatic brain injury (N=6)

	Author, Publication year, Country	Research question/Aim(s)	Study Design	Sample Characteristics				Data Collection method	Theoretical Framework
				Sample Size	Mean Age (SD)/ Age Range	Older Adults >65 (n, %)	Inclusion and Setting (Exclusion Criteria)		
3	Gross et al., 2018 Switzerland	Describe long-term outcomes to older and younger major trauma patients. Investigate if the QOLIBRI can be reliably used for older adults	Prospective cohort	N=326 Younger adults ≤ 64: (n=216) Older adults > 65: (n=110)	Younger adults ≤ 64: 43.24(14.95)/ 16-64 Older adults > 65: 73.56(6.75)/≥ 65	(110, 34%)	Admitted to the ED at one trauma center from January 1, 2011 to December 31, 2015 within 24 hours of injury. (Patients <16 years old, ISS<8, or and AIS head=0, vegetative state as defined by GOS)	Questionnaires mailed to participant	NR
4	Asselstine et al., 2019 Canada	Determine the association between baseline RPQ score and future disability in older adults with mTBI	Prospective cohort	N=46	NR(NR)/ Reported majority of participant age was 65-85 years old	(46, 100%)	Adults 65 years and older who visited a participating ED in Ontario, Canada between November 5, 2012 and November 13, 2013 within 72 hours of mTBI injury. Ontario resident with less severe CT findings such as edema, smear subdural hematoma, and/or contusion. (Adults who lacked comprehension at any follow up time period, reinjury during study, positive CT scan with intracranial bleeds, sustained mTBI due to drugs, alcohol, medications, and/or caused by other injuries or treatments related to other problems	Computer-Assisted telephone interview (CATI)	NR

HRQoL Health Related Quality of Life **GCS** Glasgow Coma Score **NR** Not Reported **ASI** Abbreviated Injury Scale **HAIS** Abbreviated Head Scale of the head region **ISS** Injury Severity Scale **GOS** Glasgow Outcome Scale

Table 2.2. (continued) Study characteristics; Functional status outcomes and health-related quality of life among older adults after traumatic brain injury (N=6)

	Author, Publication year, Country	Research question/Aim(s)	Study Design	Sample Characteristics				Data Collection method	Theoretical Framework
				Sample Size	Mean Age (SD)/ Age Range	Older Adults >65 (n, %)	Inclusion and Setting (Exclusion Criteria)		
5	Bouzat et al., 2019 France	Among those with TBI, describe the relationship between age and 1-year quality of life outcomes	Prospective cohort	N=380	44(22)/NR	(NR, NR)	Adult patients seen in two level-one trauma centers admitted to the ICU between July 2014 and July 2016 for TBI associated with a type-AIS (NR)	Structured phone interview with patient or general practitioner	NR
6	Thompson et al., 2020 United States	To describe and compare the recovery and disability trajectory at 1-year post injury for younger and older adults with TBI	Prospective longitudinal cohort	N=33 Younger adults 21-64 (n=18) Older adults 65 and older (n=15)	Younger adults ≤ 64: 38.9(NR)/23-63 Older adults > 65: 77.5(NR)/65-91	(15, 45%)	Adults 21 years and older were recruited from a level one trauma center and see in the ED with mild to moderate TBI within 24 hours of injury, primary dx of TBI, GCS score of 9-15. (Cervical spinal cord injury, lower extremity fracture, history of TBI, stroke, or dementia, hospitalized in the last 6 months, non-English speaking.	Face-to-face interviews with subjects	NR

HRQoL Health Related Quality of Life **GCS** Glasgow Coma Score **NR** Not Reported **ASI** Abbreviated Injury Scale **HAIS** Abbreviated Head Scale of the head region **ISS** Injury Severity Scale **GOS** Glasgow Outcome Scale

Table 2.3: Measurement tools, assessment tools, and study results; Functional status outcomes and health-related quality of life among older adults after traumatic brain injury (N=6)

	Author and Publication year	Outcome Scales Utilized				Results	
		Functional Status/disability	Assessment Timepoint	Health-Related Quality of Life	Assessment Timepoint	Functional/disability	Health-Related Quality of Life
1	Haller et al., 2017 Switzerland	GOSE	3, 6, 12 months	SF-12	3, 6, 12 months	-GOSE score significantly improved among all age groups between 3-12 months. -Improvement of GOSE score was dependent on age and TBI severity -GOSE outcome score improved significantly among non-geriatric group only between 3-12 months -Improvement was lower in patients with critical TBI (HAIS=5) compared with severe TBI (HAIS=4)	-Mental component score of SF-12 was similar across all time points for all patients regardless of age -Physical component of SF-12 showed significant improvement among all age groups between 3-12 months -Increase in score was significant for non-geriatric patients and reached significance with a smaller likelihood for geriatric patients

OA Older adults **YA** Younger Adults **MCS** Mental health Component **PCS** Physical Health Component **RPQ** Rivermead Post Concussion Symptom Questionnaire **GOSE** Glasgow Outcome Scale Extended **GOS** Glasgow Outcome Scale **FSE** Functional Status Examination **SF-12** 12-item Short Form health survey **SF-36** 36-item Short Form health survey **EQ-5D** Euro Quality of Life group health related quality of life on five dimensions **QOLIBRI** Quality of Life after Brain Injury

Table 2.3 (continued): Measurement tools, assessment tools, and study results; Functional status outcomes and health-related quality of life among older adults after traumatic brain injury (N=6)

	Author and Publication year	Outcome Scales Utilized				Results	
		Functional Status/disability	Assessment Timepoint	Health-Related Quality of Life	Assessment Timepoint	Functional/disability	Health-Related Quality of Life
2	Cheng et al., 2018 United States	FSE	3, 6, 12 months	SF-12	Pre-injury (within first week injury)	-Among all ages, pre-injury physical health was significantly associated with ability to travel and social reintegration at 12 months. -Older adults had significantly worse functional performance in the following domains: mobility, ability to travel, home maintenance, overall functional status -During 6-12-month time period, significant declines were observed in the personal care and overall functional status over time compared to younger adults -Functional mobility was positively associated with the ability to travel, home maintenance, and social integration	-No difference in pre-injury quality of life between younger and older adults -Higher QoL prior to injury among older adults was associated with better functional status. -At each time point, higher physical QoL was associated with better ability to perform home maintenance among older adults. -At 12-months, significant association between pre-injury QoL and functional status only occurred among OA -Higher MCS prior to injury was associated with worse functional outcomes among OA at 3 months post-injury -At 6 months, higher pre-injury MCS was associated with worse functional outcomes in six domains (travel, home maintenance, leisure/recreation, social integration, executive functioning, and overall performance). -Among younger adults, pre-injury PCS was correlated with executive functioning at 3-months post-injury -YA better pre-injury MCS was associated with better 6-month social integration functioning. -At 12-months YA, higher PCS at pre-injury was associated with better social integration - At 12-months YA, better MCS at pre-injury was associated with worse travel, home maintenance, and overall functioning

OA Older adults **YA** Younger Adults **MCS** Mental health Component **PCS** Physical Health Component **RPQ** Rivermead Post Concussion Symptom Questionnaire
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Table 2.3 (continued): Measurement tools, assessment tools, and study results; Functional status outcomes and health-related quality of life among older adults after traumatic brain injury (N=6)

	Author and Publication year	Outcome Scales Utilized				Results	
		Functional Status/disability	Assessment Timepoint	Health-Related Quality of Life	Assessment Timepoint	Functional/disability	Health-Related Quality of Life
3	Gross et al., 2018 Switzerland	GOS	12-months post-injury	EQ-5D SF-36 QOLIBRI	12-months post-injury	1-year outcomes show no differences across age groups for younger versus older adults in overall function	-1-year outcomes show no differences across age groups for younger versus older adults in overall HRQoL -Cognitive domain of QOLIBRI trended towards a lower outcome in older adults -SF-36 two physical oriented subscores were lower in older adults -Older adults >80 years, had significantly reduced outcome as measured by the QOLIBRI in all domains except "social relationship" and "self"
4	Asselstine et al., 2019 Canada	GOSE	Baseline and 6-months post-injury	SF-12	Baseline and 6-months post-injury	-There were no associations between baseline RPQ and SF-12 physical health component -Association between baseline RPQ and 6-month GOSE scores. Those with more RPQ symptoms at baseline had poorer overall disability (measured by GOSE) than adults who had fewer RPQ symptoms	-Associations between baseline RPQ and GOSE, and SF-12 mental health component suggests that overall disability and mental health outcomes at 6 months later are associated with more RPQ symptoms at baseline.

OA Older adults **YA** Younger Adults **MCS** Mental health Component **PCS** Physical Health Component **RPQ** Rivermead Post Concussion Symptom Questionnaire
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Table 2.3 (continued): Measurement tools, assessment tools, and study results; Functional status outcomes and health-related quality of life among older adults after traumatic brain injury (N=6)

	Author and Publication year	Outcome Scales Utilized				Results	
		Functional Status/disability	Assessment Timepoint	Health-Related Quality of Life	Assessment Timepoint	Functional/disability	Health-Related Quality of Life
5	Bouzat et al., 2019 France	GOSE	1-year post-injury	SF-12	1-year post-injury	-44% had favorable outcomes (GOS-E 7 and 8) -Predictors of death and poor outcomes (measured by GOS-E 1-4) were age, pupillary abnormalities, initial GCS score, and CT scan findings -After 70 years of age, dramatic increase in the odds of death and poor neurological outcome	QoL at 1-year, mean physical and mental scores corresponded to mild incapacity. No differences according to age categories was found (<20, 20-39, 40-59, 60-69, ≥70).
6	Thompson et al., 2020 United States	GOSE FSE	1-week, 3, 6, and 12 months post-injury	SF-12	1-week, 3, 6, and 12 months post-injury	-Functional health status was significantly worse (higher disability) among older adults compared with younger adults at all timepoints assessed by GOS-E and FSE	-Older adults reported consistently poorer overall physical PCS HRQOL -No significant differences in mental MCS HRQOL score between the younger and the older adults from 1-week to 6-months post injury. -At 1-year post-injury, older adults reported significantly higher average mental HRQOL compared to younger adults.

OA Older adults **YA** Younger Adults **MCS** Mental health Component **PCS** Physical Health Component **RPQ** Rivermead Post Concussion Symptom Questionnaire
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SF-36 36-item Short Form health survey **EQ-5D** Euro Quality of Life group health related quality of life on five dimensions **QOLIBRI** Quality of Life after Brain Injury

Table 2.4: Outcome measure domains; Functional status outcomes and health-related

Functional Status Outcomes Measures	Traumatic Brain Injury Specific	Domains Measured
Glasgow Outcome Scale (GOS) **Glasgow Outcome Scale-Extended (GOSE)**	√ √	Consciousness Independence at home Independence outside home Work Social and Leisure Activities Family and Friendship Return to Normal Life
Functional Status Examination (FSE)		Executive Functioning Social Integration Personal Care Ambulation Standard of Living Home Management Travel Financial Independence Majority activity involving work or school Leisure and recreation
Quality of Life Outcomes Measures		
12-Item Short Form Health Survey (SF-12) **36-Item Short Form Health Survey (SF-36)**		Limitations in physical activities because of health problems Limitations in social activities because of physical or emotional problems Limitations in usual role activities because of physical health problems Bodily pain General mental health (psychological distress and well-being) Limitations in usual role activities because of emotional problems Vitality (energy and fatigue) General health perceptions
Quality of Life after Brain Injury (QOLIBRI)	√	Cognition Self Daily life and autonomy Social relationships Emotions Physical problems
Euro Quality of Life group health related quality of life on five dimensions (EQ-5D)		Mobility Self-care Usual activities Pain/discomfort Anxiety/depression

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Chapter 3: Transforming Research and Clinical Knowledge in Geriatric Traumatic Brain Injury (TRACK-Geri TBI) Pilot Study: The value and reliability of proxy informants

Abstract

Background. Older adults with pre-existing medical conditions are often excluded from participation in longitudinal TBI research, given concerns about inability to complete outcome assessments and validity of data collected. In order to support feasibility of inclusion of this population in TBI research, co-enrollment with a study partner may be valuable. The routine use of proxy informants in acute geriatric TBI research is uncommon and reliability has not been established.

Methods. A prospective longitudinal pilot study of older adults (age 65y+) were recruited from a level 1 trauma center within 72 hours of a mild TBI and co-enrolled with a study partner (SP) between March 2017-January 2018. Functional recovery was assessed among both the participant and the SP using Glasgow Outcome Scale Extended (GOSE), Activity of Daily Living (ADL) and Instrumental ADL (IADL) outcomes at 2-weeks, 3-months, 6-months, and 12-months. Descriptive statistics, follow-up completion rates, percent agreement and agreement within 1-point among functional recovery outcomes were analyzed and stratified by participant pre-injury cognition.

Results. N=30 participant/study dyads were included in analysis. 36% had pre-injury MCI/dementia. Time point completion was increased at each time-point as a result of co-enrollment with the SP. Agreement within 1-point among all functional domains was high: 78-100% with statistical significance in ADL agreement between those with pre-injury normal cognition (NC) (100%) vs. MCI/dementia (80%) $p<.005$. There was more variability in GOSE

score differences in MCI/dementia group. Participants rated themselves as higher functioning compared to SP on all functional domains regardless of cognitive status.

Conclusions/Implications. Older adults continue to be underrepresented in TBI research. Research is feasible among medically complex older adults, and the inclusion of a study partner improves longitudinal follow up. Study partner reports of functional outcomes may improve the quality of data by accurately capturing functional recovery among participants, especially among those with pre-existing cognitive impairment and improve feasibility of retaining medically complex older adults with TBI in longitudinal research.

Keywords: traumatic brain injury, aged, geriatric, functional recovery, proxy report, functional outcomes.

Introduction

As the U.S. population continues to grow and age, the number of older adults who experience a TBI will continue to increase (Gardner et al., 2017; Sendroy-Terrill et al., 2010). Approximately, 99% of older adults who present to trauma centers with TBI have pre-existing conditions, most commonly Alzheimer's disease and related dementias, depression, diabetes, cardiovascular disease, and/or pulmonary disease (Albrecht, Kiptanui, et al., 2015; Albrecht, Liu, et al., 2015; Hawley et al., 2017; Kumar et al., 2017). These conditions are often exclusionary criteria for participation in longitudinal TBI research, given concerns about inability to complete outcome assessments. This approach limits our knowledge of recovery trajectories among older adults.

In order to support feasibility of inclusion of this population in TBI research, co-enrollment with a study partner may be valuable. While proxy informants or study partners are routinely required in dementia research to report on function, cognitive, and quality of life (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004; Howland et al., 2017; Tay et al., 2014), the routine use of proxy informants in acute geriatric TBI research is uncommon and reliability has not been established. Our study aims were to 1) investigate the value of co-enrollment with a study partner for improving follow-up completion 2) evaluate level of agreement between participant and study partner report of functional recovery, stratified by pre-injury cognitive status.

Methods

Design and protocol approval

The pilot TRACK-GERI study is a single-site prospective observational cohort study conducted at Zuckerberg San Francisco General Hospital (ZSFG). This pilot study was approved by the Institutional Review Board of the University of San Francisco, California (CHR# 12-09465) and all study participants and study proxy's provided informed consent or surrogate consent.

Participants and enrollment

A convenience sample of older adults (age 65y+) were recruited from our level 1 trauma center within 72 hours of a mild TBI and co-enrolled with a study partner (SP) between March 2017-January 2018. Participants were eligible for the pilot study if they presented to the ED with a traumatic brain injury, received head CT, and had at least one of the following American Congress of Rehabilitation Medicine criteria: any loss of consciousness, peri-traumatic amnesia, alteration of mental status at time of trauma, or focal deficits. Participants who have severe pre-existing cognitive impairment, no study partner, unable to self-consent and no designated surrogate or caregiver for consent, prisoner, patient in custody, pregnant, or non-English speaking were excluded from the study.

Data Collection

Outcome measures were collected at 2-weeks, 3-months, 6-months, and 12-months post-TBI among all participants and their SP using a combination of TBI Common Data Elements (Thurmond et al., 2010) and validated dementia outcome assessments. Study participants and SP's were contacted at each time point and given the option to conduct the follow up assessment either in-person, or over the telephone.

Measurements

Pre-injury characteristics and demographics

Demographics, pre-existing conditions, and injury characteristics were collected at the time of the injury, during the baseline interview with study participants, and via chart review in the patient medical record. Follow-up timepoint completion between the participant and the SP was assessed at 2-weeks, 3-months, 6-months, and 12-months post-injury.

Pre-injury cognition was measured via retrospective SP interview using the Clinical Dementia Rating Scale (CDR). The CDR semi-structured interview was conducted at baseline with the study proxy only and a global score was calculated: normal cognition (CDR=0), mild cognitive impairment (MCI) (CDR=0.5), mild dementia (CDR=1), moderate dementia (CDR=2), and severe dementia (CDR=3).

Outcome Assessments

The participants global level of function was assessed at 2-weeks, 3-months, 6-months, and 12-months post-TBI via structured interview with both the participant and the SP using the Glasgow Outcome Scale-Extended (GOSE). The GOSE scores are based on an ordinal score 1-8 ranging from death (1) to Upper Good Recovery (8). Time-point completion was defined as completion of GOSE. Percent agreement among participant and SP GOSE scores was defined as within 1 GOSE score difference. The participants Activity of Daily Living (ADL), Instrumental ADL (IADL), and mobility was assessed at 2-weeks, 3-months, 6-months, and 12-months post-TBI via interview. Both the participant and the SP were asked if the participant needed help or had difficulty with four activities of daily living (ADLs): bathing, dressing, eating, and toileting; and seven instrumental ADLs (IADLs): shopping, housework, meal prep, medications, finances, phone calls, and transportation; and five mobility questions: ability to get in/out of a chair, walk up 10 stairs, lift 10lbs, assistive device used, and walk around their home independently. Each of the respective questions in the ADL, IADL, and mobility domains were totaled and domain scores between participant and the SP were compared at each timepoint.

Statistical Analysis

All analyses were conducted using Stata SE version 16.0. Descriptive statistics, follow-up completion rates, and percent agreement between participant and SP of Glasgow Outcome Scale-

Extended (GOSE; ordinal score 1-8) scores and Activity of Daily Living (ADL)/instrumental ADL/mobility impairment (needing help or having difficulty with 4 ADL, 7 IADL, 5 mobility questions) were analyzed at 2-weeks, 3-months, 6-months, and 12-months post-injury, stratified by pre-injury cognition (normal vs. MCI/dementia). Kappa agreement was not calculated due to small sample size. Chi-square analysis were performed for differences in time-point completion between participant only versus dyad, and among overall ADL, IADL, and mobility domains between those with pre-injury normal cognition and MCI/dementia.

Results

Thirty participant/study partner dyads were enrolled over the one-year study period. Baseline characteristics are shown in Table 3.1. The SP relationship to participants was: 43% adult children, 33% spouse/significant other, 17% friend, and 7% other family members. Of the 25 participants with completed pre-injury CDR interviews, 36% had pre-injury MCI/dementia. Time-point completion was increased at each time-point as a result of co-enrollment with the SP: 77% of participants vs. 93% of either participant and/or SP at baseline; 54% vs. 85% at 2 weeks ($p<.005$) ; 58% vs. 73% at 3-months; 54% vs. 73% at 6-months; 56% vs. 64% at 12-months, respectively. Reasons for loss to follow-up (LTF) are shown in Figure 3.1.

Glasgow Outcome Scale-Extended

Percent agreement between participant and SP for GOSE score was high. Across all time points, percent agreement was 90% overall; 94% among those with pre-injury normal cognition, and 85% among those with pre-injury MCI/dementia (See Figure 3.2). Overall, when dyads were not in perfect agreement, the majority of participants regardless of cognition, rated themselves higher on the GOSE compared to SP; 57% (n=8) among pre-injury normal cognition participants and 56% (n=5) among pre-injury MCI/dementia. When GOSE agreement was not perfect or within 1-point,

10% (n=2) participants with normal cognition rated themselves 2-points higher compared to SP. Among the participants with pre-injury MCI/dementia, 11% (n=1) rated themselves 2-points lower, and 22% (n=2) rated themselves 3-points higher compared to the SP.

Activities of Daily Living

Across all time points, perfect participant-partner agreement for ADLs was 72% and 91% when agreement was within 1-point. Overall, ADL agreement was higher among those with pre-injury normal cognition (79% perfect agreement; 100% within 1-point ($p<.005$)) compared to those with pre-injury MCI/dementia (65%; 80% within 1-point.) (See Figure 3.2). Among dyads with normal cognition when agreement was not perfect, ADL agreement varied by one ADL. Among dyads with MCI/dementia when agreement was not perfect, total ADL agreement was more variable with differences in 1-4 ADLs.

Instrumental Activities of Daily Living

Overall, IADL perfect agreement was significantly higher among those with pre-injury normal cognition (61%) compared to those with pre-injury MCI/dementia (15%) ($p<.005$). When agreement was not perfect, 67% of proxies for those participants with pre-injury normal cognition rated the participant more impaired compared to participant. Among the dyads with MCI/dementia, who were not in perfect agreement on number of IADL help/difficulty, 91% (n=10) of participants reported they required less help/difficulty compared to their proxy. A majority of participants reported not needing any help/difficulty with any IADL while their informant identified at least 1-3 IADLs.

Mobility

Agreement on assistance with mobility was higher among those with pre-injury MCI/dementia (67% perfect agreement; 83% within 1-point) compared to those with pre-injury

normal cognition (61% perfect agreement; 78% within 1-point). Among those with normal cognition, 80% of participants reported needing less assistance with mobility compared to their SP's report of their mobility.

Discussion

This analysis among older adults with TBI demonstrates that research in this population is feasible despite the inclusion of medically complex older adults with pre-existing conditions and neurological disease, and that longitudinal follow-up among this frail and vulnerable population can be improved with the inclusion of a study proxy. Inclusion of a SP improved follow-up completion at all timepoints. Particularly at the 2-week timepoint, follow-up with the participant alone was 54% and having access to both the participant and the SP significantly increased follow-up to 85%. Overall, co-enrollment with a SP in this pilot study resulted in improved timepoint completion at all time-points. Remarkably, our 12-month timepoint completion was 64%, which is comparable to the 18-site Transforming Research and Clinical Knowledge (TRACK-TBI) Phase 1 Mild TBI cohort of older adults (66.5%), which enrolled mostly younger, healthier participants. (Nelson et al., 2019)

Our analysis demonstrates high agreement on GOSE, ADL, and IADL despite differences among both cognition groups. However, among all functional domains there were agreement differences observed based on pre-injury cognition. Overall, when there was not perfect agreement between participants and SP on the GOSE, the majority of both participant groups rated themselves as higher functioning compared to their SP. Although there are no other studies that examine participant-partner report of the GOSE in this population, the GOSE is validated as a proxy-reported measure, which allows for the instrument to be completed by a SP among those severely injured patients. However, the GOSE has yet to be validated among older adults with pre-existing cognitive impairment and mild TBI.

Our findings are consistent with other cohort studies among older adult populations that assess physical function. A cohort study analyzing ADL and IADL agreement among acutely hospitalized older adults with and without cognitive impairment demonstrated moderate to good levels of agreement (70-90%, $p<.001$) on IADL functioning. Our study's findings were similar in that the groups with normal cognition had greater levels of agreement compared to those with MCI/dementia (Pol, Buurman, de Vos, & de Rooij, 2011). A prospective cohort study by Maxwell et. al assessed proxy report of older adults' pre-injury function and frailty found the agreement was high with those of older adults for three screening tools (VES-13, mBI, and LSA; ICC$\geq$ 0.80) (Maxwell, Dietrich, Minnick, & Mion, 2015). Howland et al. study among older adults with varying degrees of cognitive function found participant-proxy-rated IADLs were highly correlated at baseline and at 1 year follow up (Howland et al., 2017).

A Medline review which identified 24 studies that used proxy data among older adults with and without cognitive impairment found substantial relationship between participants and proxies on measures of functioning related to both physical activities of daily living (PADL) and IADL (Neumann, Araki, & Gutterman, 2000). Several studies reported proxies identified more functional impairment, which is similar to our findings for IADLs and mobility. Additionally, they found that proxies described more limitations in functioning compared to reports from participants with dementia and was more marked for IADLs than other types of function. These findings suggest that proxy reports may be more sensitive to the full extent of disability in older adults, particularly those with cognitive impairment. Thus, proxy reports may not only improve timepoint completion in older adults but may improve the quality of the functional outcomes data that is collected.

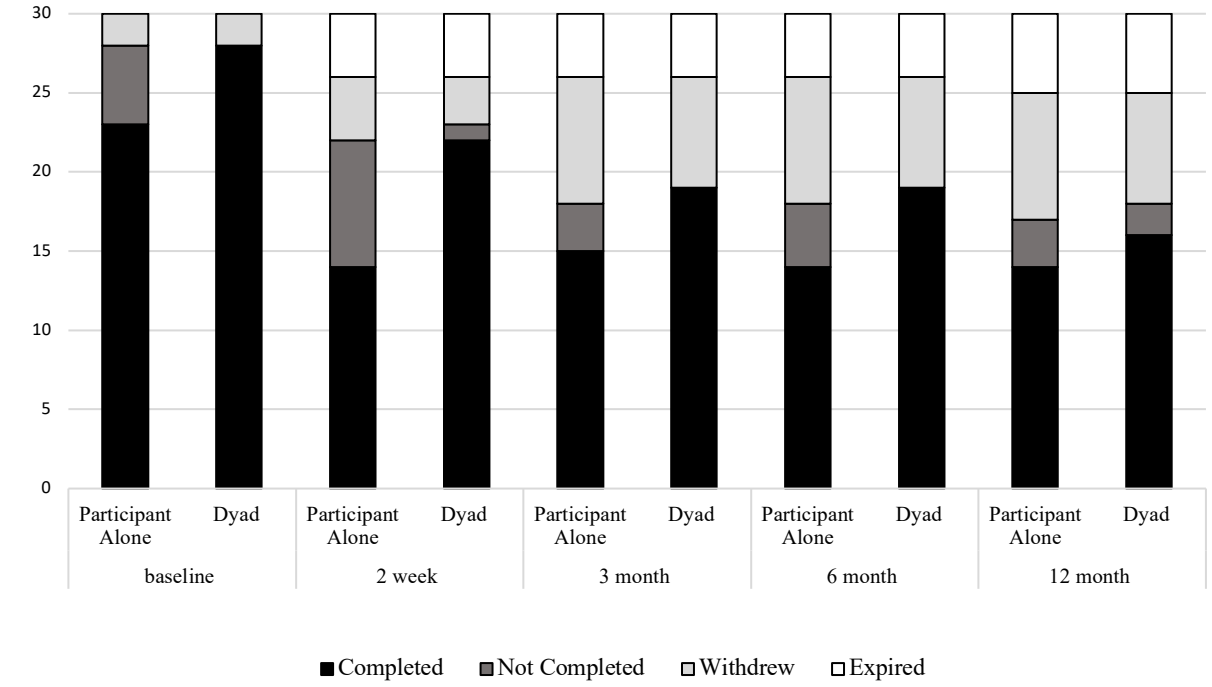
This pilot study has limitations, including small sample size, no kappa statistical analysis, conducted at a single-site trauma center, and study generalizability may be limited due to the

homogeneous sample for race and education. Additionally, participants with very severe pre-existing dementia were excluded. Future research could investigate co-residence, relationship to person, gender, and caregiving burden as there may be systematic differences in proxy responses which may depend on the nature of the relationship to the participant. Additionally, more systematic examination of these factors in large samples should be investigated. To the knowledge of the authors, however, this is the first study to report on agreement of longitudinal functional outcome reporting between older adults with acute TBI and a study partner.

Our pilot study findings suggest the inclusion of a study partner improves feasibility of retaining medically complex older adults with TBI in longitudinal research. Additionally, SP reports of functional outcomes may improve the quality of data by accurately capturing functional recovery among participants, especially among those with pre-existing cognitive impairment. We propose that clinicians and researchers may depend on proxy informants for obtaining health information especially when obtaining it from the participant is not feasible. The inclusion of proxy informants may help to better understand physical and cognitive function among participants with pre-exiting medical conditions pre-injury and post-TBI.

Table 3.1. Demographics, pre-existing conditions, and injury characteristics

Characteristic (Mean (range) or N (%))	*All Study Participants* N=30	*Pre-injury Normal Cognition* N=16	*Pre-injury MCI/dementia* N=9	*P Value*
Age, y	78.1 (65-98)	77.18	77.88	0.829
Female	10 (33%)	5 (31%)	3 (33%)	0.915
Caucasian	26 (87%)	14 (87.5%)	7 (78%)	0.396
Pre-existing medical conditions				
Hypertension	16 (53%)	7 (44%)	6 (67%)	0.271
Diabetes	6 (20%)	4 (25%)	2 (22%)	0.876
Lung disease	11(37%)	5 (31%)	4 (44%)	0.509
Heart disease	21 (70%)	11 (69%)	7 (78%)	0.629
Cancer	9 (30%)	4 (25%)	3 (33%)	0.656
Level of Education				
Some college or more	13 (43.5%)	12 (75%)	9 (100%)	0.812
High school or less	17 (56.5%)	4 (25%)	0 (0%)	
Living Status				0.207
Independent, lives alone	12 (40%)	5 (31.25%)	6 (67%)	
Independent, lives with others	12 (40%)	10 (62.5%)	3 (33%)	
Subacute SNF	1 (3%)	1 (6.25%)		
Unknown	2 (7%)	2 (7%)		
Employment				0.636
Employed	4 (13%)	3 (19%)	1 (11%)	
Retired	22 (73%)	10 (63%)	7 (78%)	
Disabled	2 (7%)	2 (12%)		
Unknown	2 (7%)	1 (6%)	1 (11%)	
Mild TBI (GCS 13-15)	28 (93%)	14 (87.50%)	8 (89%)	0.918
Loss of Consciousness (LOC)				0.362
No	2 (23%)	3 (19%)	3 (33.3%)	
Yes	17 (57%)	10 (62%)	4 (44.44%)	
Unknown	6 (20%)	3 (19%)	2 (22.22%)	
Post Traumatic Amnesia				0.093
No	5 (17%)		3 (33.5%)	
Yes	20 (67%)	12 (75%)	5 (55.5%)	
Unknown	5 (17%)	4 (25%)	1 (11%)	
Intracranial Trauma on CT	21 (70%)	12 (75%)	5 (56%)	0.317
Mechanism				0.172
Fall	23 (77%)	14 (88%)	6 (67.5%)	
MVA	6 (20%)	1 (6%)	3 (33.5%)	
Assault	1 (3 %)	1 (6%)		
Emergency Disposition				0.814
Discharged home	5 (17%)	3 (19%)	1 (11%)	
Admitted to ward	14 (47%)	6 (37%)	3 (33%)	
Admitted to ICU	11 (37%)	7 (44%)	5 (56%)	



Completed: GOSE completed at time-point by participant and/or partner.
Not Completed: Time-point completion not completed due to LTF reasons which included cognitive/neurological reason, non-neurological/physical reason, cognitively able but poor effort/refused/intoxicated, illness, and other/logistical.

Figure 3.1. Timepoint completion with reasons for loss to follow-up (LTF) for Participant Alone vs. Dyad

Functional Outcome			All Participants	Normal	MCI/Dementia	Chi² Coefficient	P-value
GOSE	Overall	**Dyad (N)**	**52**	**32**	**20**		
		% Perfect Agreement (%)	50	56	50	0.19	0.660
		% Agree within 1 GOSE score+ (%)	90	94	85	1.08	0.297
ADL	Overall	**Dyad (N)**	**44**	**24**	**20**		
		Perfect Agreement (%)	72	79	65	1.10	0.293
		% Agree within 1 point+ (%)	91	100	80	5.28	**0.021***
IADL	Overall	**Dyad (N)**	**36**	**23**	**13**		
		Perfect Agreement (%)	44	61	15	6.96	**0.008***
		% Agree within 1 point+ (%)	81	78	85	0.21	0.643
Mobility	Overall	**Dyad (N)**	**35**	**23**	**12**		
		Perfect Agreement (%)	57	52	67	0.68	0.410
		% Agree within 1 point+ (%)	86	87	83	0.08	0.771

+Combined perfect agreement and agreement within 1 GOSE score; Percent agreement within 1-point of the total score for each functional domain: ADL (0-5) IADL (0-8), mobility range (0-6)
*p-value statistically significant: $p<0.05$

Figure 3.2. Overall Functional outcome % agreement between participant and partner stratified by cognition

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Chapter 4: Feasibility and acceptability of a virtually adapted yoga and mindfulness program for adults with traumatic brain injury, stroke and their caregivers at a level 1 trauma center: A Quality Improvement Project

Abstract

Background. Individuals who live with a traumatic brain injury (TBI) and stroke may experience ongoing physical, cognitive, emotional, and behavioral disabilities post-incident. The impact of a TBI or stroke can affect caregivers who may experience ongoing anxiety, stress, disappointment, loneliness, and a sense of overwhelm. Evidence-based research suggests that adapted-yoga and meditation can offer ongoing supportive physical and emotional benefits to those with TBI, stroke, and their caregivers by providing opportunities to develop enhanced quality of life. Studies demonstrate that online delivery of yoga and meditation is a feasible and acceptable with no significant difference in satisfaction or overall improvement between in-person or online sessions.

Methods. This Quality Improvement (QI) project evaluated the feasibility, acceptability, and safety of delivering a 6-week, virtual, Yoga and Meditation program for adult TBI, and stroke survivors, and their caregivers at a level 1 trauma center utilizing the International Assessment tool for QI SQUIRE 2.0 guidelines. Participants were included in the QI project evaluation if they participated in a virtual 6-week Yoga and Meditation program between June 2020 and July 2021. Participant pre-and post-quantitative and qualitative feedback was evaluated for feasibility and acceptability of the program. Facilitator feedback was also collected to evaluate the feasibility and safety of delivering the program virtually.

Results. Among those who registered, 76% (n=35) attended at least one session and 66% (n=23) of participants completed the series of which 57% (n=12) were participants with TBI, 78% (n=7)

with stroke, and 80% (n=4) were caregivers. Overall participant satisfaction was rated 9.16 out of 10 [*SD* 1.32]. TBI and caregiver satisfaction was highest 9.3 [*SD* 1.10] compared to participants with stroke, 8.6 [*SD* 2.19]. Facilitator satisfaction was also high, 9.0 out of 10 [*SD* 0.71]. 100% of participants who completed the series reported they would participate in the virtual series again. Participant's experience of participating in the virtual yoga and meditation series was mostly positive, with all participants expressing at least one positive opinion about the program. Safety considerations were discussed and modified throughout the series to prioritize participant safety throughout the duration of the program offering.

Conclusions/Implications. A live, virtual yoga and meditation program is feasible, acceptable, sustainable, valuable, and a well utilized resource at a Level 1 Trauma Center. The virtual adaptation is safe and a cost-effective intervention and served as an ongoing resource for populations who have limited access to illness-specific wellness programs and psychoeducation. Program participation rates and positive qualitative feedback demonstrates benefit of continuing virtual program and demonstrated that the program added value to the care and recovery in several health domains.

Keywords: brain injury, yoga and meditation, health-related quality of life, recovery, quality improvement, virtual adaption, Love Your Brain

Background and significance

Individuals who live with a traumatic brain injury (TBI) and stroke may experience ongoing physical, cognitive, emotional, and behavioral disabilities post-incident (CDC, 2019). Additionally, the impact of a TBI or stroke can affect caregivers who may experience ongoing anxiety, stress, disappointment, loneliness, and a sense of overwhelm (Manskow et al., 2017; Shindo & Tadaka, 2020).

Depending on economic resources and insurance status, individuals after TBI and stroke may face health-related disparities and are less likely to have access to ongoing rehabilitation and treatment that may improve overall daily function. Limited follow-up care can impact quality of life for people months to years after injury (Seabury et al., 2018).

Evidence-based research suggests that adapted-yoga and meditation can offer ongoing supportive benefits to those with TBI, stroke, and their caregivers by providing opportunities to develop enhanced quality of life (Chauhan, Zeller, & Donnelly, 2020; K. Z. Donnelly, Goldberg, & Fournier, 2020; Miller, 2019). Participants in several studies describe physical benefits such as improved balance, strength, flexibility, and mobility, as well as reduced fatigue (Acabchuk et al., 2021; K. Z. Donnelly et al., 2020; Stephens, Van Puymbroeck, Sample, & Schmid, 2020; Walter, Van Puymbroeck, Bosch, & Schmid, 2020). Other studies describe the emotional benefits including reduced anxiety, depression, stress, and improved well-being and adjustment to injury (Acabchuk et al., 2021; Azulay, Smart, Mott, & Cicerone, 2013; K. Z. Donnelly et al., 2019; Silverthorne, Khalsa, Gueth, DeAvilla, & Pansini, 2012). Finally, research highlights quality of life benefits from yoga and meditation such as improved confidence, self-awareness, resilience, connection and belonging (Kyla Z. Donnelly, Linnea, Grant, & Lichtenstein, 2017; Walter et al., 2020). A literature review assessed the availability and accessibility of virtual yoga

and meditation programs as an effective post-rehabilitation therapy for people with TBI or stroke and their caregivers. Several studies demonstrate that online delivery of yoga and meditation is a feasible and acceptable with no significant difference in satisfaction or overall improvement between in-person or online sessions (Brosnan, Nauphal, & Tompson, 2021; Schulz-Heik et al., 2017).

The Zuckerberg San Francisco General (ZSFG) Hospital and Level 1 Trauma Center is recognized for its excellent Centers of Excellence in Neurotrauma and Stroke. The Traumatic Brain Injury (TBI) and Stroke Programs identified the need for a free-of-cost, ongoing wellness resource for patients and caregivers after TBI and stroke. Many patients who were seen at in-network clinics and support groups additionally reported struggling with limited programs to improve their health-related quality of life.

This Quality Improvement (QI) project evaluated the feasibility, acceptability, and safety of delivering a 6-week, virtual, Yoga and Meditation program for adult TBI, and stroke survivors, and their caregivers. The overall goal of the ZSFG program is to provide ongoing wellness resources, free of cost, by having this program available to community participants, to remove financial and/or geographic barriers to ongoing wellness, promote engagement in community, and improve quality of life after TBI and stroke, or as a caregiver.

Methods

This evaluation of the quality improvement project used the International Assessment tool for QI SQUIRE 2.0 guidelines (Ogrinc et al., 2016). The QI project evaluated a patient program offered by the UCSF Department of Neurosurgery at Zuckerberg San Francisco General Hospital.

Participants

Participants were included in the QI project evaluation if they participated in a virtual 6-week Yoga and Meditation program between June 2020 and July 2021. During the period of evaluation, five 6-week series were completed virtually. Participants were eligible if: 1) were at least 18-years old 2) lived in the Bay Area 3) had a history of a TBI of any severity or a stroke without severe aphasia 4) had not been told by a medical professional to avoid gentle exercise 5) were a caregiver for someone who experienced a TBI or stroke.

Setting

The ZSFG Neurosurgery department collaborated with the LoveYourBrain (LYB) Organization (https://www.loveyourbrain.com) to integrate LYB yoga-based tools into clinical services as an outpatient patient program. As a clinical affiliate, the program used the LYB yoga and meditation curriculum and adapted the skills-based group according to our participant demographic needs. Initially, this program was created for participants to complete in-person on-site at the ZSFG Wellness Center. Given the program could not be safely offered in-person due to the COVID-19 pandemic, the ZSFG Neurosurgery department adapted the LYB curriculum to be delivered virtually via Zoom. The program effort was led by a Neurotrauma Outcomes Coordinator (a Registered Nurse). The yoga and meditation were taught by four rotating certified yoga instructors, and the psychoeducation was led by a social worker.

Recruitment

Participants were referred to the Yoga and Meditation program by both ZSFG and out-of-network clinical providers. Program promotion and recruitment to the program was accomplished primarily through telephone outreach, listservs, and word of mouth.

Intervention

All facilitators completed a 20-hour comprehensive, yoga training developed by the LYB organization. The curriculum is tailored to people affected by brain injury, ensuring poses and sequences are communicated slowly, simply, and with repetition. The weekly psychoeducation class themes and discussion are aimed to address the challenges experienced after a brain injury. The six weekly themes included: feeling whole and acceptance, positive thinking, strength and resilience, social support and community, and gratitude (K. Z. Donnelly et al., 2020).

Participants interested in attending the free series contacted the Neurotrauma Outcomes Coordinator and received an online registration link to complete. If they met program eligibility requirements, they received the Zoom meeting information prior to the start of the series. The 6-week Yoga and Meditation series based on the LYB curriculum (originally 90 minutes) was modified to 75-minutes for the virtual adaptation. Each session had the same structure in this sequence: 5-minutes of breathing exercises, 35-minutes of gentle yoga, 10-minutes of guided meditation, and 25-minutes of facilitated discussion with psychoeducation.

Each session had at least two facilitators (one group discussion facilitator and one certified yoga instructor) present to ensure adequate support related to technical difficulties and participant safety during yoga instruction. The yoga instructor led the breathing exercises, yoga practice, and guided meditation, and the social worker or Neurotrauma Outcomes Coordinator facilitated the group discussion. The ZSFG Yoga and Meditation Program integrated the Neurotrauma Outcomes Coordinator and social worker roles within the ZSFG Neurosurgery department funding and compensated the yoga instructors as consultants for each session.

Measures and data collection

Participant self-reported quantitative and qualitative data was collected via electronic forms. To determine eligibility, participants completed a registration questionnaire. The registration survey took about 5-20 minutes to complete, depending on the participant type (TBI, stroke, or caregiver). Given the LYB program was primarily aimed towards the participation of TBI patients, the six clinical outcome measures included (QOLIBRI, Rivermeade, Satisfaction with Life, TBI-QOL Resilience, TBI-QOL Cognition, and Brief Symptom Inventory) were only applicable to those participants who experienced TBI. At the end of the program, if participants attended at least one session, participants were sent an electronic feedback survey. Feedback surveys took 15-25 minutes to complete and included the same clinical outcome measured at registration (TBI participants only) and feedback questions for all participants.

Outcomes

Participant pre-and post-quantitative and qualitative feedback was evaluated for feasibility and acceptability of the program. Facilitator feedback was also collected to evaluate the feasibility and safety of delivering the program virtually. Program feasibility and acceptability was evaluated utilizing the same definition described by the Love Your Brain organization when evaluating the acceptability and feasibility of their community-based yoga program (Donnelly et al., 2019). Program feasibility was evaluated by the total number of participants who signed up, participants who signed up and attended at least one session, participant series completion (defined as attending 4 or more sessions per series), repeated participation, and number of series cancelled due to low enrollment (less than seven participants registered).

Program acceptability was evaluated by participant and facilitator satisfaction using numerical scores ranging from 1-10, direct participant experiences though quotation answering the following open-ended questions: (1) How did the ZSFG yoga and meditation series add value to your care and/or recovery? (2) What was your experience like participating in the series virtually? (3) How can the virtual program be improved? Participants who did not complete the series were asked to respond to the question, "Why did you not attend or complete the ZSFG LYB program?"

Facilitators completed a feedback survey and answered open-ended questions related to their experience as a facilitator: (1) What was your experience like as a facilitator delivering the content virtually? (2) Do you feel the adaption of the LYB program adds value to the care and recovery of participants? (3) How can the virtual adaption of the program be improved? (4) Do you have any safety concerns about delivering this program virtually? (5) Do you have comments, questions, concerns about delivering the LYB program virtually?

Analytic Strategy

Feasibility and acceptability were evaluated among those participants who submitted both an eligibility form and feedback form. If participants completed the series more than one time, data from the first participation was used for data analysis, and subsequent times were excluded. If participants had missing outcomes data, they were excluded in the data analysis. To evaluate quantitative feasibility and acceptability data, descriptive statistics were used to report on acceptability and feasibility.

The qualitative data describing direct participant and facilitator experiences through quotation was summarized and synthesized using inductive content analysis; classifying the text from feedback responses into categories or themes. The analysis was led by the Neurotrauma

Outcomes Coordinator (RN) and team member (MG) who independently coded and identified themes. Both team members discussed potential themes and collaboratively defined and redefined themes. Additionally, themes identified in the qualitative evaluation of the LYB organization informed the final coding structure used to explore participants perceptions of their experience participating in the virtual program (K. Z. Donnelly et al., 2020).

Results

Participant characteristics

The majority of the participants who enrolled in the virtual ZSFG Yoga and Meditation program were TBI survivors (62%). As a result, the injury characteristics in Table 4.1 are limited for stoke patients. Among those participants with TBI, 80% had experienced their most recent TBI in the last 0-5 years, and 100% of stroke participants experienced their stroke in the last 1-5 years. Chronic symptoms as a result of injury was prevalent in 86% of TBI participants, and 89% of stroke participants. All caregivers who participated in the program were caregivers/family of a participant with TBI.

Feasibility

Over the course of the year when the program was offered, five six-week series were completed. Overall, 46 participants registered and 100% were eligible to participate. See Flow diagram of participants in Figure 4.1. Among those who registered, 76% (n=35) attended at least one session and 66% (n=23) of participants completed the series of which 57% (n=12) were participants with TBI, 78% (n=7) with stroke, and 80% (n=4) were caregivers. Each class had an average of 10 participants, with attendance ranging from 5-16 participants. 48 % of TBI participants signed up for the program once, and 52% signed up at least two or more times. Among those who signed up to participate more than one time, four (19%) participants

completed at least one series, two (9 %) completed three series, and one (5%) completed all five series offered. Among the stroke participants who signed up more than once, two (29%) participants completed two series, and one (14%) participant completed one series. Three caregivers (60%) registered and completed a total of five series.

Acceptability

Overall participant satisfaction was rated 9.16 out of 10 [*SD* 1.32]. TBI and caregiver satisfaction was highest 9.3 [*SD* 1.10] compared to participants with stroke, 8.6 [*SD* 2.19]. Facilitator satisfaction was also high, 9.0 out of 10 [*SD* 0.71]. 100% of participants who completed the series reported they would participate in the virtual series again.

Among the 12 participants who did not complete the series, 75% (n=9) were TBI participants, 17% (n=2) stroke, and 3% (n=1) caregivers. Nine participants responded to the feedback question of why they were unable to complete the series, and reasons for not completing the series included: scheduling conflicts with work or school (n=3), yoga was too easy/not challenging enough (n=2), personal reasons (n=1), yoga was not adapted to people with one arm paralysis (n=1), forgot meeting days (n=1), only joined one time as a guest to accompany family member with TBI (n=1).

Those who completed one series evaluated the program by answering three open-ended questions. Participant's experience of participating in the virtual yoga and meditation series was mostly positive, with all participants expressing at least one positive opinion about the program, and one-third articulating something negative about the program. Key themes were synthesized based on participant feedback and depicted in Figure 4.2 as a tree map showing both positive and negative feedback representing frequency of each category. Participant's feedback on how the

program could be improved expressed a desire to continue the program free of cost and to offer it more frequently with longer sessions.

All facilitators reported that the program added value to the care and recovery of the participants and overall reported their experience facilitating the series was positive. Facilitators felt the virtual adapted yoga was more accessible to participants especially since they were able to practice in the comfort of their home, felt supported by additional staff present at each session, and expressed gratitude for the technology used to be able to offer this program.

Program modifications

Prior to the COVID-19 pandemic, the ZSFG Yoga and Meditation Program was offered one-time in person onsite at the community wellness center in the hospital. The in-person pilot program had its own set of challenges such as increased facilitator time to set up and clean up, and commuting and parking for participants, which were mitigated by offering the program virtually because of the COVID-19 pandemic.

To offer the program virtually, modifications were made. The curriculum was designed to be 90-minutes in length, with yoga sequences that were primarily done standing with modifications available for sitting. For the first virtual series, the length of each class was adapted to be only 75-minutes to reduce screen time and reduce Zoom fatigue. The yoga was taught as a seated yoga sequence which was simpler, safer, and easier for all participants to follow. Additionally, this modification only required the need for one yoga instructor and one facilitator, which was more cost-effective. It was helpful to have one yoga instructor and one psychoeducation facilitator at each series; the psychoeducation facilitator was the designated person to help with any technical questions and challenges participants had during each class.

Program Safety

Safety considerations were discussed and modified throughout the series to prioritize participant safety throughout the duration of the program offering. To be eligible, participants were asked to confirm they have not been told by a medical professional to avoid gentle exercise. At time of registration, participants were required to provide an emergency contact and address of where they were planning to engage in the virtual yoga. In case of an emergency, the instructor could respond timely and appropriately. Prior to participation, and weekly during each series, reminder emails were sent to participants ensuring they participated in a chair that did not have rollers. Yoga instructors, throughout the yoga portion of class, would check in with participants to ensure they were feeling okay during the movement portion of the class. Initially, at least 2-3 staff members were present to help manage any technical difficulties, help participants with their set up, and to be an extra staff to observe participants during the movement portion of each series. After staffing several sessions, the program staff felt comfortable with having just two staff present at each series.

At the end of the program, as a part of the feedback questionnaire, facilitators were asked if they had any safety concerns about delivering the program virtually. Four of the five instructors (80%) did not have any concerns. One yoga instructor specifically felt we did a "good job with screening participants, getting their contact info & emergency contacts, teaching safely, and giving a lot of instructions and guidance." Another instructor "appreciated that there were several staff on the calls so that staff can watch clients while the teacher is demonstrating a pose. Teaching the chair poses also felt more safe than mat movements, as there is more visibility of the participants." One facilitator expressed concern about "how to respond if someone loses consciousness or presents another risk and would like more clarity about what to do and what our

responsibility is as a facilitator". Throughout the time the yoga program was offered, one participant who had pre-existing orthostatic hypotension expressed feeling dizzy during the yoga sequence. He was sitting on the couch and reported slipping onto the carpeted floor. The group facilitator ensured he was okay and able to resume participating in the yoga and group discussion. After the class ended, the Neurotrauma Outcomes Coordinator contacted his emergency contact to ensure he was safe and feeling well. This process demonstrated our safety plan was adequate and feasible in ensuring participant safety during each session.

Discussion

This QI project evaluation suggests that offering a virtual Yoga and Meditation program for those affected by brain injury or stroke and their caregivers is feasible and acceptable. The success of the program, driven by the ongoing program evaluation and pivots, and program participation rates demonstrate the benefit for continuing a Yoga and Meditation program as a wellness resource for those affected by brain injury. The majority of participants were 0-5 years post injury and 86-89% continued to have ongoing symptoms related to their injury suggests that offering a Yoga and Meditation program after the acute phase of the injury may be beneficial to recovery trajectory. Participant feedback demonstrates the program added value to the care and recovery in several domains: physical, mental/emotional, community, and resilience with ease of participation virtually. The negative feedback received by participants was related to frustration with having technical difficulties with home equipment, finding it challenging to focus virtually, and missing in-person interactions. Research demonstrating perceived barriers to online yoga and meditation sessions include: technical challenges including WiFi connection, computer / application unfamiliarity, disruptive noise, and setting which was similar to our QI feedback (Brosnan et al., 2021; Snyder, Silva, Whisenant, & Milbury, 2021).

Strengths of the QI project included the inclusive eligibility requirements and ongoing adaptations throughout each series offering. Additionally, this program was available and accessible to participants during a time where social isolation and reduced movement may have been more prevalent due to the COVID-19 pandemic and restrictions. This program provided an inclusive and safe space for participants to continue to process their injury and learn tools and physical movement that is adaptable despite ongoing symptoms post-injury or stroke, as well as for caregivers who are supporting those affected by brain injury. This program provided the opportunity for participants and caregivers to engage in wellness activities together. This may be one of the only free of cost Yoga and Meditation programs that is offered virtually, taught live, and facilitated by brain injury trained yoga instructors with psychoeducation for this population. The program allowed for participants to repeat each series which promoted a sense of community and an ongoing opportunity to continue to engage in integrative complementary therapies. Additionally, this program was inclusive by opening registration to those participants affected by stroke and adults over the age of 70 (LYB exclusion).

This program will continue to be offered as an ongoing virtual program and allow participants to participate as desired. Program pre- and post-quantitative and qualitative data will continue to be collected, and outcome measures will be modified to ensure the same outcome measures are collected for all participants regardless of injury type allowing outcome measures to be analyzed similarly for all participants to explore the efficacy of program.

The virtual adaptation was more cost-effective given facilitation time was reduced virtually and the program only required one yoga instructor at each session. Additionally, offering the program virtually mitigated the need to find a space within the hospital to offer this series, which had potential to limit the time and frequency of offering the series. This program

would have not been feasible without the financial support from the ZSFG Neurosurgery department and their support with paying for yoga instructor consultants.

Limitations

Limitations of this QI include the outcome measures utilized in the pre-and post-series surveys. TBI participant feedback forms included seven clinical outcome measures that were long in nature. Given the stroke participants' forms did not include clinical outcome measures, it was not possible to determine efficacy of the program for both TBI and stroke participants. Future series surveys will be reconsidered to shorten the outcome measures and find outcome measures that may be inclusive for all brain injury types. Given the convenience sample, selection bias is a possibility leading people to participate and have a more positive or negative experience of the program. Additionally, this program may have not been accessible to those who do not have internet, or the mental capacity to learn technology like Zoom which limits their ability to participate.

Key Learnings

This quality improvement project has led us to the following conclusions. See Figure 4.3 for best practices for implementing a virtual yoga and meditation program.

- A virtual yoga and meditation program is feasible and acceptable among adults with TBI, stroke, and caregivers at a level 1 trauma center.
- Offering this program virtually is safe and an effective intervention for those with ongoing symptoms after TBI and stroke.
- Staffing a designated program lead is imperative to plan and coordinate series dates, manage consultant yoga instructor staffing, and lead program evaluation.
- Obtaining streamlined pre-and post-feedback is necessary for program evaluation.

- Participants who completed the program expressed this program added value to their care and recovery, specifically, in the realm of physical, mental / emotional, and community benefits enhancing resilience and ease of participation.
- Yoga and psychoeducation facilitators are engaged in the offering of the program and believe the program is beneficial to care and recovery of participants.

Conclusion

The virtual Yoga and Meditation program for participants with TBI, stroke, and caregivers is sustainable and is a valuable and utilized resource to the TBI and Stroke Program at a Level 1 Trauma Center. The program served as an ongoing resource for populations who have limited access to illness-specific wellness programs and psychoeducation. Given the population served by ZSFG is diverse, next steps include expanding the program to include Spanish and Cantonese speaking participants. To achieve ongoing programmatic and financial sustainability, the program lead plans to apply for grants to secure funds to pay trained yoga instructors and expand to additional languages.

Table 4.1. Sample demographics and injury characteristics, Total n=35

Characteristic	TBI (n=21) (N, % of sample)	Stroke (n=9) (N, % of sample)	Caregiver (n=5) (N, % of sample)
Age in years (*mean and SD*); (*min-max)*	47.3±14.3; *(22-69)*	55.11±16.3; *(29-73)*	64.6±10.5;*(48-74)*
Female	12 *(57)*	7 *(78)*	3 *(60)*
TBI severity		N/A	N/A
Mild	11 *(52%)*		
Moderate	5 (*24%)*		
Severe	5 *(24%)*		
Injury mechanism		N/A	N/A
Assault	2 *(9.5%)*		
Fall	5 *(24%)*		
MVA	6 *(28.5%)*		
Sports-related[1]	3 *(14%)*		
Other trauma[2]	5 *(24%)*		
Self-reported LOC		Unknown	N/A
Yes	13 *(62%)*		
No	3 *(14%)*		
Unknown	5 *(24%)*		
Time since injury			N/A
<12 months	7 *(33%)*	0 *(0)*	
1-5 years	10 *(48%)*	9 (100%)	
6-10 years	2 *(9.5%)*	0 *(0)*	
>11 years	2 *(9.5%)*	0 *(0)*	
Assistive Device*			
Yes	4 *(19%)*	4 *(44%)*	
Cane	3 *(14%)*	3 *(33%)*	
Brace	1 *(5%)*	1 *(11%)*	
Walker	1 *(5%)*	1 *(11%)*	
Wheelchair	0 *(0)*	2 *(22%)*	
Chronic symptoms from injury*			N/A
Yes	18 *(86%)*	8 *(89%)*	
PCS	11 *(52%)*	N/A	
Light Sensitivity	13 *(14%)*	1 *(11%)*	
PTSD	9 *(43%)*	1 *(11%)*	
Seizures	1 *(5%)*	0 (*0)*	
Hemiparesis	2 *(10%)*	5 *(56%)*	
Hemiplegia	0 (*0)*	2 *(22%)*	

[1]Includes sports-related, leisure-related, or crushing injury [2]Includes bicycle vs. auto, bicycle vs. ground, pedestrian vs. auto, motorcycle collisions, struck by or against an object and work related
*Some participants reported use of multiple assistive devices and/or chronic symptoms from injury.
LOC: Loss of Consciousness; PCS: Post-concussive syndrome; PTSD: Post-traumatic stress disorder

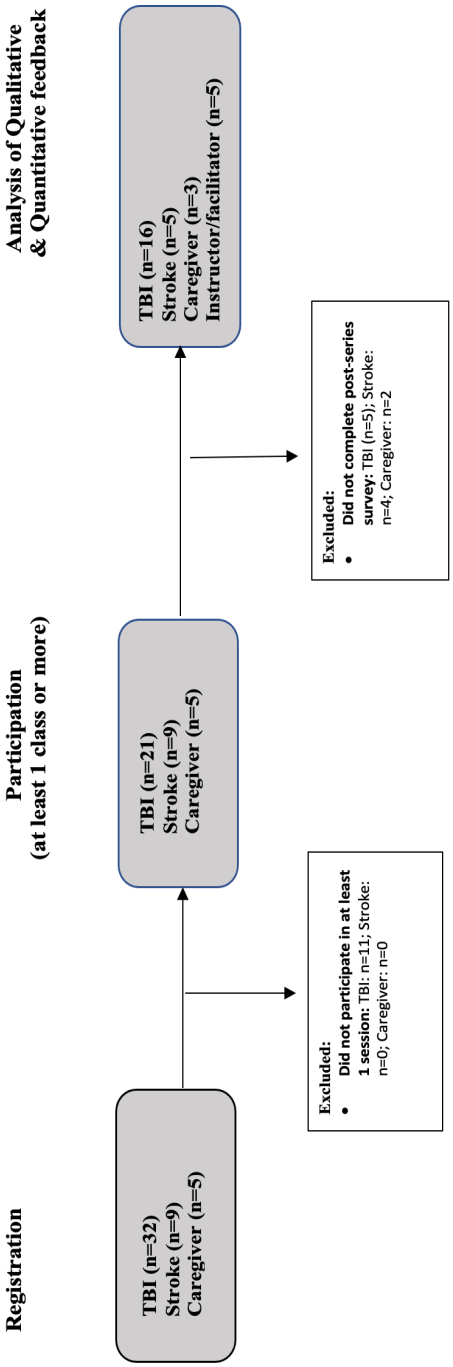

Figure 4.1. Flow diagram of participants included in program evaluation

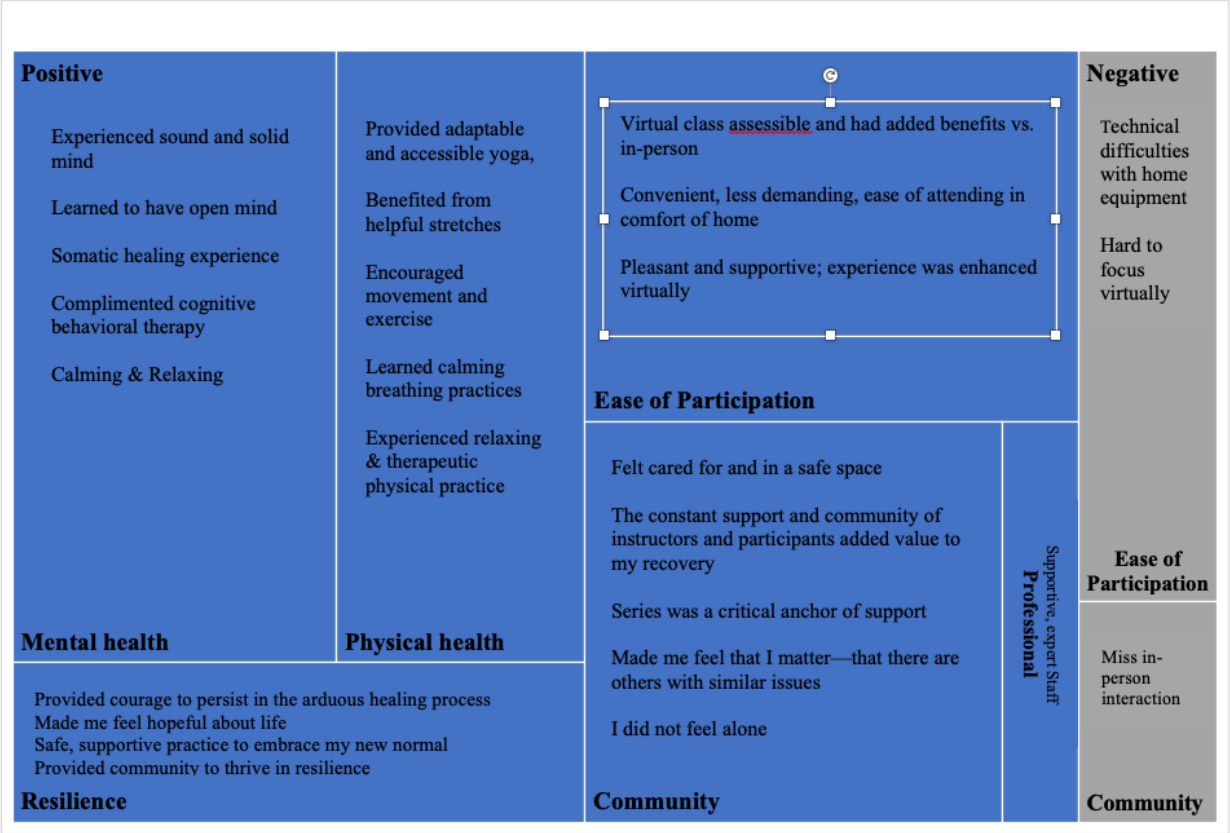

Figure 4.2. Tree map of participant feedback after completing 6-week series. Abbreviated quotes and themes were synthesized from feedback question "What was your experience like participating in the virtual series? *Many participants had experiences in more than one category." (TBI: n=11, Stroke=4, Caregiver=3)

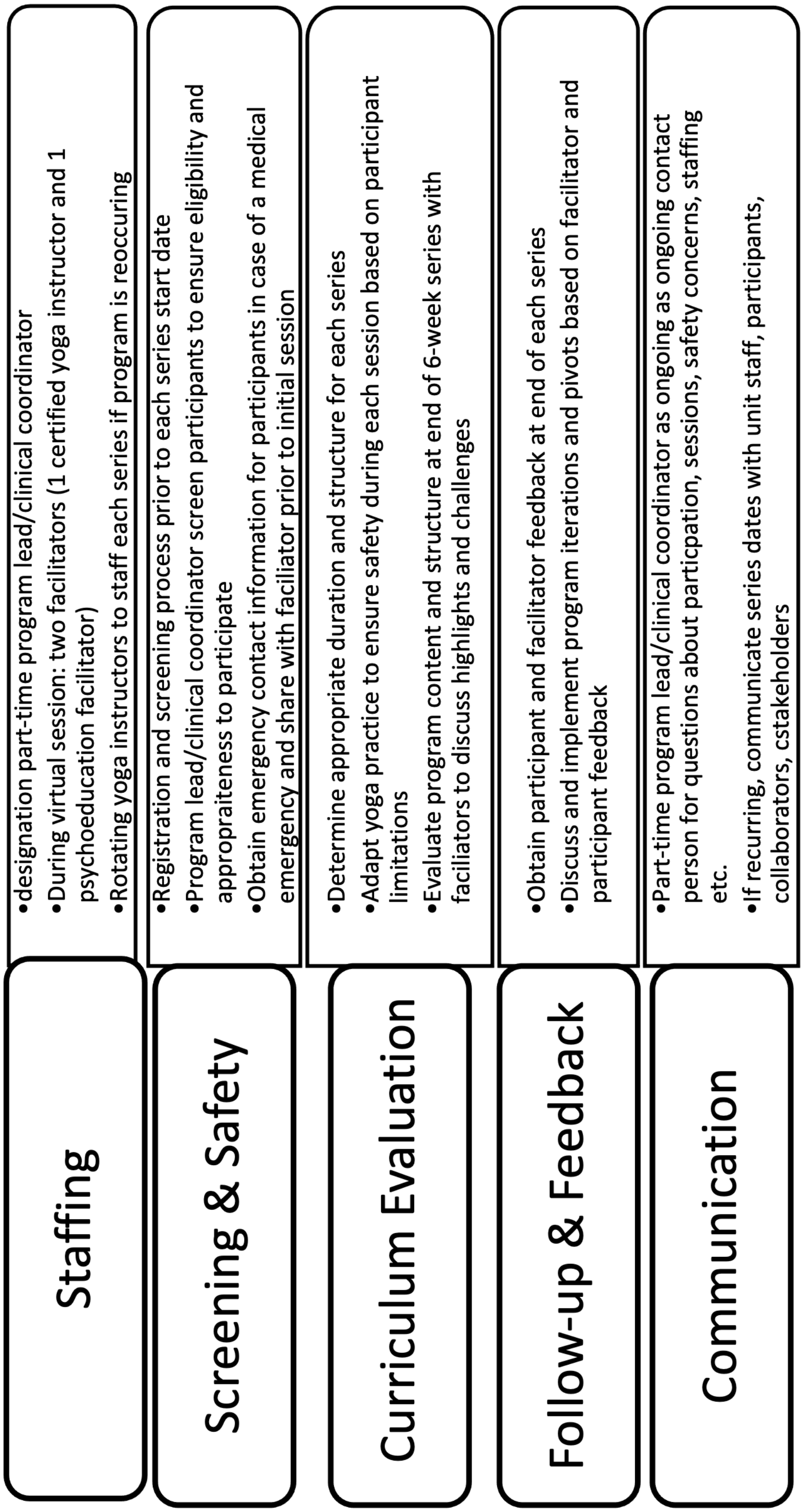

Figure 4.3. Best practices for implementing virtual yoga and meditation series

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Chapter 5: Discussion

This dissertation adds to the body of research exploring HRQoL, functional recovery, and the inclusion of older adult populations with TBI in longitudinal research. Additionally, this dissertation evaluates a Quality Improvement program that provides an ongoing wellness resource to adults affected by TBI, stroke, and their caregivers to improve HRQoL after TBI or stroke. The Quality Improvement evaluation describes the implementation of a program at a level-1 trauma center that is innovative and offers post-incident resources to a population who may have limited access after the acute phase of recovery. This dissertation uses both quantitative and qualitative evidence to evaluate the specific aims in each chapter. This program of research represents areas of literature that are less explored and contributes to existing gaps in the literature specifically in geriatric TBI research. A summary of the study's aims and a discussion of the significance of the findings will be discussed. Lastly, the implications for future research and nursing considerations will be described.

Summary of findings

AIM 1: The systematic review of the literature demonstrated variability in HRQoL and functional outcomes in older adults with TBI. Specifically, the six studies included in the review demonstrated methodological differences in inclusion/exclusion criteria, study administration processes, follow-up time periods, and the assessment of HRQoL and functional status making it difficult to synthesize results. Although five studies compared functional status and HRQoL outcomes of older adults versus younger adults and/or studied relationships between age and outcome, older adult representation in study samples was limited (Bouzat et al., 2019; Cheng et al., 2018; Haller et al., 2017; Thompson et al., 2020b). The five studies that evaluated age-related differences in outcome yielded differing results and conclusions.

AIM 2: The pilot study findings suggest the inclusion of a study partner improves feasibility of retaining medically complex older adults with TBI in longitudinal research at all timepoints, especially at the 2-week timepoint (54% vs. 84%; p<.005). The analysis demonstrated high agreement on functional recovery, specifically, on the GOSE, ADL(p<.005), and IADL (p<.005) despite differences in cognition. Among all functional domains there were agreement differences observed based on pre-injury cognition. Findings are consistent with other cohort studies among older adult populations that assess physical function. The groups with normal cognition had greater levels of agreement with their study partner compared to those with MCI/dementia. Additionally, both groups

AIM 3: The Quality Improvement evaluation of the virtual Yoga and Meditation program for participants with TBI, stroke, and caregivers demonstrates the program is feasible and acceptable. 66% (n=23) of participants completed the series. Overall participant satisfaction was rated 9.16 out of 10 [*SD* 1.32], and TBI and caregiver satisfaction was highest 9.3 [*SD* 1.10] compared to participants with stroke, 8.6 [*SD* 2.19]. Facilitator satisfaction was also high, 9.0 out of 10 [*SD* 0.71]. Qualitative participant feedback was positive; all participants expressed at least one positive opinion about the program, with one-third reporting negative comments related to only the ease of participation virtually (i.e., technology limitations, distractions) and missing in-person community engagement. All program facilitators reported that the program added value to the care and recovery of the participants and overall reported their experience facilitating the series was positive.

Significance of Findings

An approach to the research questions included in this dissertation was informed by the HRQoL model which explains five biological, social, and psychological levels of health which are useful in the formulation of strategies to improve function. This dissertation explores functional status and HRQoL outcomes and identifies knowledge gaps regarding functional status and HRQoL outcomes in older adults after TBI. Assessment of pre-and post-TBI functional status, using subjective and objective measures, is important to understand the effects the injury may have on an older adult after TBI. Among older adults with TBI, a physical symptom such as fatigue, poor coordination, or loss of balance may impair function related to performing activities of daily living, resulting in loss of independence, depending on how disabling the physical symptoms may be post-injury.

The systematic review of the literature is a quantitative analysis that analyzes a research area and theoretical concepts that has been minimally explored among older adult populations. Findings suggest the inclusion of older adults and further exploration of HRQoL outcomes at varying timepoints pre-and post-injury in TBI research is imperative. The analysis of the TRACK-Geri TBI pilot study investigates the value of co-enrollment to understand if the inclusion of a study partner can improve longitudinal follow-up among medically complex older adults with TBI. The value of a study partner and the assessment of proxy agreement is innovative and demonstrates use of proxy informants may improve representation in longitudinal research among this population by serving as an additional report in circumstances where participants are too frail or ill to perform follow-up timepoints. Additionally, including proxy reports may aide in the quality of data that is collected from older adults with pre-existing cognitive impairment.

The Quality Improvement project is both a quantitative and qualitative evaluation of a wellness program offered at a trauma facility demonstrated that the program is feasible and acceptable. The ongoing participation demonstrates sustainability and the delivery of the program ensures safety among participants. Overall, this project represents an investigation into feasible programs among populations where generalizable research is limited.

Study Strengths and Limitations

This original research provides a fundamental contribution to the body of literature for functional outcomes among older adults with TBI and pre-existing medical conditions. Older adults are underrepresented in TBI research and the generalizability of existing geriatric TBI studies are limited by exclusion criteria that excludes older adults with pre-existing conditions. The TRACK-Geri TBI pilot study is inclusive of older adult with pre-existing conditions, including pre-existing cognitive impairment. Findings of this study provide informative insight into ways to increase participation of those with medically complex older adults. Additionally, it is the first study among this population that investigates the value of a proxy informant and agreement between functional outcomes. The Quality Improvement project is pioneering as it is the first live, virtual, Yoga and Meditation wellness program that is offered by a trauma setting for adults with TBI, stroke, and their caregivers. Additionally, this program was available and accessible to participants during a time where social isolation and reduced movement may have been more prevalent due to the COVID-19 pandemic and restrictions. This program provided an inclusive and safe space for participants to continue to process their injury and learn tools and physical movement that is adaptable despite ongoing symptoms post-injury or stroke.

While this original research offers a unique exploration of understanding HRQoL and functional outcomes among older adults there are limitations to acknowledge. Limitations of the

systematic review of the literature yield potential for publication, search, and selection biases due to only searching two electronic data bases, limiting included studies to English language, published in the last 20 years, and review was only conducted by one reviewer. Factors such as the pilot study's small sample size and inclusion of a single-site trauma center were noted limitations of the pilot study analysis. Study generalizability may be limited due to the homogeneous sample specifically for race and education. The ability to assess efficacy of the Quality Improvement program using the pre-and post-series outcome measures was limited due to not streamlining the outcome measures to include both TBI and stroke participants. Given the stroke participants' forms did not include clinical outcome measures, it was not possible to determine efficacy of the program for both TBI and stroke participants. Given the convenience sample, selection bias was a possibility leading people to participate and have a more positive or negative experience of the program. Additionally, technology accessibility minimized the ability for those who do not have internet or the mental capacity to learn technology like Zoom.

Direction for Future Research

In order to improve HRQoL outcomes and provide patients who live with a TBI-related disability with appropriate rehabilitation services and access to post-injury care, applying the Wilson and Cleary HRQoL framework in clinical research when asking research questions in order to understand the holistic needs of this patient population (Ira B. Wilson & Paul D. Cleary, 1995) and to address the impact of physical function on HRQoL. Future inquiry into evaluating HRQoL outcomes among older adults with TBI is warranted especially to explore additional HRQoL domains like cognition, self-domains of health, daily life, autonomy, social relationships, emotions, and physical problems (Gross & Amsler, 2018; Nichol et al., 2010). The evaluation of HRQoL outcomes among this population will emphasize the important of

collecting patient-reported outcomes and an opportunity to continue to measure subjective HRQoL. More clinical research needs to be done to understand the effects of a TBI on well-being to understand how domains are affected throughout the life span.

Longitudinal research that is inclusive of older adults with pre-existing medical conditions would warrant more representative samples of older adult populations and should be prioritized in order to generalize research findings among this population. Additionally, future research deserves evaluating recovery outcomes in older adults with pre-existing conditions to generalize results to older adults given ~99% have pre-existing medical conditions. Future research could investigate pre-injury baseline characteristics among older adults with TBI amongst those with normal pre-injury cognition and with pre-injury MCI/dementia to understand clinically meaningful differences among both groups. Additionally, research in larger cohorts of older adult populations with TBI is necessary to validate the quality of proxy-reported outcomes compared to the participant and to assess systematic differences based on the nature of relationship or caregiving burden.

Lastly, among older adults with a TBI, it is known that older chronological age, pre-morbid and post-injury physical frailty, pre-existing comorbidities (including cognitive impairment), polypharmacy, and environmental factors may complicate recovery. Improving health-related quality of life post TBI could lead to better physical and mental functioning, improved quality of life, shorter hospital stays, quicker return to baseline social and leisure activities, and reduce costs to the individual, family, and/or health care system. Given our limited knowledge to understand TBI functional disability patterns among older adults, paired with the complexities of managing their care, there is an important need to close existing knowledge gaps. Utilizing the HRQoL theoretical models as frameworks to assess and manage function is an

approach to tackle the overwhelming need to improve recovery outcomes and provide evidenced based care throughout recovery after TBI.

Nursing considerations

Longitudinal prospective studies which include and follow older adults during the acute and rehabilitation phase of recovery is limited. This study provided evidence which contributes to increasing nursing knowledge as it relates to long-term recovery among adults and older adults with TBI. The systematic review aids to improve understanding between functional status and HRQoL outcomes and impact on the lives of older adults with a TBI-related disability during the various rehabilitation phases. This research can aid in understanding the heterogeneous nature of global outcomes for this populations and inform evidence-based management of post-injury care with the goal of improving function and HRQoL. Findings may increase understanding of the acute and chronic effects of a TBI on overall well-being helping to determine which HRQoL domains should be focused on and measured in older adults throughout the life span.

Findings explored in this study may contribute to improving nursing clinical knowledge which can aide to inform clinical care for adults and older adults after TBI. Additionally, dissemination of implementation strategies of Quality Improvement programs and participant feasibility and acceptability yields the opportunity for other trauma and outpatient settings to develop and provide such programs with guidance for adults with TBI, stroke, and their caregivers.

Given the complex medical, behavioral, physical, and cognitive sequelae of TBI among older adults, it is crucial that future nursing research and clinical practice among this population is conducted. For example, nurses caring for older adults with TBI can assess outcomes and incorporate measurement tools to obtain objective and subjective outcomes related to HRQoL,

and functional status. The nursing practice can also facilitate appropriate post-injury interventions and treatment while considering the strengths and limitations imposed on patients within the person, environment, and health/illness dimensions.

This program of research contributes to nursing research which can improve health care providers clinical understanding of physical, cognitive, emotional, and behavioral recovery trajectories and outcomes among these vulnerable populations. Given outcomes are variable and a TBI can affect physical, cognitive, and emotional domains, a holistic nursing approach using the HRQoL conceptual framework to disseminate findings is imperative. More specifically, understanding how TBI impacts functioning and HRQoL in older adults is important to inform managing acute care, rehabilitation, and community health needs.

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