

IDENTIFYING THE PHYSICAL ACTIVITY NEEDS OF OUTPATIENTS
WITH A TRAUMATIC BRAIN INJURY

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Traumatic brain injury (TBI) is a significant public health issue due to the incidence, complexity, and cost associated with treatment – emphasizing the need for effective rehabilitation programs. One mode of rehabilitation that has been demonstrated to improve health and reduce healthcare costs is health promotion programs (HPPs) that incorporate physical activity (PA). However, PA is not currently incorporated into the standard of care post-TBI. The purpose of this study was to conduct group interviews among individuals with a TBI undergoing outpatient rehabilitation to determine PA knowledge, attitudes, intentions, and barriers. Results will be used to develop a HPP that focuses on facilitating PA participation as part of the rehabilitation process. Seventeen participants completed a series of group interviews (2-3 people/group) regarding their PA needs. A qualitative research design was adopted and trustworthiness was established through triangulation of data (i.e., theoretical underpinning; multiple researchers and data-coders). A cross-case analysis was completed to identify themes and conceptual patterns. The main themes identified were (1) an inability to differentiate between PA and physical therapy, (2) a limited knowledge of PA health benefits and the relationship to rehabilitation, and (3) an interest in participating in a PA HPP as part of their rehabilitation. HPPs for outpatients with a TBI should educate individuals about PA, the associated health benefits, and the role PA plays in the rehabilitation process. A well designed HPP may increase the likelihood that individuals adopt and maintain PA as part of the rehabilitation process, thus reducing the risk of morbidity and mortality.

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by

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TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS.....	iii
LIST OF TABLES AND FIGURES.....	vi
INTRODUCTION AND LITERATURE REVIEW	1
Disability and Public Health.....	3
Theoretical Framework.....	5
Previous Research on the Efficacy of Health Programs.....	7
Preliminary Research in the Outpatient Rehabilitation Setting.....	12
METHODOLOGY	14
Participant Recruitment	14
Participants.....	15
Group Interview Procedures	16
Group Interview Questions.....	17
Qualitative Design	18
Qualitative Analysis.....	18
RESULTS AND DISCUSSION.....	22
Attitude to PA and Amount of PA Completed	22
Experiencing and Overcoming PA Barriers	25
Motivation and Importance of PA	27
Knowledge of PA.....	30
What Participants Hoped to Gain from PA.....	33
Participants’ Past, Present, and Future PA Levels.....	36
CONCLUSION.....	39
Appendices	
A. TBI GROUP INTERVIEW QUESTIONS.....	48
B. NOTICE OF INFORMED CONSENT	52
C. DEMOGRAPHIC QUESTIONNAIRE.....	58

D.	CODEBOOK LIST.....	61
E.	CODEBOOK ORGANIZED BY THEME.....	63
F.	THINK S.A.F.E. LIST.....	65
	REFERENCES.....	68

LIST OF TABLES AND FIGURES

	Page
Tables	
1. Participant Demographics	43
2. Participant and Group Characteristics	45
Figures	
1. Social cognitive theory	46
2. Transtheoretical model of behavior	47

INTRODUCTION AND LITERATURE REVIEW

Traumatic brain injury (TBI) is a significant public health issue in the United States due to the incidence, complexity, and cost associated with treatment. TBI is estimated to result in approximately 50,000 deaths in the United States per year. Additionally, 2% of Americans (5.3 million people) require long-term care and assistance in performing activities of daily living due to their TBI (Langlois, Rutland-Brown, & Thomas, 2004; Centers for Disease Control and Prevention, 2010; Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999).

TBIs can be caused by a bump, blow, jolt, or penetrating head injury that disrupts the normal function of the brain (Langlois et al., 2004). Due to the complex nature of the brain, myriad of associated (e.g., spasticity, seizures, apraxia) and secondary conditions occur post TBI (National Institute of Neurological Disorders and Stroke, 2002). Secondary conditions are health concerns that are not a direct result of the primary disability but rather are acquired at a later time due to lifestyle changes associated with the disability (Rimmer & Rowland, 2008). For example, secondary conditions associated with disability (specifically TBI) include changes in thinking, sensation, language, and/or emotions, as well as an increased risk for epilepsy, Alzheimer's disease, Parkinson's disease, weight gain, pressure sores, pain, fatigue, and depression (Rimmer & Rowland, 2008). The negative spiral of health caused by associated and secondary conditions is compounded as individuals are placed at a greater risk of developing chronic conditions (e.g., cardiovascular disease, diabetes, arthritis) post TBI.

Due to the high incidence and complexity of TBI (i.e., interaction of associated, secondary, and chronic conditions), considerable medical costs are incurred. For example, in 2000, direct and indirect (e.g., loss of productivity) medical costs for TBI totaled an estimated \$60 billion in the United States (Finkelstein, Corso, & Miller, 2006), with the average per-person

lifetime cost of care for TBI reaching as high as \$1,875,000 (National Institute of Health, 1998). Thus, researchers and clinicians are presented with a challenge to decrease the conditions resulting from a TBI as well as reducing the resultant healthcare costs (e.g., decreased utilization of medical services, medications for symptom management, frequency of re-hospitalization, or institutional placement). Public health initiatives, such as health promotion programs (HPP) that incorporate physical activity (PA), can play an important role in this rehabilitation process (Lollar & Crews, 2003; Rimmer & Rowland, 2008), although HPP are not currently part of the standard of care post TBI. Therefore, due to the gap in services provided, it is important that well-designed HPP are created (Rimmer & Rowland, 2008).

The present study is part of the first step toward a HPP development, following guidelines recommended by the United States Department of Health and Human Services (U.S. Department of Health and Human Services, 1999). Specifically, this project conducted group interviews with TBI patients enrolled in a comprehensive outpatient program to create an “audience profile” (U.S. Department of Health and Human Services, 1999) of the target population. The group interview is part of a PA “needs assessment” involving a series of studies (Driver, 2009; Driver, Ede, Dodd, Stevens, & Warren, 2010) that identifies and qualitatively describes TBI patients’ PA needs, as well as their PA knowledge, expectations, attitudes, motivation, barriers, and intentions (U.S. Department of Health and Human Services, 1999). For this study, PA is considered any planned movement or exercise (e.g., walking, resistance training, swimming, playing sports) or activity of daily living (ADLs) (e.g., household chores, gardening) (U.S. Department of Health and Human Services, 2008) that increases energy expenditure above resting levels. PA is a leading indicator of health and is associated with reduced morbidity and mortality (Kahn et al., 2002; U.S. Department of Health and Human

Services, 2008). Cumulatively, each part of the ‘needs assessment’ (i.e., group interviews, identification of PA barriers, and stage of change studies) (Driver, 2009; Driver et al., 2010) will be used to develop and implement a HPP into the current standard of care for individuals enrolled in a comprehensive TBI rehabilitation program. The aim of the HPP is to facilitate the adoption and maintenance of PA behaviors (proximal goals), as well as improve the rehabilitation outcomes and reduce the healthcare costs (distal goals) of individuals after a TBI.

Disability and Public Health

Traditionally, people with disabilities have been overlooked in public health initiatives, as the focus has been on preventing disabling conditions (e.g., drunk driving campaign to prevent TBI) rather than living a healthy life with a disability. Healthy People 2010 was the first federal document to address the importance of public health initiatives in the management of associated conditions and prevention of secondary conditions for people with disabilities (Lollar & Crews, 2003). Objectives addressing the health issues for individuals with disabilities in Healthy People 2010 include (1) reducing the number of individuals with disabilities that are institutionalized, (2) eliminating employment disparities between the general population and people with disabilities, (3) reducing environmental barriers to participating in society, and (4) integrating disability and health programs into state public health initiatives (Lollar & Crews, 2003; U.S. Department of Health and Human Services, 2000). Perhaps one of the most important objectives for people with disabilities is the recognition that disability and HPPs need to be included into public health initiatives. This is particularly critical among individuals with a TBI due to the growing need to reduce the effect of associated, secondary, and chronic conditions as well as the escalating medical costs (Finkelstein et al., 2006; Langlois et al., 2004; Lollar & Crews, 2003). Consequently, there is a call for public health initiatives to address the growing needs of

individuals living with a TBI (Driver, 2009; Driver & Ede, 2009).

The purpose of a HPP is to make possible behavior change (e.g., facilitate adoption and maintenance of PA behaviors), in attempts to improve health and reduce healthcare costs (Kahn et al., 2002; U.S. Department of Health and Human Services, 1999). A variety of HPPs in the past decade have been used to target people with disabilities including informational campaigns (e.g. accessible mammography), environmental modification initiatives (e.g. assessing fitness facilities for accessibility and accommodation), as well as training programs (e.g. lifestyle and behavioral changes) (Abdullah et al., 2004). Despite some promising results (Ravesloot, Seekins, & Young, 1998; Rimmer, Braunschweig, Silverman, Riley, Creviston, & Nicola, 2000; Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2003), HPPs that include PA are not currently integrated into the standard of care for individuals undergoing TBI rehabilitation, indicating a gap in the services provided. For example, TBI rehabilitation outpatients currently undergo education sessions on smoking, substance abuse, and physical safety during inpatient rehabilitation and recreational programs focusing on volunteering and community participation during comprehensive outpatient. However, PA educational sessions are not included in their standard of care post-TBI. Not only are rehabilitation outpatients not receiving PA education, they are also reporting completion of only 46 minutes of PA each week (Driver et al., 2010) which is only 31% of the recommended 150 minutes per week (U.S. Department of Health and Human Services, 2009), placing individuals at greater risk of morbidity and mortality (Driver, 2010). This lack of PA participation has been shown to worsen for long term outpatients with a TBI ($N= 384$) who reportedly completed only 40 minutes each week (27% of recommended amount) (Driver et al., 2009). Results emphasize the need for HPPs during comprehensive outpatient programs to increase PA participation across the lifespan post injury.

However, it is essential that if HPPs are to reduce secondary conditions and healthcare costs, strategies to facilitate the successful adoption and maintenance of health behaviors must be included. Based on previous research, the US Department of Health and Human Services (Kahn et al., 2002; USDHHS, 1999; USDHHS, 2000) suggests that certain informational, social, and behavioral strategies be incorporated in an attempt to increase an individual's self-efficacy (i.e., individuals' beliefs about their capabilities to produce effects (Bandura, 1997) and intention to be physically active (Kahn et al., 2002). Consequently, in order to implement a successful HPP, it is important that a behavioral theory and process for behavior change are in place to guide program development and increase the likelihood of behavior change (Driver, 2006).

Theoretical Framework

Two specific theoretical frameworks have been used extensively to direct HPP development and research, including social cognitive theory (SCT) (Bandura, 1977) and the transtheoretical model of behavior (Prochaska & DiClemente, 1983). Bandura's SCT (Figure 1) suggests that personal, environmental, and behavioral factors operate as determinants acting reciprocally to predict PA adoption and maintenance. Specifically, SCT describes an individual's ability to succeed in specific situations (Bandura, 1977), with self-efficacy (or "perceived capability") being a major determinant. For example, self-efficacy shapes how an individual approaches goals (e.g., being physically active for 30 minutes, 5 days/week), tasks (e.g., getting up at 6am to walk in the park before work), and challenges (e.g., walking when tired or raining) (Bandura, 1986). Health behaviors such as PA, smoking cessation, and dieting are typical behaviors that are affected by an individual's level of perceived self-efficacy that determines whether health behavior change will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and failures (Schunk, 1990).

Self-efficacy is thought to be one of the strongest predictors of behavior change, and is derived from four sources: past performance, vicarious experiences, social persuasion, and physiological/affective states (Bandura, 1986). An understanding of SCT is meaningful in the adoption of PA behaviors given that people with high self-efficacy are more likely to view difficult tasks as something to be mastered rather than avoided (McAuley, 1993) and that individuals will be more likely to take on a task if they believe they can succeed. For example, if individuals with a TBI views PA as something that is beneficial (e.g., as part of rehabilitation program) and necessary (e.g., reduce the risk of secondary conditions post injury) instead of a task that is difficult, it is more likely that it will become part of their lifestyles. SCT also predicts that enhanced self-efficacy can influence mood states (e.g., depression, anxiety, stress) and cognitions (e.g., perceived quality of life) in response to PA participation (Driver, 2006; Driver & Ede, 2009). However, as behavior is a dynamic phenomenon, it may take individuals several attempts to increase self-efficacy as they initiate or restart PA behaviors into a part of their regular routine (Grodesky, 2008; Prochaska & DiClemente, 1983), emphasizing the need for specific informational, social, and behavioral strategies to facilitate behavior change. This dynamic process of behavior change can be described using the Transtheoretical Model.

According to the transtheoretical model (Prochaska & DiClemente, 1983), an individual's intention and readiness to change their behavior will vary. The model (Figure 2) suggests that behavior change occurs as individuals progress linearly through specific stages and that change is not immediate, but rather a process (e.g., individuals do not suddenly decide to begin an exercise regimen) (Bandura, 1986; Lox, Martin, & Petruzzello, 2003). Individuals move through a series of five stages of behavior change (i.e., pre-contemplation, contemplation, preparation, action, and maintenance), and specific strategies have been demonstrated to facilitate change and

help individuals move through each stage (USDHHS, 1999). Movement through the stages is dependent on the individual's (1) perception of PA, (2) perception of themselves, and (3) environmental factors that influence PA behavior (Prochaska & DiClemente, 1983). In addition, self-efficacy is recognized as a critical variable in facilitating an individual's progression through the stages. For example, research among comprehensive outpatient patients with a TBI ($N = 28$) demonstrated that as an individual's self-efficacy increased so did their intention to be active (e.g., people in the pre-contemplation stage had lower self-efficacy than those in the contemplation stage, etc.). In addition, individuals who reported greater self-efficacy also completed more PA each week (Driver et al., 2010).

Therefore, when developing a HPP and building an "audience profile" of your target population (i.e., individuals with a TBI enrolled in a comprehensive outpatient program) it is important to understand their self-efficacy and intention so that appropriate informational, social, and behavioral strategies can be included into the HPP to facilitate behavior change (USDHHS, 1999). A HPP that does not demonstrate an understanding of the targeted population and fails to utilize the appropriate strategies and implements a "one size fits all" program is likely to fall short of the intended outcome (Lox et al., 2003; Prochaska & DiClemente, 1983). Studies that have successfully utilized informational, social, and/or behavioral strategies within a HPP to facilitate behavior change in people with disabilities provided guidance when researching for the current study.

Previous Research on the Efficacy of Health Programs

Research studies have demonstrated how HPP can help individuals manage and prevent secondary conditions and improve quality of life (Abdullah et al., 2004; Ravesloot, Seekins, & White, 2005; Ravesloot et al., 2007; Rimmer et al., 2000; Rimmer & Braddock, 2002; Rimmer,

Silverman, Braunschweig, Quinn & Liu, 2002; Stuijbergen et al., 2003). Specifically, HPPs that empower people with disabilities to better manage their health in addition to enabling their environment can have a significant impact on health, function, community participation, and quality of life (Rimmer & Rowland, 2008). Despite an increase in funding through the NIH and CDC supporting HPP research (Dunn & Blair, 2002; Rimmer, 2006), programs that include PA educational components remain a relatively innovative area in research.

Rimmer et al. (2000) examined the effects of a 12-week HPP on biomedical (e.g., cholesterol), fitness (e.g., cardiovascular fitness, strength, flexibility), nutritional (e.g., food checklist), and psychosocial health (e.g., social isolation, life satisfaction) in 35 urban African-American stroke survivors (M age = 53, SD = 8). The intervention consisted of multiple components: fitness and exercise instruction, nutrition education, and health behavior modification sessions. The exercise intervention consisted of a warm-up, aerobic activity, strength activity, and a cool-down, with duration lasting between 45-70 minutes per session. The nutrition portion of the intervention included three meetings a week, one hour per session, and was led by a registered dietician. The health behavior education classes met for 60-90 minutes per session, two to three days a week. Participants reported an improvement in physiological (e.g., strength, flexibility, weight, cholesterol) and psychosocial health (e.g., social isolation, life satisfaction, ability to manage self-care needs). These findings emphasize the potential benefits of a HPP for people with a TBI who typically exhibit reduced physical and psychosocial health.

In a separate study, Rimmer et al. (2002) investigated the impact of a 12-week HPP on the health (i.e., blood measures, exercise, nutrition, health behaviors) of 30 African American women (M age = 54.9, SD = 12.6) with Type 2 diabetes. In addition the researchers were interested in identifying if the removal of barriers (e.g., lack of transportation, fatigue, lack of

support) improved compliance to the program and consequently health. The university-based intervention consisted of educational sessions addressing diet, nutrition, and health behavior, with transportation provided to and from the intervention at no cost to the participants. Seventy-three percent of participants complied with the HPP, making significant improvements in health variables including total cholesterol and LDL-cholesterol levels, cardiovascular fitness, muscular strength, endurance, and knowledge of nutrition. Results highlight the importance of identifying and removing barriers (e.g., lack of transportation, fatigue, lack of support) to facilitate PA participation.

Stuifbergen et al. (2003) examined the effect of an 8-week HPP followed by a 3-month follow-up on the health behaviors (i.e., PA, spiritual growth, health responsibility, interpersonal relations, nutrition, and stress management) and quality of life of 113 women (M age = 46, SD = 10) with multiple sclerosis. The intervention was intended to engage the participants in (1) assessing their present health behaviors, (2) setting meaningful goals for change, and (3) addressing the barriers, resources, and skills necessary to change those behaviors. A two-phase intervention program was employed, utilizing educational and skill-building lifestyle change classes lasting 90 minutes a session for 8 weeks, supported by telephonic follow-ups for 3 months. Results indicated that participants reported improvements in health behaviors and health related quality of life. These findings emphasize that HPPs focusing on behavior change and utilizing follow-ups with participants may increase participants' beliefs in abilities, increase healthful behaviors, and quality of life.

Abdullah et al. (2004) investigated the impact of a 2½ day HPP followed by a 6-9 month follow-up program on the health promoting behaviors (i.e., health responsibility, PA, nutrition, spirituality, interpersonal relationships, stress management) of 162 Caucasian females (M age =

47) with self-reported disabilities. Support groups were provided for 6-9 months (i.e. one 2-hour session every month) post-workshop in an effort to encourage progress and help to eliminate barriers (e.g., transportation, scheduling, duration of the program) that may have been inhibiting their goals. Workshops consisted of health information (i.e., physical, social, emotional, spiritual, and health through meaningful activities) specific to individuals with disabilities, as well as the provision of activities to participate in (e.g., yoga, non-impact aerobics). The focus of the workshops included empowering participants to 1) understand and examine personal values, choices, and health, 2) gain knowledge about the five components of a healthy lifestyle (physical, emotional, social, spiritual, and health through meaningful activities), 3) increase their ability to practice healthy lifestyles, and 4) develop and adhere to a self-appointed plan for a healthful life. Workshops concluded with participants identifying two healthy lifestyle goals to work toward. Results from the 9-month HPP indicated that participants maintained improvements in health behaviors (e.g., health responsibility, PA, nutrition, spiritual growth, interpersonal relations, and stress management) as well as an increased likelihood that individuals would actively pursue health-promoting behaviors (e.g., PA, nutrition) in the future. It is important to note that these workshops were individualized (e.g., based on disability type, issues faced, health goals, etc), and did not utilize a generalized approach to program implementation, emphasizing the need to consider the unique characteristics of the target population.

Raveslout et al. (2005) investigated the effectiveness of an 8 week (2 days week) HPP on the secondary conditions (e.g., urinary tract infections, pressure sores, depression), days with poor health (e.g., physical or mental), and healthcare costs (e.g., healthcare utilization) of 188 adults ($M_{age} = 45, SD = 13.4$) with mobility impairments. Participants reviewed the Living

Well with a Disability program and completed exercises for each chapter with facilitators reviewing content, leading discussions, and assisting with written work. After completing the program participants reported a decrease in limitation due to secondary conditions. Importantly, participants were able to avoid experiencing secondary conditions for 12 months, resulting in an overall cost savings of \$807 per person due to reduced healthcare utilization (e.g., medication, hospitalization). The significant decrease in healthcare costs appears even more profound considering the overall cost reduction for a group of patients in a HPP. Results have promising implications for the efficacy of HPP in general due to the fact that people with disabilities account for approximately 47% of total medical expenditures in the United States (Max, Rice, & Trupin, 1996). Ravesloot et al. (2007) confirmed the effect of the HPP using the Living Well with a Disability program with a convenience sample of 246 (M age = 45, SD = 13.4) with mobility impairments. Participants reported experiencing a decrease in secondary conditions, unhealthy days, and healthcare utilization.

In conclusion, HPPs for people with disabilities that incorporate PA have demonstrated a variety of physical, psychosocial, and behavioral benefits including changes in self-efficacy (Stuifbergen et al., 2003), decreased depression, increased healthy behaviors and attitudes (Abdullah et al., 2004), less limitation from secondary conditions, fewer unhealthy days, increased functional mobility, and less healthcare utilization (Ravesloot et al., 2005). Each finding has implications for individuals with a TBI due to the conditions experienced and significant healthcare costs incurred. However, for HPPs to be successful a theoretical framework needs to drive program development and specific steps and strategies need to be in place to ensure behavior change.

Preliminary Research in the Outpatient Rehabilitation Setting

When attempting to define the characteristics of a certain population, the USDHHS recommends creating an audience profile made up of the attitudes, expectations, wants, intentions, perceived motivations, and barriers among the individuals in which the group is made up of. After this information is gathered, the audience profile of the targeted population is completed, with the long-term goal being to bring positive behavior change among the group members. This type of information gathering is especially important in the outpatient rehabilitation setting when identifying what matters most to participants (e.g., overcoming barriers, gaining PA knowledge). Prior research has been conducted using this type of profiling among adults with a TBI in two settings including 1) long term outpatient (47 months post injury), (Driver, 2009) and 2) recent outpatients (43 days post injury) (Driver, Ede, Dodd, Warren, and Stevens, in press). In the first study with long term outpatients (Driver, 2009), the barriers for individuals with a TBI were identified, as well as the self-reported PA level, and importance placed on PA. 192 participants completed a short survey which included information on level of PA post injury, barriers to PA participation, and interest in starting a PA program. Results indicated that: 1) participants were highly motivated to exercise as 84% of the sample indicated they wanted to start an activity program if one provided, 2) individuals felt it was “very important” to be good at PA, and 3) participants identified, on average, 6 common barriers to participation. Perceived barriers included: 1) lack of assistance to help with PA (48%), 2) exercise making the condition worse (42%), 3) lack of transportation (40%), 4) the belief that exercise would not benefit their condition (46%), 5) cost of an exercise program (38%), and 6) lack of an accessible facility (19%). It was also noted that participants were completing, on average, an insufficient amount of PA (i.e., 46 minutes), despite demonstrating a strong desire to

be PA. This lack of PA was attributed to participants' perceived inability to overcome the significant number of barriers reported by participants. Because the results from this study identified the type of barriers faced by outpatients in a rehabilitation setting, subsequent research in the same environment has revolved around incorporating strategies to overcome outpatient barriers to facilitate PA.

In 2011, Driver et al. (Driver, Ede, Dodd, Warren, & Stevens, in press) investigated self-reported PA level, barriers to PA participation, importance placed on PA, and readiness to be active in 28 individuals with a recent TBI enrolled in an outpatient rehabilitation program (M age= 44.11, $SD = 16.23$). Results indicated that participants described themselves as being in the "action" stage of PA behavior despite only completing an average of 46 minutes PA per week. Participants of the study also reported an average of 2.25 out of nine possible barriers (compared to 6 in the previous study). Results also indicated that 85.7% of participants believed that PA was important and 73% reported a desire to enroll in PA program.

Consequently, outcomes from previous research indicate that individuals with a brain injury are: 1) willing to participate in a PA program if available, 2) lack knowledge about the benefits of PA and PA guidelines, and 3) unaware of the number of barriers to be faced post-discharge. Therefore, the purpose of the current study is to complete group interviews to assess the PA needs (e.g. knowledge, expectations, attitudes, motivations, barriers, intentions) of individuals with a TBI enrolled in a comprehensive outpatient program. The group interviews serve as part of a needs assessment that is being completed to develop the 'audience profile' of the population so that an effective HPP can be implemented.

METHODOLOGY

Participant Recruitment

Approval to complete the study was received from an institutional review board at both a medical center and university, ensuring that all procedures were considered ethical (Appendix B). Individuals were recruited from the comprehensive outpatient program at a rehabilitation center, which is a part of the post-acute continuum of care that follows inpatient rehabilitation. Patients enrolled in the comprehensive outpatient program have completed inpatient therapy, are now living at home, but attend the program between 9am-3pm, 5 days a week (*M* stay = 8 weeks). The comprehensive outpatient program involves an interdisciplinary approach (i.e., physical, occupational, speech therapy, therapeutic recreation, social work, and neuropsychology) to rehabilitation which focuses on meeting the participant's outcome goal(s) (e.g., return to work, school, or leisure activities). The program is structured to include a combination of individual and small group activities.

Participants were chosen from the comprehensive outpatient program for four reasons. First, health promotion programs (HPP) that include physical activity (PA) are not included in the patient's standard of care. Second, the comprehensive outpatient program is a critical transition period for patients as they move from hospitalization after injury to living in their community. As a result, individuals are experiencing their daily routines (e.g., at home, in the community, with family, etc.) with their new abilities, thus, as they are presented with issues they are able to discuss in the rehabilitation setting. Third, the program is conducive to integrating the HPP into the current standard of care as patients are already undergoing daily educational sessions (e.g., learning about chronic conditions associated with TBI such as smoking, depression, caregiver stress, etc.). These sessions typically include handouts, group

discussion, and therapeutic activities. Fourth, patients typically regain cognitive functioning as comprehensive outpatient treatment begins, thus increasing the likelihood that patients are able to engage cognitively in educational programs. Consequently, the structure and purpose of the comprehensive outpatient program was deemed suitable for the integration of a HPP, and thus appropriate for the group interview consideration.

Participants

Results obtained came from eight group interviews consisting of 17 participants (male = 12, female = 5), ranging in age from 18-61 years of age ($M = 28$). Additional descriptive statistics of participants included ethnicity, marital status, number of children, education level, role in industry, and days with moderate intensity PA reported both pre- and post-injury (see Table 1). Purposive sampling was utilized with multiple inclusion and exclusion criteria. Inclusion criteria included (1) female or male, (2) ages 18 to 60, (3) first-time TBI, (4) undergoing comprehensive outpatient rehabilitation, and (5) high cognitive functioning (determined by clinical cognitive assessment by a neuropsychologist). Exclusion criteria included (1) non-traumatic brain injury (e.g., re-occurring injury, stroke), and (2) pre-morbid mental illness and/or pre-morbid developmental disability. During rehabilitation, individuals are assigned to a high or low cognitive group. For the present study, neuropsychologists from the rehabilitation center evaluated the cognitive functioning of potential participants, and deemed patients 'high functioning' after completing the Apathy Evaluation Scale: Clinician Version (Glenn, 2005), Awareness Questionnaire: Patient/Clinician forms (Sherer, 2004), Hopkins Verbal Learning Test – Revised (Brandt, 1991), and Trail Making Test Part B (Reitan, 1971).

Demographic data reported by each participant and included race/ethnicity, gender, age, marital status, years of education, income, occupation, family status, and more (see Appendix C

for more detail), all of which are critical when establishing an understanding of the cohorts' defining characteristics (USDHHS, 1999). Additional data were collected by clinicians to describe the physical, cognitive, and psychosocial characteristics of participants and included the Functional Independence Measures (Wright, 2000), Glasgow Coma Scale (Teasdale & Jennett, 1974), and Mayo-Portland Adaptability Inventory (MPAI-4) (Malec, 2005) (see appendix C for variables). Each measure is routinely collected by clinicians as part of outpatient programs across the U.S. and each variable is considered a key outcome measure in the rehabilitation process. The final sample consisted of 17 participants who completed a group interview session.

Group Interview Procedures

Individuals who met the inclusion/exclusion criteria were approached for consent during the third week of enrollment in the comprehensive outpatient program, in order to allow newly enrolled patients to become familiar with the structure and setting of the program before agreeing to participate in a research study. Individuals were informed about the purpose of the study, requirements, and that all information collected would be confidential and non-identifiable. Individuals who provided consent were then scheduled to attend a group interview during the last two weeks of their enrollment as an outpatient. This timeframe was chosen as patients generally exhibit increased cognitive functioning as they approach discharge, in addition to having completed the majority of education classes so their knowledge level will be higher. The group interviews took place in a private conference room consistent with other educational programs offered as part of the rehabilitation program. Each session lasted between 30-45 minutes and consisted of 2-3 participants. The group interview involved a researcher facilitating the discussion through a series of guided, open-ended questions designed to stimulate responses (Appendix A). Once the group interview discussion was completed participants were finished

with the study. Audio recordings of discussions were then transcribed and a cross-case analysis was completed to identify conceptual patterns and themes in responses (Jones, Richeson, Croteau, & Farmer, 2009).

Group Interview Questions

The current study used a group interview methodology, which enabled researchers to explore qualitatively PA (e.g., knowledge, behaviors, etc.) of TBI patients in the comprehensive outpatient program (Cresswell, 1998; USDHHS, 1999). Specifically, the group interview format allowed patients to provide greater detail about their lived experiences through their own voice as well as through a group response (Jones et al., 2009). For example, it was possible to analyze thematic tendencies from both the individual and group perspective at the conclusion of each group interview (e.g., a specific individual's PA knowledge vs. the group's PA knowledge).

Group interview questions were divided into four categories, based on recommendations from the USDHHS (1999) so that researchers could build a clear picture of the groups' PA needs. The four categories in relation to PA behaviors were (1) knowledge, (2) attitudes and expectations, (3) wants, intentions, and perceived motivations, and (4) barriers. Questions were developed to address each of the four categories by the principal researcher and then reviewed and revised by the research team, which consisted of two individuals with a background in PA for special populations.

Pilot research with the study questions was completed prior to initiation of the study and included sharing the questions with two PA experts, two clinical experts, and a group of four individuals with a TBI enrolled in the comprehensive outpatient program. Based on the feedback, modifications to the original questions were made including changing the order of questions (e.g., all questions assessing intention were group together) and removing redundant

questions (e.g., repetitive). The group interview questions (Appendix A) were finalized after this process.

Qualitative Design

After the final group interview was completed, a qualitative research approach was used to analyze the results of this study (Der Ananian, Wilcox, Saunders, Watkins, & Evans, 2006).

Qualitative designs have been used in past research to obtain “a more naturalistic, contextual and holistic understanding of human beings in society” (Todd, Nerlich, & McKeown, 2004). This is important in the context of the current study because the results were dependent on interpreting participants’ responses with the meanings that the responses were intended to have. These meanings, themes, and patterns of participant responses regarding their lived experiences could have been lost if other more traditional quantitative research measures were used.

Qualitative Analysis

The process of qualitative content analysis includes condensing raw data into themes based on valid inference and interpretation (Zhang & Wildemuth, 2009). This process utilizes inductive reasoning to extract themes from the data through careful examination and constant comparison of the data by the research team. Constant comparison analysis was used to identify underlying themes, or codes, presented through the data (Todd et al., 2004). The process of constant comparison analysis includes the researchers reading through the entire set of data, chunking the data into smaller parts, and labeling each chunk with a descriptive title or code. Similar chunks are labeled with the same code.

A pilot study using similar data analysis techniques was preformed to validate the coding scheme for the eight group interviews. Upon the completion of the final group interview, audio files from each group interview were transcribed into written text. All questions from the

interviewer, as well as all responses from the participants were included in the transcriptions. In addition, all audible behaviors (e.g., intonation, sounds, pauses) were transcribed and observations were noted (e.g., fidgeting, nervousness, uncertainty) in the transcriptions. Once transcribed, the data were coded by three investigators (investigator triangulation) with backgrounds in PA knowledge, thus establishing credibility. Coding the raw data entailed initially reading through the text data in order to identify and label specific segments of information. Approximately 35 codes were created after the initial coding process. These codes were then input into Atlas.t.i., a qualitative computer analysis program used to systematically organize codes from text and allows researchers to locate, code, and evaluate the importance of designated pieces of data within the whole series of interviews. The 35 codes were then reduced to 27 to diminish redundancy and overlap among the codes (Thomas, 2003). After the 8 group interviews were coded, the 27 codes were grouped by similarity, thus producing a theme (e.g., attitude, barriers, knowledge) for the grouping (Leech & Onwuegbuzie, 2007).

Code lists were generated from Atlas.t.i., creating a codebook to ensure consistency of coding throughout the group interviews. Using codebooks employs the constant comparative method (Glaser & Strauss, 1967) of qualitative data analysis, which allows researchers to systematically compare new text with text that has already been coded to ensure that later data are coded similarly to earlier data. The codebook was constantly modified and updated when new codes in later group interviews were discovered. Because three data coders were involved in the group interview transcription analysis, the use of a codebook provided consistency among coders. For the current study, the codebook included a current list of every used code, categories of codes, and definitions of codes (refer to Appendix D and E). After each group interview was

coded, the three researchers met together to compare coded transcripts, thus establishing inter-coder agreement (Zhang & Wildemuth, 2009).

Trustworthiness of the study was established through theoretical and investigator triangulation (Cresswell, 1998), as well as utilizing three data-coders (Goodwin & Compton, 2004; Meadows & Morse, 2001). Theoretical triangulation was achieved through comprehensive literature reviews related to the study (Abdullah et al., 2004; Cabana & Jee, 2004; Grodesky, 2008; Hughes, Nosek, Howland, Groff, & Mullen, 2003; Kahn et al., 2002; Ravesloot et al., 2005, 2007; Rimmer et al., 2002; Rimmer & Rowland, 2008; Stuijbergen et al., 2003), while investigator triangulation was accomplished using multiple researchers with a background in PA knowledge, qualitative inquiry, and interview technique to analyze the recordings from the group interview sessions to determine themes of responses. After each group interview was conducted, researchers debriefed and clarified their initial thoughts to participants' responses (Jones et al., 2009). Few disagreements between coders occurred, but were dealt with on a case-by-case basis and did not affect significant pieces of data. In addition, a "critical friend" with a background in PA research and with no involvement to the present study also reviewed the coding submitted by the investigators to ensure that coding was consistent throughout the group interviews. To accomplish this, the "critical friend" was given the research objectives of the present study as well as the text previously coded by the three researchers and then tasked with verifying the consistency of the coded data. Researchers then conducted a cross-case analysis to establish similarities and differences in responses to identify themes and conceptual patterns among the group (Cresswell, 1998). As a result, themes and representative quotes were identified from responses, which were then confirmed between the researchers. In an attempt to further triangulate the data and increase trustworthiness, a

stakeholder check was utilized, in which a group of individuals with a brain injury who met the same inclusion criteria were given the opportunity to review researchers' coding of previous participants' responses from previous group interview {{1171 Thomas, D. 2003; }}. The individuals participating in the stakeholder check supported the researcher's findings. Finally, current literature related to the research question was used to give credibility to the design and measures used (Bandura, 1977; Prochaska & DiClemente, 1983; Rimmer & Rowland, 2008).

RESULTS AND DISCUSSION

The six broad categories used to facilitate discussion from the eight group interviews included higher level themes covering participants' attitude, barriers, motivation, knowledge, expectations, and intentions toward physical activity (PA) (Appendix D and E). After data collection, these categories were composed of hierarchy of responses consisting of two levels. The higher level of the hierarchy was more broad than the lower level, and was made up of the codes used in the qualitative data analysis (e.g., positive attitude to PA, goal-setting, importance of PA). The lower level of the hierarchy was more specific than the higher level in that it included direct quotes from the individuals in the study that were coded during analysis of the group interview transcriptions (e.g., "I think it [PA] is important"). The six categories of discussion then resulted in six discussion areas based on commonality of response.

Attitude to PA and Amount of PA Completed

For the purpose of this study, "positive attitude toward PA" was coded when participants demonstrated a desire to be physically active. Overall, participants exhibited a positive attitude to PA as they considered PA to be an important part of their rehabilitation. In fact, two individuals recognized the role that their pre morbid level of PA played in their recovery: "I don't think that I would have recovered as fast if I hadn't been in as good of shape" (Female 1, Table 2) and "If I wasn't as active [before], I wouldn't have recovered as fast" Male 1. Similarly, one participant discussed PA as a tool to prevent future surgeries, while another felt that it prevented depression. In addition to attributing in part their recovery to PA, participants also identified PA as something that is done for fun, or is enjoyable: "It's [PA] a great way to just release and makes my body feel good" Female 2. Finally, nearly every group interview participant demonstrated a desire to be active, even if they had not been pre-morbidly, and

declared that they would be active despite their present and future physical limitations caused by the injury. Therefore, the fact that participants demonstrated a positive attitude towards PA has encouraging implications for HPP implementation given their (1) importance placed on PA, (2) attribution of recovery due to PA, (3) enjoyment of PA, and (4) desire to be PA.

When evaluating participants' attitude to PA, it was observed that when asked the benefits of PA, there seemed to be a different level of importance placed on PA between older and younger individuals. For example, one 18 year old male participant differentiated between the PA benefits of the young and old stating: "[Benefits of PA] for kids, less chance of becoming obese or something. For adults, less chance for heart attack or anything that would cause problems" Male 3. Attributing health benefits of PA as something that is only important to older individuals is notable as Male 3 considers appearance (or the desire to be lean vs being overweight or obese) the most important benefit of PA for himself and his peers (and not the secondary health conditions associated with obesity). Similarly, when asked for the health benefits associated with PA participation, a fifty-one year old female participant dismisses the risk of health problems attributed to inactivity in youth stating:

I'm 51, she's [another participant in the group interview] still young. At this age, it's [being physically active] to make sure that I'm not in a wheelchair the rest of my life...I have a high energy level and there's still a lot of things that I want to do and see, so I have to stay healthy to do that. Additionally, the #1 [benefit associated with PA participation] is the weight benefit, at least for women anyway...I think that affects the health of your body too. Overweight people tend to have more health risks. You know, they have high blood pressure, high cholesterol. If you're exercising, you're not sitting in front of the TV eating... which a lot of people tend to do. Your heart is stronger, everything's healthier.

(Female 4)

Similarly, a 61 year old female participant also stated that "As you get older, you learn [the

importance of PA]. ‘Move it or lose it.’ And that is so true. So true. So I’m moving it” (Female 2).

The disconnect between the health benefits of PA and age is further demonstrated in another group interview of young males (ages 18 and 23) when both participants stated that weight, strength, and endurance are the most important PA benefits to them. When asked why these benefits were important to them, they answered that their main concern is to “stay fit, stay strong” (Male 11) and that “[they] want to be able to play football again, play sports. And being strong and having good endurance...I mean, I’ll lose weight doing that, but that’s not my main concern” (Male 12). Further, they stated “I don’t work out to be healthy, I just do it for fun” (Male 3). It can be interpreted from these statements that these young male participants are more concerned with the present (e.g., appearance, recreation time, enjoyment, etc.) than they are with the long-term positive health effect of PA (e.g., decreased BMI, heart disease, mobility).

Despite the fact that several participants reported positive attitudes toward PA participation, they often recognized that they were not completing sufficient PA. For the purpose of this study, PA was defined as “bodily movement produced by the contraction of skeletal muscle that increases energy expenditure above a basal level and enhances health” (Centers for Disease Control and Prevention, 2011). When asked how much PA should you complete to receive health benefits, one individual answered “probably more than I am now” (Male 7). Others stated that they were physically active three times a week, for 20-30 minutes which falls short of the CDC recommended 150 minutes per week (Centers for Disease Control and Prevention, 2011). Despite their reduced activity levels, participants believed that completing 150 min/week was “realistic” and thought that when they did achieve this amount of PA, they were “working out all the time.” Because PA health benefits have the potential to decrease

secondary and associated conditions among outpatients in a rehabilitation setting, achieving the recommended amount of PA per week is crucial for individuals in this population. Thus, outpatient PA educational programs should encourage activity with specific examples of health benefits that active individuals may experience.

Experiencing and Overcoming PA Barriers

PA barriers were defined in this study as what kept participants from achieving their goals. These barriers could be personal (e.g., motivation) or environmental (e.g., accessibility). Most individuals in comprehensive outpatient rehabilitation are limited to how much and what kind of PA they are permitted to participate in due to the nature of their injury. For these individuals, certain PA is restricted through the use of the Think S.A.F.E. (Appendix F) list which prevents high impact activities such as running or contact sports like basketball. Specifically, the Think S.A.F.E. list is used to define what is considered safe and unsafe PA for individuals to participate in post-TBI (e.g., no high impact activities such as running for 1 year). This list of precautions is reviewed and discussed between patients and therapeutic recreation specialists or nurses in order to “help protect against future injury to [patients’] heads” (Appendix F). Consequently, most participants referenced the precautions listed in the Think S.A.F.E. list (Appendix F) as barriers that prevent them from being PA. For example, when asked if PA is something that should be done as part of their rehabilitation, one participant stated “yes and no, because you can get really hurt doing PA” (Male 3). Meanwhile, other participants reported to be completely inactive due to their injury because “everybody says I shouldn’t” (Male 3). Several other group interview participants referenced the Think S.A.F.E. list that “basically states you can’t do PA” (Male 7) and that participants are “just trying to figure out safe things [they] can do” (Male 11). As numerous participants similarly justified their

inactivity with the Think S.A.F.E. list, it is possible they may be living an unnecessarily inactive lifestyle. Potentially, individuals in outpatient rehabilitation may be completely restricted from PA, but it is unusual. Thus, this apparent misinterpretation of the Think S.A.F.E. list as something that limits all PA may cause individuals to be overly cautious or intimidated by PA and, therefore less likely to be active. Notably, several participants expressed a desire for a more positive way to restrict PA among outpatients with a TBI, such as a list that details what they can participate in, in addition to what they can not.

Though it seems that the Think S.A.F.E. may augment individuals PA, participants' injury was the most reported barrier to PA participation when asked what keeps them from being active. This is demonstrated in statements such as “everybody says I shouldn't [due to injury restrictions]” (Male 3) and “I can't drive [to places to be physically active] because I had a seizure” (Male 9). Often, individuals have had lasting effects from their injuries such as being “in a coma for like three weeks...and [losing] over forty pounds” (Male 5) that inhibited their ability to be physically active, while other participants “physically can't [be active]” due to assistive devices (e.g., halo braces) (Male 9).

Personal barriers to PA were not limited to physical restrictions, as several participants mentioned social and environmental barriers. Specifically, busy schedules, health (e.g., asthma), depression, laziness, work, school, and family were cited as barriers. Environmental barriers that were identified included accessibility (e.g., “I don't have access to a gym” – Male 2) and transportation (e.g., “You can ask people to take you, but you get tired of having to ask” – Female 3). One participant also spoke of nervousness when speaking to therapists in that they “weren't sure if [they] wanted to ask them about that [PA]” (Male 4).

Due to the large number of potential barriers that would prevent individuals with a TBI

from being physically active, it is important to develop strategies for overcoming these barriers with participants. For example, when participants stated that they did not have access to facilities such as gyms or weight-rooms, they mentioned they may do exercises that do not require equipment in and around their homes (e.g., “pushups,” “pools,” and “walking”). A handful of participants did however state that they possessed their own equipment (e.g., weights, treadmills) in order to overcome accessibility and transportation issues. If transportation was a barrier though, most participant’s recognized the importance of PA and were willing to walk or ask for a ride: “There’s still one [gym] pretty far, but I can walk it. There aren’t any excuses for me” (Male 3).

Notably, numerous participants claimed that they would “be physically active no matter what” (Male 5) and that they would be “physically active with [their] limitations” (Female 3). In fact, when confronted with time or motivational barriers, individuals from the group interviews discussed that even “if you’re only looking at thirty minutes in the morning,” (Female 2) it is still possible and beneficial to be active. In addition, participants considered “getting there (to a state of being physically active) is half the battle” (Male 5).

Motivation and the Importance of PA

In the current study, “Motivation” was defined as what kept participant’s wanting to improve their state of being, while “importance of PA” was used to code participant responses that included discussion of health as a part of their rehabilitation. Goal-setting is an integral part of rehabilitation programs, with the primary goal being to improve the individual’s quality of life post-injury. The importance of this is demonstrated when over half of participants indicated their main goal was to return to their pre-injury lifestyle and ability level. For example, participants identified wanting to get back to activities such as walking, weightlifting, playing football,

boxing competitively, and staying in shape. One participant's long-term goals included "to get back to where I was, at my skill level" (Male 3), while another summarized the sentiment: "I have one goal: to get better" (Male 1). Perhaps most notable, however, were the participants' acknowledgement of the difference between their goals pre-injury versus their goals post-injury. Specifically, when asked what role PA plays in helping patients overcome secondary health issues, one participant responded "I had goals before the injury as far as PA and those kind of got changed and the road redirected so I want to get back to those and that's a pretty serious motivator so I can either get back to those goals or make new ones" (Male 7). Additionally, a participant in a later group interview spoke of the "reality and realization that it [their previous goals] wasn't going to happen" (Male 7). These realizations signify an important step in their rehabilitation process which is acceptance of their injuries and the changes they have experienced. Specifically, previous PA goals of participants may no longer be feasible, but old goals can be replaced with new goals.

Additionally, when taking the "age factor" code into consideration, age seems to negatively affect young participants' PA goal-setting within comprehensive outpatient. For example, when asked what their PA goals were, one young male (age 18), stated that "it's hard to say...because we're pretty much the youngest ones here" (Male 7), inferring that the outpatient rehabilitation setting is geared more towards their older peers (e.g., getting back to their career, family life, etc.) and that the goals of younger members were not addressed as consistently or clearly.

Nearly all participants believed that PA was something that should be part of their outpatient rehabilitation and discussed "overall wellness" as a benefit of PA, but were unable to provide specific examples of why they should be active. For example, participants knew that PA

was important to their health and rehabilitation, but were unsure of the specific benefits that they would receive from being physically active (e.g., “I think it’s important” and “[benefits for the] heart...I don’t know”). A handful of participants, though, were able to list health-related benefits of PA such as stress reduction, better sleep, weight control, decrease in fatigue, increase in life longevity, increase in happiness, improved self-image, and prevention of hospital visits.

Notably, two participants discussed the importance of PA as they attributed their recovery to their pre-injury activity levels. A younger male participant (age 25) stated: “They gave me a 1% chance to live [after a resulting three-week coma due to the TBI] and they pretty much told me that if I hadn’t been in the shape I had been, I wouldn’t be here” –Male 5. In addition, a 61 year old female participant whose injury was attributed to a fall at home stated:

Well, I’m older than both of them (the two male participants in the group interview, ages twenty-five and thirty), but as you get older, it’s [PA] so important. I mean, if all of this had happened to me and I had been overweight, not in good shape, not in overall good health, I probably wouldn’t be sitting here. I mean, it was that close...I just hope to be a source of encouragement or inspiration for some of my friends here and people that I know because it’s [PA] just so important. You don’t come out of this [TBI] on the other side with what you came into it with. (Female 2)

As a whole, group interview participants’ main motivation to be physically active was to return to their pre-injury lifestyles. For example, when participants were asked if they had the motivation to be physically active, responses were very consistent with this individual’s sentiment: “I want to get better. I want to get to 100%” –Male 1. In addition to returning to “100%,” participants also used enjoyment of PA (e.g., “I just do it for fun”), social influences (“[I do it for] my kids” or “my mom”), and their career (“My job requires me to be PA”) for motivation to be active. One individual specifically cited the health benefits from PA as a motivating factor to be active:

It [PA] helps stress-wise, get better rest at night, take care of your needs, not stressed, not worried about things, helps burn calories, helps live a healthier life, helps with a lot of

things. Kind of calms you down, mellows you out...I use it for that reason. It works for me to work out and stuff. Burn stress and not to mention calories and not to mention other necessary things. (Male 6)

Another participant also reported energy gains from being active: “I like doing physical stuff in the morning, because that keeps me charged up during the day” (Female 2).

In addition, participants also reported that they felt that regression in their rehabilitation was an important factor to avoid: “All the progress I’ve made in rehab, if I don’t keep it [PA] up and pump it up, it’s just going to set me back and that’s not going to happen” and “I don’t want to go to the hospital again” (Female 2).

Participants cited several sources of social support including friends, significant others (e.g., husbands, boyfriends, etc.), roommates, parents, co-workers (“firefighting buddies”), teammates, and peers. Most participants stated that social support “plays a big part” in being physically active, though some were confident in their motivation to keep them active: “I need support from others...but really, I’ll be physically active no matter what” –Male 10. One participant not only discussed her own desire to be physically active, but also extended this desire to “get my husband inspired to walk again” –Female 2. This statement suggests that participants may also consider themselves a source of social support to others around them.

Not all significant others provided social support as some were recognized as being negative influences. For example, a sixty-one year old female participant cited her mother as being a source of negative modeling: “I came from a family of four sisters...my mother was heavy, and she always said ‘If I haven’t taught you anything else, I’ve taught you what not to do’” –Female 2.

Knowledge of PA

Participants’ knowledge of PA was determined through the level of understanding of the

benefits, characteristics, etc. of PA demonstrated throughout their responses. An individual's knowledge level of PA is important, especially during rehabilitation, because it may help to encourage participation in PA, thus allowing participants to experience health benefits from being active. Group interview participants who exhibited "general knowledge" of PA demonstrated a moderate level of PA understanding (e.g., what PA is, the benefits, and examples). When asked what types of PA people should conduct, participants identified activities with characteristics such as "whatever breaks a sweat," something that gets "my heart rate up to 155 frequently," and "anything that you would do that would exert any kind of extraordinary force upon your body." Similarly, another participant also stated that "anything that is going to get your heart to react in a healthy way is better than sitting there and doing nothing." As a whole, participants were able to list activities and characteristics that can be considered PA, and knew that it was something that they should do, even if they didn't do it.

A handful of participants demonstrated a 1) lack of PA knowledge, 2) uncertainty of what constitutes PA, 3) what the national guidelines for PA are, and 4) what the benefits of PA are. For example, when asked what the top three benefits of PA are, one participant responded: "I just assumed it was doing something good for me" while another replied "I don't know, what are they? I mean, are there three [benefits]?" The majority of other responses demonstrated a lack of PA knowledge expressed by responses such as "I don't know." Other responses included "I can't come up with it [a benefit of PA]" and guessing/uncertainty sounds such as "um" and "uh."

Participants also discussed what makes up or defines PA and stated characteristics of PA such as "getting your heart rate up," "breaking a sweat," and "getting muscles." Another participant went into further detail: "[PA is] anything that involved you moving your body. Anything besides sitting down or watching TV or getting on the computer. So any sport,

something” –Male 3. When asked what were examples of PA, participants commonly listed activities such as running, playing sports (e.g., football, basketball), lifting weights, walking, and cycling.

Perhaps one of the most interesting areas of responses was participant’s inability to differentiate between PA and physical therapy (PT). As previously noted, for the purpose of this study, PA is defined as activity with the goal of enhancing health, while PT is used to improve or restore mobility. When comparing PA to PT, statements minimizing the importance of PA health benefits such as lowering blood pressure, increasing strength, etc., were common: “PT is for recovery; PA is recreation” (Male 1) and “PT teaches you how to be physically active again. It teaches you how to be mobile or independent. PA is like things you do for fun or to strengthen your body” (Male 3). The commonality of statements minimizing PA may be a function of the state of rehabilitation that the outpatients are currently in or the severity of their injury. For example, time is set aside each day during rehabilitation for outpatients to work both individually and as a group in PT, but not for PA. It is possible that this made a meaningful (and incorrect) impression on outpatients that PT is more important than PA. This is epitomized in the following response from a sixty-one year old female group interview participant:

“[In physical] therapy, they [therapists] usually work on things you have a problem with. Like I have a new leg from my knee down and a titanium rod. Before PT, I couldn’t even walk on it. And it was ‘bend your foot, lift your butt’...you know, things you need to do to keep in shape or you’ll need to be able to get dressed to make your life easier, make your recovery better. That’s a lot different than when I think of PA, which sometimes can be for fun or because you’re working out, trying you get your PA in. PT is geared more towards you as an individual and what your needs are or are going to be.” –Female 2

Conversely, an eighteen year old male participant stated “For me, PT is just getting me back to

the point where I can do PA again. I don't know, they gave us a sheet [the Think S.A.F.E. list] that's basically 'you can't do PA.' It says we can jog, but can't do serious PA for a year. So, if I can't do serious PA for a year but am allowed to do this therapy stuff, then it's [PT] the building blocks of getting back to being able to do that" (Male 7).

Several participants identified their career as the source from which they completed the majority of their physical activity. When asked how realistic it was that they complete the recommended 150 minutes of moderate to vigorous PA per week, one such participant believed that his work with cars accounted for their PA, while another stated that the 150 minutes was "very realistic, because I'm a firefighter" (Male 10). As a firefighter, this individual also cited his occupation when asked what types of things they do to stay in shape: "Well obviously I have to lift heavy objects (e.g., firehoses), so I have to go to the gym and lift weights" (Male 10). He also attributed much of his activity time to when he was on duty at the fire station, a career that necessitates health and strength and allows time to be PA during work hours (e.g., weightrooms, station gyms, etc).

What Participants Hoped to Gain from PA

For the purpose of this study, expectations were defined as what participants anticipated to gain from being PA, while intentions were participants' determination or purpose for being PA. The participants' expectations for PA included benefits such as "lower cholesterol, lower weight. I'm very convinced lately of the long term mental benefits of PA" (Female 1). Others expected to "get back into [their] old way of living" (Male 3) as a result of being physically active, post-injury. One individual responded in this manner stating that "if you don't really work out and take care of yourself, your body isn't going to respond the way you want it to [in rehabilitation]" (Male 5). Another participant went into further detail and demonstrated a

realistic perception of their recovery expectations: “it will probably take a year or a couple months to get back to where I was” (Male 3). Participants also had different expectations in regard to the amount of PA that should be completed per week to receive health benefits. For example, when asked if it is realistic for someone to complete 150 minutes per week of PA, one participant replied “well, over the year, yes, but not in like a week or something” (Male 3). This response not only demonstrates a misunderstanding of the expectations for amount of PA per week to gain health benefits, but also a probable illustration of inactivity in their own life.

When asked what health benefits were important to group interview participants, individuals often identified benefits related to their rehabilitation, such as stress relief and increased energy. It can be inferred that these benefits were often mentioned as important due to the stressful nature of rehabilitating from a serious and life-altering TBI. For example, outpatients in the rehabilitation setting may exhibit both high stress levels and increased depression due to insurance concerns, re-integrating into society (leaving the secure “cocoon” of inpatient hospital care), and attempting to re-establish their “old lives.” Because of PA’s ability to reduce or alter these negative psychological concerns in individuals with a TBI such as stress and depression (S. Driver & O’Connor, 2003; S. Driver, O’Connor, Lox, & Rees, 2004; S. Driver & Ede, 2009; Irwin, Ede, Buddhadev, & Driver, 2011) in addition to the known physical benefits (Bateman et al., 2001; S. Driver, 2005; Ede, Buddhadev, Irwin, & Driver, 2011), PA’s importance to participants in the group interviews was obvious. In fact, one individual stated “all the PA they’ve [outpatient therapists] had me do has been just as important in my mental rehab as they have been in my physical rehab” (Female 1). Another participant responded similarly, speaking of the importance to “fight fatigue since my accident, so if I don’t exercise, my brain’s not going to get better. It [mental and physical benefits of PA] kind of goes hand in

hand” (Male 5).

The increased feeling of energy (both mental and physical) that results from PA participation was also described as an important health benefit of group interview participants. Extra energy is especially important in the rigorous rehabilitation setting due to the intense structure of therapies and classes that outpatients participate in, as outpatient rehabilitation is often tiresome. Because outpatient rehabilitation is the first step toward living independently after several weeks or months of inpatient rehabilitation (where participants were often heavily medicated), participants are coming out of the medication ‘fog’ during comprehensive outpatient and commonly express feeling extreme fatigue. One participant spoke specifically about fatigue during their hospitalization, as well as the benefits of PA:

With brain traumas, which we’ve all had, if you’re mentally fatigued, I mean just being awake and around people, and if I didn’t have the physical exercise to go along with that, I would be even more tired. So it’s a great way to just release and makes my body feel good like it’s doing something because mentally, I don’t always know! (Female 2)

She elaborated further stating that, “I’m exhausted by Friday afternoon (after a week of outpatient rehabilitation) but if I wasn’t doing all that [PA], I’d be tired by Tuesday” (Female 2).

When group interview participants were asked what they expected they would need to be active, common responses included social support, transportation, motivation, time (if they are restricted from PA due to their injury), a place to be active, and equipment. When participants were asked where they expected to be physically active, they frequently cited home and nearby gym facilities. Most participants stated that they would improvise locations to be PA when accessibility to sites was limited, such as this 25 year old male who stated: “It [accessibility to PA] depends on where I’m at. In the gym, on the lake, Colorado, the ocean. Wherever I’m at, I’m going to be doing something active” (Male 5).

Participants' Past, Present, and Future PA Levels

During the course of each group interview, participants were asked how much PA they completed per week. Most participants reported to be active 2-3 hours per week, though three participants stated that they counted the time they spent at their job as activity time.

Occasionally, participants stated that they were unsure of how much PA they completed per week, while it is probable that others greatly over-estimated their PA time per week: "I'd say per week about 40 hours" (Male 3). This statement brings up potential issues with relying on self-reported data being accurate. In order to check the reliability of their reported PA, participants were also asked on their demographic form how much PA they completed both pre and post-injury, thus allowing researchers to compare responses for reliability. By comparing participant's responses made during the group interview with the questionnaire data it was evident that there was a contradiction in their self-reported data.

Interestingly, among responses concerning pre-injury PA, there seemed to be confusion between the participants' past level of PA (pre-injury) and their current level of PA (post-injury). For example, participants used the present tense when describing their pre-injury (or past) amount of PA, when they should have used the past tense. This confusion of tenses is especially meaningful in qualitative studies when researchers are analyzing participant responses (Zhang & Wildemuth, 2009). Researchers may not be able to prove if self-reported data (e.g., amount of PA) is correct, such as when participants spoke in the present tense when actually describing the amount of time they were physically active pre-injury. Because the group interviews are composed of TBI outpatients who are often restricted in PA, when they describe their time in the gym as being sufficient, it may be unlikely that they are actually completing the type and amount of PA that they say they are. Thus, when participants are discussing what they believe they

complete in terms of PA, it is difficult for the researcher to determine if what the participants say is true or false. With this particular study, however, it was possible for researchers to compare the responses of participants in group interviews with their demographic questionnaire that they filled out pre-group interview. In each case that the researcher felt participants were incorrectly speaking in the present tense about past activity levels, it was possible to compare their verbal responses with their written responses concerning how much PA per week they accumulated both pre and post-injury. When comparing the verbally reported answer and the written answer, it was clear that though participants spoke as if they were still sufficiently physically active, they in fact were not (e.g., states they are meeting post-injury PA time per week time in group interview, but reports “0 min” PA per week post-injury on their demographic form).

For the purpose of this study, the code “Present and Future Intention” was used for responses that indicated what participants hoped to achieve as a result of PA. Most participants discussed the importance of PA as related to their injury, and participated in PA due to the associated health benefits. One participant claimed that “It’s [PA] even more important to me [post-injury] to stay fit, stay on top on it” (Female 1). Perhaps it is because of this newly increased sense of importance to be PA as a result of their injury that participants stated that they “were never going to stop working out” (Male 5) and that they “want to do it everyday to be good” (Male 7). It is notable that even if participants believed they were not sufficiently active before their TBI, they found PA post-injury beneficial. When asked if a participant intended to be PA once they left the outpatient rehabilitation environment, a twenty-one year old male responded that they wanted to be “more [PA] than I am now” (Male 8). This particular individual also discussed how they can make time for PA in their busy schedule: “I have two jobs and am writing a thesis and taking full loads of courses right now; it’s [PA] not really a

priority. So I guess that would be the first step: making it a priority” (Male 9). In addition to discussing the health benefits associated with being active and how to make PA a part of their lives, participants also intended for their PA during rehabilitation to return them to their PA levels pre-injury. For example, “[PA] will take me to where I want to be” (Male 12) or “I want to be back to bench-pressing 300 pounds like I was before my injury” (Male 10).

CONCLUSION

The purpose of this study was to conduct group interviews among individuals with a TBI undergoing outpatient rehabilitation to identify their physical activity (PA) knowledge, attitudes, intentions, and barriers. Results will be used to develop a health promotion program (HPP) that incorporates facilitation of PA participation as part of the outpatient rehabilitation process. Results demonstrated the need for integrating a HPP into the TBI outpatient rehabilitation setting. Because HPPs in prior research have positively impacted individuals with a disability (Abdullah et al., 2004; Ravesloot et al., 2005; Stuifbergen et al., 2003), a PA based HPP program for people with a TBI is warranted. Results also have significant implications for the development and implementation of a HPP.

First, during the course of the eight group interviews, participants as a whole demonstrated a positive attitude toward PA. As a result, the implementation of a HPP for individuals with a TBI in a setting such as outpatient rehabilitation may be easier. Despite the fact that participants expressed a desire to be PA, they were not sufficiently active based on national recommendations (Centers for Disease Control and Prevention, 2011). The lack of PA completed by participants is shown in responses demonstrating a lack of understanding regarding how much activity is required to receive health benefits, as well as participants reporting insufficient PA time per day post-injury. Thus, in order to improve the amount of PA completed, HPPs are necessary to increase participants' understanding of what PA is and how much is required.

Second, because participant motivation and program behavioral strategies are essential in driving behavior change, motivational pieces should be incorporated into HPPs. Motivation in HPP settings is based on the antecedents of self-efficacy theory that include past performance

(e.g., previous PA), vicarious experiences (e.g., guest speakers with TBIs addressing the importance of PA in rehabilitation to HPP participants and the role it has played for them in their recovery), and social persuasion (e.g., clinicians encouraging PA). Thus, strategies to enhance motivation should be included into HPPs such as educational components on factors that improve motivation (e.g., social support, goal-setting, etc.), as well as factors that inhibit motivation (e.g., negative social influences). Social support is an important resource for an individual's motivation to be successful in rehabilitation, therefore, HPPs should utilize caregiver involvement to facilitate behavior change. For example, HPP directors may challenge participants with evidence of significant others who are not active themselves or are good role models of PA individuals.

Third, though participants did exhibit a positive attitude toward achieving the recommended amount of PA, they were often unsure of what constituted PA and how much PA was necessary to receive benefits. Due to this lack of knowledge, it is important for HPP to include instructional pieces to educate participants of what constitutes PA, what the national guidelines for PA are, and what the benefits of PA are. Therefore, HPPs should include an educational component that focuses on defining PA, the requirements of PA (specifically how much PA/week is necessary to receive health benefits), and local PA resources available to participants (e.g., YMCAs). As participants demonstrated their inability to distinguish the characteristics of what constitutes PA, it is clear that outpatients need to know about the types of PA that they can participate in post-injury, as many activities are not appropriate for them to complete. With these considerations, HPPs should also improve participants' ability to clearly define the differences between PA and PT to increase the likelihood that individuals accurately self-report their amount of PA and therefore are closer to completing the recommended

guidelines. When HPP participants are educated about what constitutes PA, they will be more likely to accurately report the amount of PA. Strategies to accurately report amount of PA should be encouraged during HPPs and facilitated through objective methods of PA collection (e.g., pedometers, accelerometers) in addition to subjective self-reported PA data.

Fourth, based on PA-related goals from participant responses, outpatient HPPs should focus on assisting individuals in recognizing that pre-injury goals may need to change post-injury. Modification of the Think S.A.F.E. list to include permitted activities may result in increased PA among individuals with a TBI. An individualized list of safe activities for members of the HPP is also recommended based on group interview participant responses. By focusing of what individuals can do instead of what they cannot, environmental (e.g., assessability to fitness facilities, transportation, etc.) and personal barriers (e.g., motivation, time, etc.) may be overcome.

Finally, due to perception of age differences present in outpatient rehabilitation (ages ranging from 18 to 61), it is important to relate PA to rehabilitation outcomes (e.g., increased energy, decreased depression, increased range of motion, improved mobility) rather than age specific objectives. Consequently, HPPs should assist participants in finding motivating factors to be PA that are not limited to age, such as weight control, cholesterol levels, abandoning the use of a wheelchair, etc. In this way, HPPs will take on the role of using exercise as medicine (Durstine et al., 2009), a concept that is critical in every age and disability. Specifically, it is important to utilize exercise as treatment for disease and disability instead of drug prescriptions in order to decrease chronic disease, premature deaths, and medical costs (Durstine et al., 2009).

Limitations to this study may include the number of outpatients that participated, although it is important to note that the current study's number of participants (n = 17) is

comparable to similar qualitative studies (Goodwin & Compton, 2004; Jones, et al., 2009). Also, due to the nature of outpatient rehabilitation, it was necessary to use a purposive sampling method, rather than random sampling, to assure that participants were considered to be sufficiently “high cognitive functioning” (e.g., memory recall, attention, independent thinking) to take part in the group interviews. These patients also experienced variable length of stays in outpatient rehabilitation, which may have an impact of their PA knowledge, intention, expectation, etc. As previously discussed, participants were also asked to provide a self-report of the amount of weekly completed, which may be affected by social desirability, memory recall, or a lack of knowledge about what constitutes PA. Thus, it may be beneficial for future studies to ask questions and provide information about participants’ PA and compare this data to participants’ actual PA participation. Finally, as the current study was qualitative in nature, coding of participant response data was interpretative rather than value driven. Despite these potential limitations, individuals post-TBI were enthusiastic about PA, so a HPP incorporated into the standard of care would not only be beneficial for participants, it would also be well-received. Further, results from the current study will enable specialists to create a meaningful PA-based HPP that will aim to 1) increase the self-efficacy and intention to be active of individuals post-TBI; 2) improve rehabilitation outcomes; and 4) increase the amount of PA completed each week. If the HPP is appropriately designed, previous research suggests that individuals will be more likely to adopt and maintain PA behavior, experience fewer secondary and chronic conditions, experience a greater quality of life, and have decreased healthcare costs. Thus, as clinicians in TBI outpatient rehabilitation look for ways to improve the functioning of people with a TBI, the findings of this study provide basis for HPP development to improve the lives of individuals after TBI.

Table 1

Participant Demographics

Independent Variable	Group	Mean %	SD
Age	N=17	28.2 years	13.5
Days with Moderate Intensity PA	Pre-Injury	4.6	2.5
	Post-Injury	2.5	2.7
		Frequency	
Gender	Male	12	
	Female	5	
Marital Status	Divorced	1	
	Married	4	
	Separated	1	
	Single	11	
Number of Children	Zero	6	
	One	2	
	Two	2	
	Three	1	
	Missing	6	
Ethnicity	Black	3	
	Caucasian	9	
	Hispanic	3	
	Latino	2	
Education	Grammar	2	
	High school	3	
	Some College	8	
	Bachelor's	2	
	Master's	1	
	Missing	1	
Area Lived	Urban	3	
	Suburban	12	
	Rural	1	
	Missing	1	

Role in Industry	Admin	1
	Student	8
	Professional	2
	Other	2
	Missing	4
Income	\$20-29K	1
	\$30-39K	1
	\$50-74K	1
	\$75-99K	1
	\$100-150K	1
	Rather not say	4
	Missing	8

Table 2
Participant and Group Interview Characteristics

Participant	Group Interview Number	Group Interview Length (Min:Sec)	DOB	Time between injury and group interview (days)	Etiology *MVA = Motor Vehicle Accident	Mobility	Glasgow Coma Scale Severe ≤ 8 Moderate = 9-12 Minor ≥ 13
Female 1	1	39:03	2/12/63	42	Fall from horse	Independent	14
Male 1			1/17/86	94	Fall	Independent	-
Male 2			8/2/89	371	MVA	Independent	3
Male 3	2	30:24	10/31/92	294	MVA	Independent	-
Male 4			12/6/93	-	-	Independent	-
Male 5	3	30:00	4/4/85	78	MVA	Independent	3
Female 2			9/19/48	60	Fall	Independent	-
Male 6			4/8/80	235	MVA	Walker	-
Female 3	4	30:04	11/17/90	39	MVA	Independent	3
Female 4			9/9/58	97	Motorcycle	Independent	3
Male 7			11/02/92	47	Skateboard	Independent	7-8
Male 8			3/4/90	48	Lake accident	Independent	3
Male 9			4/7/89	55	Hit by motorcycle	Wheelchair	-
Female 5			5	32:00	3/15/66	162	Fall
Male 10	1/14/85	89			MVA	Independent	-
Male 11	8/21/87	141			Hit by train	-	-
Male 12	7/27/92	131			MVA	Independent	3

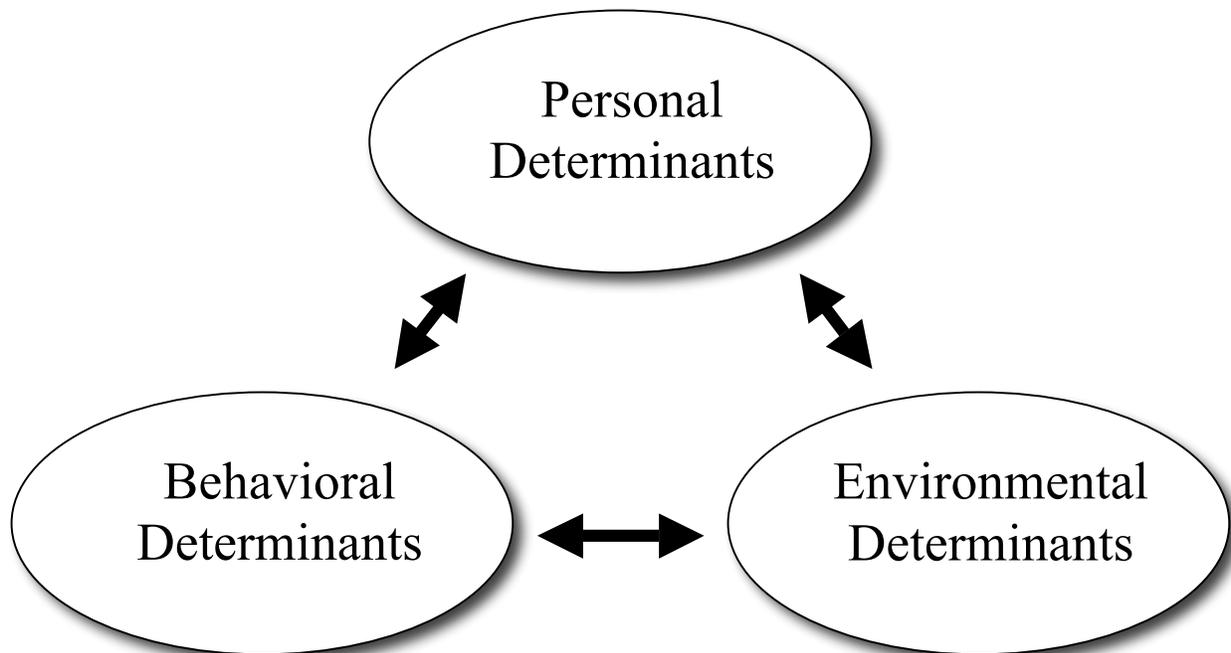


Figure 1. Social cognitive theory (Bandura, 1977).

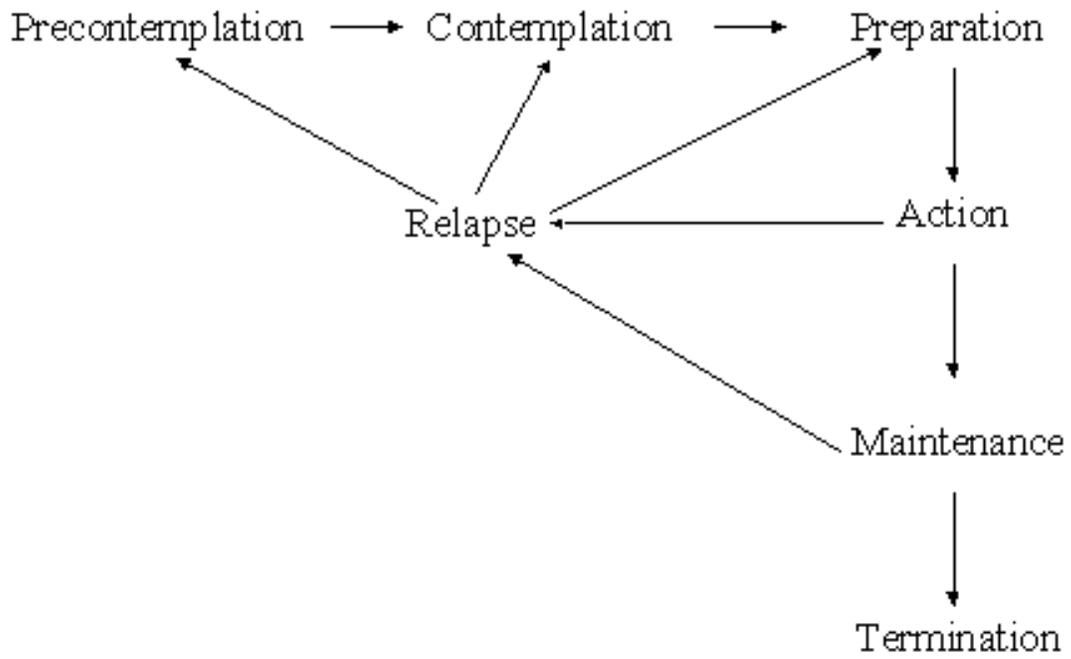


Figure 2. Transtheoretical model of behavior (Prochaska & DiClemente, 1983).

APPENDIX A
TBI GROUP INTERVIEW QUESTIONS

TBI Group interview Questions

1. What does the term physical activity mean to you? (Knowledge)
 - a. What are some examples of physical activity?
 - b. What is the difference between PT and physical activity?
 - c. What types of physical activities should people conduct?
 - i. Can you describe these activities for me?
 - d. Are you familiar with national guidelines for physical activity sufficient for a health benefit?
2. What are the top 3 health benefits associated with physical activity participation? (Expectations)
 - a. Which health benefits are most important to you?
 - b. Why are those health benefits most important to you?
3. How much physical activity do you need to complete to get those health benefits? (Expectations)
 - a. How realistic is it that you complete that amount of physical activity?
 - b. What barriers are preventing you from engaging in PA?
 - i. I can't set and stick to goals
 - ii. I don't have the social support I need
 - iii. I'm not motivated enough
 - iv. I don't have the time or resources (equipment, too tired, accessible facility)
 - v. I don't have the money
 - vi. I don't have enough confidence
 - vii. I don't know enough about how to do the exercises? Use the machines? Design a workout?
 - c. How much physical activity do you think you will be able to complete?

4. Is physical activity something you should do as part of your rehabilitation? (Attitude)
 - a. What role does physical activity play in your rehabilitation process?
 - b. What role does physical activity play in helping you overcome secondary health issues throughout your rehabilitation? (pain, range of motion, weight management, depression).
 - c. Why would you not be physically active? (it is painful, not good for me?)
5. What do you hope to learn during Day Neuro to help you be physically active once you leave? (Expectations)
 - a. What types of physical activity I should do?
 - b. The amount of physical activity I should do?
 - c. Where I should go to be physically active?
 - d. How to set goals?
 - e. How to overcome barriers?
 - f. How to create a social support network?
 - g. What would you like to learn?
6. Do you intend to be physically active once you leave Day Neuro? (Expectations)
 - a. Why or why not?
 - b. Do you have long-term physical activity goals? (1-yr, 2yr, etc)
 - c. Who are you most likely to be physically active with?
 - d. Where do you think you will be physically active?
7. What are the main motivating factors for you to be physically active? (Motivation)
 - a. What are your top 3 motivating factors?
 - b. Why do these factors motivate you?
8. What 3 things do you need to help you be physically active in the future? (Barriers)
 - a. I need more skills – goal setting? Someone to show me how to do it?

- b. Support from others?
 - c. Someone to be physically active with?
 - d. Greater motivation?
 - e. Resources? (equipment, transport, accessible facility)
9. Were you physically active before the injury? (Intention)
- a. Were you physically active enough to meet the guidelines?
 - b. Do you want physical activity to be a part of your life in the future?
10. Which mode of presentation do you learn most from?
- a. Presentation, handout, group discussion, I like a workbook.
11. Which resources do you think are most likely to help you stick with being physically active in the future?
- a. Handbook, online resources, telephone conversations, group discussion, buddy?

APPENDIX B
NOTICE OF INFORMED CONSENT

BAYLOR RESEARCH INSTITUTE
Ann Marie Warren, PhD
Laurel Stevens, SLP, CCC
Simon Driver, PhD
Megan Self, B.S

PARTICIPATION EXPLANATION AND CONSENT FORM

PROJECT TITLE: Physical Activity Needs Assessment for BIR Day Neuro Patients

INVESTIGATORS: Ann Marie Warren, PhD
Laurel Steven, SLP, CCC
Simon Driver, PhD
Megan Self, B.S

INTRODUCTION:

Before you say that you will be in this research study you need to read this form. It is important for you to understand all the information in this form. This form will tell you what the study is about and how it will be done. It will tell you about some problems that might happen during the study. It will also tell you about the good things that might happen for you during the study. When you read a paper like this to learn about a clinical trial it is called “informed consent.” The people who are doing this research study are giving you very important information about the study. When you give your consent for something, it is the same as giving your permission. This consent form may contain words that you do not understand. Please talk with someone from the research staff if you have questions. Do not sign this consent form unless all your questions have been answered and you feel comfortable with the information you have read. You will be given a copy of the form to keep.

You are being asked to take part in this study because you are a patient in Baylor Institute of Rehabilitation’s Day Neuro program.

Why Is This Study Being Done?

The purpose of this study is to conduct a physical activity needs assessment. The information gathered will help improve the physical activity content of the health program in Day Neuro.

What is the Status of the Procedures or Techniques Involved in this Study?

The group discussion format used is an approved procedural technique.

How Many People Will Take Part In The Study?

About 30 people will take part in this study worldwide/nationwide. About 30 of these people will take part at this location.

What Is Involved In The Study?

The procedures for the needs assessment will consist of Simon Driver and/or Megan Self leading a guided discussion over physical activity. Sessions will be completed in a Day Neuro conference room at the beginning and middle of every month on a Tuesday and Friday and will last 30 minutes. Discussion in the needs assessment will focus on your physical activity knowledge, attitudes and expectations, wants and intentions, perceived motivations and barriers. The session will be recorded and transcribed to ensure all information is collected accurately but the information will not be used to identify participants.

In addition, you will be asked to allow the researcher to review your demographic records so that some information can be copied into a chart. This information will be used as demographic data for the study and will not be made public.

How Long Will I Be In The Study?

You will be in the study for about 3-4 weeks and participation will include attending a group discussion on physical activity that will take 30-45 minutes total.

The researcher may decide to take you off the study if s/he feels that it is in your best interest, if you are not able to follow the rules of the study, if the study is stopped before it is finished or if new information becomes available that indicates it would be best for you to stop being in the study.

You can stop taking part in this study at any time. If you decide to stop taking part in the study, you should let the researcher or his/her staff know so that they can make sure you are safely taken out of the study.

What Are The Risks, Benefits and Options of The Study?

There are no risks or benefits to you for being in the study. We hope that what the information you provide can be used to improve the physical activity behaviors of people with a traumatic brain injury in the future. Your other option is to not be in the study.

If you have additional questions about these risks, ask the researcher.

What About Confidentiality?

You have a right to privacy. This means that all the information about you from this study will only be shown to the people working on the study. The results of this study may be published in a scientific book or journal. If this is done, your name will not be used. All information about you from this research project will be kept in a locked office or other locked area. Information that is kept on computers will be kept safe from access by people who should not see it.

- The privacy law requires that Baylor Research Institute get your permission before giving any of your health information to other people. There are people who need to review

your information to make sure the study is done correctly. These people may look at or copy your information while they are doing this review. When you sign this form you give permission to Baylor Research Institute to give other people information about your health as needed for the research project. These groups include people who work for Baylor Research Institute (including the Institutional Review Board), the US Food and Drug Administration, the Office for Human Research Protections and the Association for the Accreditation of Human Research Protection Programs. This also includes the following groups of people who are working with the sponsor of the study: Megan Self and Simon Driver, PhD, of the University of North Texas. Even though we usually remove your name from the information, the people who get this information may be able to figure out who you are. The kinds of health information that might be given to these people include results from the surveys you complete, notes from the doctor doing the research or other similar events. This also might be information about diseases like Human Immunodeficiency Virus (“HIV”) or Acquired Immune Deficiency Syndrome (“AIDS”), information about mental illness (except for specific notes of psychotherapy sessions), and/or information about drug or alcohol abuse.

You do not have to give this permission and it is all right to refuse to sign this form. Your doctor will still treat you and your insurance company will still pay your medical bills (according to their policy) even if you do not give your permission for us to release this information. However, since it is important for the people listed above to have access to your information, if you do not sign this form, you cannot be in the research study.

If you give permission to Baylor Research Institute to give other people information about your health and the other people are not part of the group that must obey this law, your health information will no longer be protected by the privacy law. However, we will take all reasonable measures to protect your information from being misused.

If you change your mind and later want to withdraw your permission, you may do so. You must notify Baylor Research Institute in writing at 3310 Live Oak, Suite 501, Dallas, TX 75204. If you decide to do this, it will not apply to information that was given before you withdrew your permission.

You may not be allowed to look at your health information during this study. However, at a later time, you will be able to look at this information. This later time will be sometime after the study is completed.

Unless permission is withdrawn, this permission will expire at the end of the research study.

What Are the Costs and Will I be Paid?

There are no costs to you for being in the study and you will not be paid for being in the study.

What are My Rights As a Participant?

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. If you agree to take part and then decide against it, you can withdraw for any reason.

Deciding not to be in the study, or leaving the study early, will not result in any penalty or loss of benefits that you would otherwise receive.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

All of the people working on the project must be careful not to carelessly harm you. If you are hurt during this project, you have the right to seek legal counsel. Nothing in this consent form takes away that right if you are hurt during this research.

Whom Do I Call If I have Questions or Problems?

If you have concerns, complaints or questions about the study or have a research-related injury, contact Ann Marie Warren, PhD.

For concerns, complaints or questions about your rights as a research subject or if you simply wish to speak with someone who is not a part of the research staff, contact Lawrence R. Schiller, M.D., IRB Chair.

Statement of Person Obtaining Consent:

I have explained to _____ the purpose of the research project, the procedures required and the possible risks and benefits to the best of my ability. They have been encouraged to ask questions related to taking part.

Signature of Person Obtaining Consent

Date

Time

Confirmation of Consent by Research Subject:

You are making a decision about being in this research study. You will be asked to give your written consent if you want to be in the study. Giving consent is like giving permission. You should not give your permission to be in this study until you have read and understood all the pages in this form. If you cannot read, then someone can read the form to you. Make sure that all your questions about this research project have been answered before you sign this form. When you sign this form, you are giving your permission to be in the study. By signing this form, you have not given up any of your legal rights or released anyone from liability for negligence.

_____ has explained to me the purpose of the research project, the study procedures that I will have, and the possible risks and discomforts that may happen. I have

read (or have been read) this consent form. I have been given a chance to ask questions about the research study and the procedures involved. I believe that I have enough information to make my decision. I have also been told my other options. To the best of my knowledge, I am not in any other medical research. Therefore, I agree to give my consent to take part as a subject in this research project.

Signature of Subject

Date

Time

APPENDIX C
DEMOGRAPHIC QUESTIONNAIRE

Physical Activity Group interview: Demographic Form

Name: _____

Date of Birth: _____ Age: _____

Gender: _____

Height: _____ Weight: _____

Date of injury: ____/____/____

How did the injury occur:

Where do you reside (pre-injury)?

City, State:

What is your primary language?

- English
- Spanish
- Other _____

What is your current marital status?

- Divorced
- Living with another
- Married
- Separated
- Single
- Widowed
- Would rather not say

If you have children, how many children do you have? (include age)

How many children under the age of 16 year old live in your household?

- None
- 1
- 2
- 3
- 4 or more

How would you classify yourself?

- Arab
- Asian/Pacific Islander
- Black
- Caucasian/White
- Hispanic
- Indigenous or Aboriginal
- Latino
- Multiracial
- Would rather not say
- Other _____

What is the highest level of education you have completed?

- Grammar school
- High school or equivalent
- Vocational/technical school (2 year)
- Some college
- Bachelor's Degree
- Master's Degree
- Doctoral Degree
- Professional Degree (MD, JD, etc.)

Which of the following best describes the area you live in?

- Urban
- Suburban
- Rural

How much time do you usually spend sitting or reclining on a typical day?

Pre-Injury (Hours:Minutes) _____

Post-Injury (Hours:Minutes) _____

In a typical week, on how many days do you do moderate-intensity sports, fitness or recreational (*leisure*) activities?

Pre-Injury (# of days): _____

Post-Injury (# of days): _____

APPENDIX D
CODEBOOK LIST

CODES AND DEFINITIONS	# of quotes coded
Positive Attitude to PA – participants demonstrate a desire to be physically active	26
Access to PA – describes whether participants have a place to be PA (and where that is)	2
Accuracy of Self-Report – questions the participants ability to quantify their amount of PA	4
Achieving PA – participants are physically active	10
Age Factor – considers the participants’ age when evaluating their response	5
Coders Non-Agreement – designates a section of transcription that needs to be re-visited	2
General Knowledge – participants demonstrate a moderate level of PA understanding	41
Goal-setting – e.g., achieving characteristics of pre-injury behavior, improvement	16
Importance of PA – in regard to improved health and as a part of their rehab	31
Lack of PA Knowledge – demonstration of low levels of PA understanding	22
Motivation – what keeps the participants wanting to improve their state of being	33
Overcoming Barriers – achieving goals regardless of obstacles	24
PA Knowledge – broader theme (general knowledge and lack of knowledge form this)	63
PA at work – the PA that participants get through their occupation	6
PA Barriers – keeps participants from achieving their goals (personal or environmental)	38
PA Characteristic – what makes up or defines PA (e.g., increased HR)	8
PA Expectations – what participants anticipate to gain from being PA	22
PA Health benefit – e.g., decreased depression, increased range of motion	32
PA Needs – What participants require to be PA	5
PA Safety – considers the medical restrictions and conditions of the patient/participant	12
PA/week – how much PA is reported each week	4
Pre-Injury PA – how much PA participants were achieving prior to injury	21
Post-Injury Changes – how participants’ lifestyles, health, habits, etc have been altered	12
Present & Future Intention – participants’ determination or purpose for being PA	38
PT vs PA – how participants differentiate between physical therapy and physical activity	10
Self-efficacy/Confidence – how PA affects these levels in their personal lives	2
Social support – how the network around them affects their rehab and PA	17

APPENDIX E
CODEBOOK ORGANIZED BY THEME

ATTITUDE

Positive Attitude to PA – participants demonstrate a desire to be physically active

Achieving PA – participants are physically active

Age Factor – considers the participants' age when evaluating their response

BARRIERS

Goal-setting – e.g., achieving characteristics of pre-injury behavior, improvement

PA Barriers – keeps participants from achieving their goals (personal or environmental)

Overcoming Barriers – achieving goals regardless of obstacles

Post-Injury Changes – how participants' lifestyles, health, habits, etc have been altered

MOTIVATION

Importance of PA – in regard to improved health and as a part of their rehab

Motivation – what keeps the participants wanting to improve their state of being

Self-efficacy/Confidence – how PA affects these levels in their personal lives

Social support – how the network around them affects their rehab and PA

PA Safety – considers the medical restrictions and conditions of the patient/participant

KNOWLEDGE

General Knowledge – participants demonstrate a moderate level of PA understanding

Lack of PA Knowledge – demonstration of low levels of PA understanding

PA Knowledge – broader theme (general knowledge and lack of knowledge form this)

Coders Non-Agreement – designates a section of transcription that needs to be re-visited

PA Characteristic – what makes up or defines PA (e.g., increased HR)

Accuracy of Self-Report – questions the participants ability to quantify their amount of PA

PT vs PA – how participants differentiate between physical therapy and PA

Types of PA – e.g., basketball, running, weightlifting, cardiovascular

EXPECTATION

PA at work – the PA that participants get through their occupation

Access to PA – describes whether participants have a place to be PA (and where that is)

PA Expectations – what participants anticipate to gain from being PA

PA Health benefit – e.g., decreased depression, increased range of motion

PA Needs – What participants require to be PA

INTENTION

PA/week – how much PA is reported each week

Pre-Injury PA – how much PA participants were achieving prior to injury

Present & Future Intention – what participants hope to achieve

APPENDIX F
THINK S.A.F.E. LIST

This list is designed by your doctor and therapists to help protect against future injury to your head.

This list will be reviewed with you by your Therapeutic Recreation (TR) Specialist or nurse. Your doctor and therapist may feel activities not on this list may be dangerous for you, as well. These will be discussed when you meet with your TR. After reviewing this list your TR will meet with you and develop a list of appropriate activities that will be safe for you to participate in before and after discharge and to assist you with working on skills you have been developing during your in-patient rehabilitation stay.

NO DRIVING UNTIL APPROVED BY YOUR DOCTOR AND THERAPISTS!

For AT LEAST ONE YEAR from your date of injury:

- No contact sports, including basketball, baseball, softball, football, soccer, hockey, wrestling, boxing, etc.
- No cheerleading or gymnastics
- No diving or scuba diving
- No water skiing, snow skiing, or snowboarding
- No four wheeling or go-cart driving
- No sprinting or extreme jogging (distance may not exceed 3 miles)
- No rock climbing or mountain climbing, except on well established pathways, with a responsible adult
- No jumping on a trampoline
- No roller-skating, rollerblading, or skateboarding
- No horseback riding
- No amusement park rides, including Six Flags, carnivals, fairs, water parks or any high speed or spinning rides
- No skydiving, hang gliding, parasailing, or bungee-jumping
- No motorcycling
- No surfing, wind surfing, wake boards, boogie boards, wave runners, jet skis
- No using a lawn mower, riding lawn mower, tractors or other large gardening or farming equipment
- No hunting, handling guns, weapons, hunting knives, ammunition, fireworks or other weapons without an adult who knows how to operate the above items.
- No power tools
- No climbing ladders (except in therapy)
- No water rafting, canoeing, tubing, boating or swimming unless you have an adult capable of supervision who can swim well enough to help you in an emergency situation

For AT LEAST 6 MONTHS from your date of injury:

- No bicycling (after six months you should wear a helmet). You must have permission from your doctor and/or physical therapist.
- No fishing without an adult present who is capable of supervision and can swim
- No racquetball, tennis, squash

- Weightlifting guidelines and recommendations (check with your doctor or physical therapist for individual programs.) Free weights and Nautilus equipment may be used with the following guidelines:
 - For the first 2 months after your injury- weights no greater than 30 pounds
 - For the 3rd and 4th months-weights no greater than 50 pounds
 - For the 5th and 6th months- weights no greater than 100 pounds
 - After six months, there's no specific limit. (This should be decided between you and doctor or physical therapist)

Other recommendations may be given by parents, spouse, friends, etc., as deemed necessary by them, in keeping you safe. These include: _____

It is recommended that you never drink alcoholic beverages again for the rest of your life. It will dull your senses, impair your judgment, and may cause seizures. It will affect your ability to drive and be safe in doing any physical activity.

If you have any questions about any activities after discharge, please feel free to consult your doctor and/or outpatient therapists.

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